



Meeting of Minds

European Citizens' Deliberation on Brain Science

THE PUBLIC PRESENTATION OF THE EUROPEAN CITIZENS' ASSESSMENT REPORT AT THE EUROPEAN PARLIAMENT, 23 JANUARY 2006

Welcome note

The chair, **Silvana Koch-Mehrin**, MEP opened the session.

Welcome to the European Parliament. I am very happy that you found the way here and that you are holding your closing ceremony here. I am Silvana Koch-Mehrin from the Alliance of Liberals and Democrats. It is an honour to be here and an honour to be your moderator here in the European Parliament. I would just like to say a few brief words about our group because not everyone knows about the facts at the European Parliament. Our group is the third biggest group after the Conservatives and the Christian Democratic Group and this is, of course, their meeting room. The second biggest group are the Socialists and then we are in third position. We have 90 MEPs and I am the deputy group leader. I am happy that our group can be your host today.

I am very impressed that we are able to speak several languages here and I heard how you worked this weekend. I have prepared a short introductory note in English and I will be reading it in English. Perhaps some of you will have to put on your headsets. I think it is wonderful that you were able to manage in so many languages seeing as you come from so many countries. Of course, it is important to learn to work with that because not everybody speaks the same language and sometimes it can be a challenge to the mind and, of course, you have to concentrate as well and sometimes there can be some translation or interpreting mistakes.

I was very impressed about the title 'Meeting of Minds' because the issue is about an instrument that most people try to use at least several times a day – the brain - and work with it, especially when you then go into the details and you realise that it contains about 100 billion neurones and weighs around 1.4 kg. Then you realise that the human brain is a highly complex and delicate organ. It is the driver of humanity and it allows us to make sense of our past and to shape our future. It is also the place of personality, reasoning emotions and social interaction.

Most people know these facts today, but when I was asked to address the Meeting of Minds Deliberation on Brain Science, I was astonished by how recently a lot of the discoveries were made. For example, the tragic tale of Phineas Gage. It is one of the most famous stories in the history of medicine and one which, little over a century ago, completely revolutionised the way scientists think of brains. An explosion on 13 September 1848 left the American railroad foreman with a severe head injury. After recovering from the physical symptoms of the accident, he was perfectly functional but his personality had changed in a very bizarre and fundamental way. Before the accident, he had been intelligent, sensitive and caring, but afterwards his character underwent a dramatic change: he became selfish, irritable undependable and course. Gage, his friends said, was no longer Gage. Phineas Gage's case was amongst of the first indications that the brain is not just used for motor functions like walking and talking, but is also the place of reasoning, emotion and socialisation. This insight

still drives many researchers today, as they build on the knowledge gained from Gage's terrible accident.

That knowledge actually has never been more necessary than at the present time. With the demands of an aging population and the uncertain effects of some modern technologies, brain disorders are on the rise. The annual cost of brain conditions already stands at 386 billion euros. That is 35% of the total health burden on Europe and a burden that could rise by up to 20% in the years to come. Shockingly, it is estimated that half of Europe's population will suffer from some form of brain disease by 2020. It is therefore imperative that brain science is fully supported both at European and at national level and that progress is made and fast. Scientists and doctors can understand the brain in ways we could not have foreseen even a decade ago and future developments could well go into the realms of what may now seem like science fiction.

The importance of the Meeting of Minds project and the participatory approach

These developments are exciting but they are also ethically challenging. If new technologies and drugs can alter, enhance and control our brains, then will they change what it means to be human? Should such practices be encouraged or should they be suppressed? How are we going to use our new-found knowledge of the brain? These are the kind of fundamental questions that the European Citizens' Deliberation on Brain Science has set out to answer. 126 citizens from nine European countries have debated the ethical, social and legal implications of our new-found knowledge of the brain with international experts. And today their conclusions, your conclusions about the use we should make use of new technologies, medicines and techniques will be offered to some European policy-makers.

I would like to thank the King Baudouin Foundation and its 12 partner organisations for pooling their expertise and experience for the benefit of the project. And for putting these to the service of the public over the course of three national level and two EU level meetings. I believe this was time consuming and energy consuming for all of you who dedicated so much emphasis to that. Since Meeting of Minds was launched in 2004, over the last two years their support has allowed ordinary people to engage with cutting-edge science in a unique and unprecedented way. For the first time, citizens of the European Union have led debate and shaped public debate. I am confident that this approach could be applied in other areas where the public has an interest and a right to greater involvement. This is not only in keeping with the Commission's plan D which is about dialogue and debate, but also with other initiatives of communicating Europe because it is about the citizens and Europe that all this is happening.

It is essential if people are to feel that Europe is acting in their best interest and is capable of adding real added value to their daily lives. The Liberals and Democrats recognise that gaining public trust will not be an easy task. This is why my group, the Alliance of Liberals and Democrats for Europe, places great emphasis on consultation and dialogue with the citizens and also with EU members. I am confident that we can learn from the methods used by Meeting of Minds to carry out a debate with the citizens, a debate which is truly democratic.

I am very delighted to be here today and I am also delighted to see so many high-level officials and representatives of the European scientific and research community in the audience. Later on the project's final report, which incorporates the deliberations, conclusions and recommendations of the Meeting of Minds panel, will be formally handed over. Before this, we will use this session to discuss the findings of the citizen's panel and to raise awareness of the crucial and increasing importance of brain research for the non-specialists among us.

Let me conclude by welcoming all of you, all the participants here today. The meeting will conclude at 1 p.m. but before this we have a lot of interesting discussion to look forward to and I hope that you will engage in it as actively as you have done over the last one and a half/two years and thanks for coming.

The Commission's commitment to brain research

The EU Commissioner for Science and Research, **Janez Potočnik**, had prepared a video message for the meeting. Firstly may I say how sorry I am not be able to be here with you in person today. I had hoped to be with you but other commitments unfortunately intervened. This conference has been organised by the partner consortium comprised of the King Baudouin Foundation. Congratulations to all the partners for all their hard work in organising such an original event.

Let be start by mentioning that the European Commission is well aware of the challenges relating to how the brain functions. It is also well aware of the huge threat that brain diseases, such as Alzheimer's, depression or addiction, represent for the European citizens. I remember the numbers communicated by the European Brain Council, stating that close to one third of the costs of all illnesses in Europe were related to brain diseases. It is for this reason that the Commission is currently financing and will keep financing research on the brain and brain related disorders as well as a component addressing mental health in a more general way. We will stimulate coordinated research to understand better how the normal brain functions and to address neurological a psychiatric diseases and disorders. This also includes searching for new therapies.

However, when I had a look at the presentation of the European Citizens' Deliberation Meeting of Minds, what struck me most was the methods used. They are good examples of how we can bridge the perceived gap between European citizens and European institutions in a number of areas, including research. Questions came to me such as: Is what we are doing clear enough for citizens? Is that what they really expect from us? Are there some concerns which we do not take sufficiently into account in our decisions? The easiest way to get the answers to these questions is to listen carefully to each other. This is why the Commission has supported projects which looked to explore the scientific dimension of European governance. The project presented today is one of them.

A new approach for European policy making

So, be aware that your involvement as citizens in Meeting of Minds is important for two reasons. Firstly, it helps us, as policy-makers from the European Parliament and the European Commission, to have a better understanding of your views on brain research. Secondly, it is important to show that we can steer European policy in a new and inclusive way. In a sense, this project is a pilot and we will have to look closely at the benefits it will bring us in the future. In fact, as far as research is concerned, these inclusive approaches are now being used more and more extensively by the Commission services.

Last December, for example, on their initiative, patients organisations were invited to express their ideas on stem cell research. In the field of human development, 26 European citizens presented, in this same building, the results of their discussions. In my opinion, the Meeting of Minds initiative is an important achievement establishing that citizens' participation is not only possible but also highly desirable. In this way, we can put the intellectual and creative capital of Europe's citizens to use in shaping a future belong to all. I am therefore happy to see that our way of making policies is becoming more participatory and closer to society.

I am convinced that this will contribute to more robust European policies. It will also allow people to understand what science is about. This will be beneficial for the future of the relationship between the research scientists and citizens. Thank you for your attention and since it is still January, I wish you all the best for 2006. And, of course, let me remind you, mind your minds!

Presentation of the background to the project

The Director of the King Baudouin Foundation, **Gerrit Rauws**, presented the project. Good morning ladies and gentlemen and thank you Ms Koch-Mehrin for your hospitality and for hosting this event. Thank you also to Commissioner Potocnik for your kind message. Ladies and gentlemen, welcome, again for many of you, to this presentation of the Meeting of Minds project and above all of the results of the Meeting of Minds project. I will be very brief because many people here in the room already know or have heard about the project, but I still think it is useful just to describe the context and the main steps we had in this project.

Tom Wolf, the American novelist wrote somewhere "neuroscience will have an impact as powerful as that of Darwinism". I'm not sure exactly what that means, and maybe it is too early to see if he is right, but it is clearly a sign of the high expectations that exist on the development in neuroscience. It is clear that neurosciences may deliver profound insight into the nature of the brain and may provide solutions for brain disorders. What are we talking about? What are some of these issues? Stem cells injected into the brain to cure disease and slow aging, drugs to enhance performance at school and work, tests to predict Alzheimer's' years before it strikes and the rapid field of brain imaging, certainly to find diseases and disorders but also for delinquency or to monitor thoughts.

It is clear that brain science raises ethical and social questions. It is important, and that is clearly the objective of the Meeting of Minds project, that we need to address these public

concerns and ensure that they are heard and they are acted on. The central question, and Ms Koch already mentioned this, we submitted to the citizens panel is how are we going to use the new-found knowledge of the brain? It is a panel of 126 randomly selected citizens from Belgium, Denmark, France, Germany, Greece, Hungary, Italy, the Netherlands and the United Kingdom. You can look around you and you can see many of them and you can see on the photograph, there are all of them.

How did it go? What was the process? It was a very long process and there were many steps in it. First, the citizens and panel members had to learn about brain research: what is this all about. Then it was important that they could frame these issues, the issues at stake related to brain research, from their own perspective. It was very important that they could understand what the new scientific developments meant and that they could talk about it in their own language, not only the scientific dimension of it, but also the social, ethical and policy-related aspects.

The panel members discussed a lot among themselves, but also with lots of researchers, many of whom are here today and I want to thank them again for their involvement. Researchers from different research areas, representatives of the pharmaceutical industry, representatives of national and European ethical committees, clinicians, representatives of patient organisations and so on and so on. There was very intense interaction at certain moments in the process between the experts and the panel members, both at national level, i.e. during meetings that went on in every country and at European level. The last step is today when we present our findings and recommendations to decision-makers and European decision-makers. It will not end today, it is in fact the phase that starts today.

More concretely, we recruited 9 times 14 citizens in all these countries who were randomly selected. Sometimes about 4,000 invitations were randomly sent out. There was a series of national meetings, the First European Convention took place in June of this year, the national assessments where every country came up with a national report that was presented to national decision-makers in the nine countries, the Second European Citizens' Convention that started on Friday. If you have the impression that some of the people in the room may look a little bit tired, that is possible.

Today we present the report. It only exists today in English. It will be translated in all the other languages involved in this project but not before midnight. Then as the last step in this process, we will organise a series of what are called policy advice and dissemination events both at national and at European level and there is an independent evaluation because we thought it was very important to learn lessons from what happened. It has been said that this was an initiative of the partner consortium of 12 organisations from 9 different countries. We started in 2004, it has been coordinated by the King Baudouin Foundation and it got a very large amount of support from DG Research within the framework of the Sixth Framework Programme and, more specifically, the science and society action plan. Here you will find a list of all the partners and I want to thank them again for the very close, constructive and inspiring collaboration.

I think on the method, and I will be brief, that it is true to say that it is the first public deliberation at European level on new development in science. It is the first method of

delivering interaction between citizens with different cultural and linguistic backgrounds. We all learnt how difficult and how interesting that was at same time to have people with different linguistic backgrounds and different languages and yet guaranteeing a real open discussion. It is a new method but based on the long-standing expertise of all the partners involved. As the Commissioner mentioned in his speech, we are convinced that it can serve as a pilot for EU-wide public deliberation projects in other policy areas. That is all I wanted to say and now it is over to the most important part of this morning: the presentation of the results. I would like to hand over to Andrea Fischer.

Presentation of the Final European Citizens' Assessment Report and Outcomes of the European Citizens' Deliberation on Brain Science

Andrea Fischer. Ladies and gentlemen. The people who were not at the Convention have been able to receive a bit of an overview of last weekend. The responsibility and the task of the citizens taking part in these deliberations was to make recommendations that would be given to political figureheads. Ten citizens that have taken part in this process will be presenting the results to you. They come from each of the countries that took part in this process. This has become a very comprehensive report. You have the report in English and, of course, we have to be quite brief, unfortunately, at the panel which means the contributions will be limited to a summarised form of the recommendations and the presentations underpinning these recommendations will be short. We are not trying to reduce your speaking time but we do need to be quite brief and you have the comprehensive explanations behind the recommendations in the report. I would like to welcome the German and Hungarian citizens to give an explanation of how it all started.

How I got involved: a personal account

András Gelencsér. When I first got the letter from Meeting of Minds, I was dubious. I thought that it was advertising and that you had to buy something and then you could travel to Brussels. It was only after the second round that I was sure it was a really serious thing. However, it was a huge task at home to explain my role in the process. The first question my friends asked me was: what kind of a connection do you have with brain science or research? After the hard work of this long work, I can now see everyone's connection with brain research in a way.

Cultural differences...and similarities

Cornelia Dodt. Yesterday evening I thought about writing something down about my European experience, but instead of that, I found myself together with our European friends in front of the hotel bar, which was closed, singing and dancing with Guillaume playing the guitar, the poor man played for three hours. But, by singing and dancing you could also see that it does not matter which country you come from.

During the first European meeting in Brussels, we had the chance to sit together at big round tables with participants from five different countries speaking five different languages at one

table. We had interpreters at every table and they had a difficult job with us. We had to be patient and listen and wait for the translation. We exercised tolerance and in the end I was astonished to see how similar the opinions of the European citizens were, and still are. This time, we were seated on national tables and discussed in all nine different languages whilst wearing headphones.

The German language often has a lot more words in a sentence than other languages and therefore in order to receive a message in German, we had to wait a long time for the whole translation to come through. This led me to the conclusion that perhaps our European friends thought we had no sense of humour or were a bit slower than everyone else because they were all laughing and clapping and we were still trying to listen. Sometimes, our message was not entirely understood and some of our suggestions were rejected for this reason. However, we did have the opportunity to make our points once again which we were very happy about. We feel that a Meeting of Minds in this format will always be somewhat problematic but this Meeting of Minds was an excellent example of the European thought and European common interest in brain research, which can actually bring people together. My personal thanks go to everyone who took part in this event, and particularly to the German team.

András Gelencsér. Personally, as a European citizen I am really satisfied with the outcome and I am proud to be a part of the process even though at the start I had some reservations about working with lots of different people in different languages. We had amazing interpreters who even put humour and sometimes irony into the translations. But it was not just the translations who were professional, but also the organisers and coordinators. I can confidently say that it was good to have professionals who paraphrased our ideas and views in a proper way in the field of brain research.

I would also like to say that I was very happy to be able to meet so many very nice people. Any time a problem arose over the last two days we were always able to work through it. I am sure that I will never forget the time I spent on the national tables and all the conversations in Budapest, in the pubs and houses where we met. We had a very good time, we did a lot of serious work but we also laughed together. Thinking back to the last couple of days and the results we arrived at together, I think that we can all be proud of having worked together with all the members of our own teams and with everyone here. I am very grateful to everyone here.

The recommendations

Herman Depré from the Flemish panel presented the recommendations for the first of the six themes: Regulation and control. On the first issue discussed, ethical control, we made the following recommendations:

1. Pan-European ethical committee

Currently, ethical committees in European Member States have mostly an advisory role, producing formal opinions that can eventually be transposed into laws, but ultimately it is the politicians that set the rules. Moreover, not all Member States have a national ethical committee. An increasing number of drug experiments are conducted in the new European countries because regulations are less strict there.

Applications of science and technology are currently being used on commercial grounds without any ethical oversight in Europe. These are only occurring at local levels and on small scales, but they provide a warning that things evolve very rapidly. We need some sort of common acknowledgment of these ethical issues, or the problem will just be shifted from one country to another.

Finally, most brain research today is being done in the USA with consideration for ethical aspects throughout the entire process. It is time that we created our own common European references; this common agreement should nevertheless respect the cultural aspects of ethics of individual countries.

- **We recommend setting up a pan-European ethical and legal advisory committee.** We want this committee to stimulate debate and lay down guidelines for brain sciences. It should draw on the results of national committees, integrate existing European agreements and include representatives of national ethical committees and of European stakeholders organisations (health care, patients families, carers, citizens ...). It should respect regional and national cultural differences.

2. Informed consent for brain-imaging techniques

The recent developments in brain imaging are increasingly causing invasion into individuals' privacy, be it privacy of medical records, privacy of potential predispositions to diseases or behavioural disorders, or even privacy of thought.

The use of brain imaging for pre-emptive diagnoses is a good example of a questionable use of brain science in society. The fact that some governments are actually planning on screening very young children for early detection of brain damage that could lead to delinquency (by means of behavioural assessment). We fear that brain imaging could become an instrument of discrimination in the near future.

- **We recommend imposing an informed consent regulation for brain imaging techniques. These techniques should be prohibited for use by the police or in judicial investigations or for public security reasons.**

On the second of the issues discussed, involving citizens in regulation and control, we made the following recommendations:

1. Dialogue between citizens and science

An initiative like Meeting of Minds showed us that scientists often appreciate hearing the opinions of lay people. They can even benefit from this kind of dialogue and feedback on their work. Therefore, the organisation of research throughout Europe should not only accept the dialogue with citizens, but should encourage it. Of course, it can be questioned whether this is not only wishful thinking, but we are convinced that citizens can be involved and motivated by being given comprehensive information.

- **We recommend organising advisory citizen participation at regional, national and EU levels.** We recommend that research universities, science organisations and pharmaceutical companies organise citizen participation at regional, national and EU level to give feedback on their research work.

2. Common methods for citizen participation

There is a need for citizens to be sure that research funding is oriented where it is the most relevant for the patients, and we think citizens can influence the direction of funding. We also

think that the participation of citizens, NGOs and stakeholders in ethical panels would help increase public confidence in research. Moreover, if citizens could be involved very early in the research processes and clinical trials, this could turn out to be more productive because of greater comprehension and confidence throughout the whole process. It would maybe change the way results are released towards better transparency. We want to be reassured about the maintenance of quality of life for patients into research and we want to be sure that all these techniques are used strictly for treatment and research and not for any manipulation of the brain. Finally, it is also very important that the voice of families and close relatives of patients should be heard.

- **We recommend establishing common European methods for citizen participation organised by national democratic institutions.** Citizens' voices should be heard, even if they don't make the final decisions. We therefore recommend that citizen participation is organised in every Member State according to common methods of debates, exchange and mutual learning, within national democratic institutions. The setting of priorities in the direction and application of brain sciences could be one of the areas of concern for this participation. If final decisions are to be made at European level, they must respect regional and cultural differences.

3. Transparency and information flows

Citizens have to be kept informed about what exists as prevention to stop diseases from aggravating and as newly found treatments. Good quality, honest and accessible information about the results of research is a necessary condition for that, and we are convinced that the involvement of citizens will be facilitated if an effort is made to bring that knowledge to them.

- **We recommend improving transparency and information flows to motivate and empower citizens to participate**

Gerda Hempel from the Danish panel presented the recommendations for the second of the six themes: Normalcy vs. Diversity. Luckily, no one in this room is normal, luckily, all of us have the possibility to change and expand our brain potential throughout life. The news about the dynamic brain will indeed influence our way of thinking of ourselves as dynamic creatures who can change, learn and create. Diversity is a necessity for development and a constant source of richness in society and a main principle for a democracy to guard. Luckily, none of us here are normal, we are just diverse.

On the first issue discussed, diversity as a source of richness in society, we made the following recommendations:

1. Promote diversity

Diversity and accepting diversity are very positive elements in society. It is not the world of science that questions diversity but rather society at large that might doubt whether diversity is richness. Our goal should be to inform all levels of society.

The European Parliament should make sure that diversity is taken into account in the schooling system and the workplace.

- **We recommend implementing a lifelong method of providing education and information so that people are aware of diversity.** Awareness should be raised amongst teachers, health care professionals and social workers about diversity during their training so that they can raise the awareness of the people they meet in their professional lives. Public

campaigns and TV programmes should be developed to provide people with better information to prevent stigmatisation. There need to be more experts whose fields are education and school psychology.

2. Foster integration

People have to be able to participate in their conventional environments, where possible. When it is not possible to integrate, we should work on acceptance. Nevertheless, we need also to recognise and accept differences and not try to integrate at all costs.

- **We recommend promoting the integration of and tolerance towards children and adults with psychiatric or neurological conditions in their homes and neighbourhoods, and at school and work.** The government has to provide the necessary resources to achieve this in a constructive way and should enlist the help of specialists.

3. Avoid medicalising society

- **We recommend clarifying which variations exist within ‘normality’ and what should be interpreted as a ‘real’ disease in order to avoid unnecessary treatment and medicalisation of society.**

On the second issue discussed, promoting brain research, we made the following recommendations:

1. Increase funding for brain research

Research contributes to societal progress, in particular it can enhance the quality of medical treatment. Proper financing of research provides work for more scientists and reduces brain drain.

- **We recommend that basic and fundamental brain research (both on healthy and sick brains) should receive more funding. This funding should be increased through the existing European Community research system.** This implies a targeted increase in financial contributions by the national governments to the European Union. The research funding should also be used for communicating the results to the public. It should be independent of the control of pharmaceutical companies. Finally, citizens’ participation should be stimulated to define and monitor the quality of research.

2. Avoid social control

Brain research is important but it should not result in normalisation or social control.

- **We recommend that the EU, in parallel to increasing support for brain research, includes this research in a framework of continuous ethical evaluation.**

3. Focus on prevention and rare conditions

Brain research should have a life span approach that includes the developing, healthy and ageing brain.

- **We recommend focusing part of the funding on prevention. In addition, more research should be conducted on rare brain conditions.**

4. Increase research on alternative treatments

It is important to try to stop or slow down the growth of brain related disorders.

- **We recommend that a part of all brain research funding, both public and private, is earmarked for research on the interaction between neurological causes and causes from the social and cultural environment in order to try to prevent brain related disorders. In addition, more research should be conducted on alternative treatment techniques.**

Isabella Somaglia from the Italian panel presented the recommendations for the third of the six themes: Public Information and Communication.

On the first issue discussed, bridging the gap between science and society, we made the following recommendations:

1. Organise a European information strategy

We think that information on brain science must be easy to understand and presented in an attractive but not too simplistic way (e.g. through the media, Internet, schools, different kinds of organisations). We need to ensure that we have different sources of information in order to preserve the plurality in our societies and ensure that everybody has access to the information.

- **We recommend developing an overall strategy at European level in order to make information about brain science as well as related ethical, social and legal aspects available to a wider public.** This information must be unbiased. In order to ensure this, the information should be distributed using public funds. One element of this strategy should be awareness-raising campaigns. Moreover, research institutions should be required to publish annual reports which are made available to the public.

2. Establish a European information and coordination structure

There should be a reliable source which makes high-quality information available to all citizens (for example, information based on a compilation of scientific publications). This information must be free from economic and commercial interests. The information should cover both the sick and the healthy brain and both medical and non-medical (e.g. psychotherapy) methods.

- **We recommend establishing a European information and coordination structure.** This source could be either a European body or a network of existing European and national organisations whose responsibility would be to disseminate information and coordinate initiatives in the different European countries. For this task, as many existing resources, institutions and information sources should be used as possible. For example, promote the creation of a ‘brainpedia’ database or some sort of centralised database that brings articles on brain science together, to which all citizens have open access.

3. Translate results into common language

We think that scientists should view information sharing with the public as an integral part of their job.

- **We recommend coaching science students from the very outset to use common language when talking about their work without oversimplifying the information.** Scientists should be encouraged to translate ‘brainy’ results and scientific texts into common language, if necessary in collaboration with skilled people (e.g. science journalists).

4. Stimulate interdisciplinary work

- **We recommend fostering interdisciplinary work among scientific experts and between scientific experts and social scientists**, for example by organising annual conferences which are open to the public and are publicised. Enough public funds should be made available for this.

On the second issue discussed, improving education curricula, we made the following recommendations:

1. Focus education on prevention and learning how to learn

It is important to empower people to deal with problems later in life, to take responsibility for the consequences of their actions and to understand how life style influences the brain. They should also be enabled to use their brains creatively.

- **We recommend that education and training raise awareness of the prevention of brain disorders and stimulate learning potential (learning how to learn).** Such education and training should be provided from an early age and continue throughout life. Parents and society should help children to use their brains creatively and teachers should be given resources and the freedom to use them as they see fit.

2. Raise awareness among future parents

It is important to offer future parents the opportunity to educate themselves on the possible risks and potentials for the unborn child's brain. Future parents are free to take advantage of this opportunity but they should be encouraged to do so.

- **We recommend that public funds should be provided to produce information brochures, for example on neuroscience, aimed at future parents.** These brochures could be made available in maternity wards and gynaecologists. Proactive measures should be taken to encourage parents to make use of the information and opportunities available. In addition, the health system needs to provide more time for doctors, midwives and health visitors to provide support and treatment

3. Constantly adapt health (care) education programmes to new knowledge of the brain

There is a gap between the new knowledge of the brain which exists and the knowledge which reaches the target groups in the health care systems. We therefore want to try to use our new knowledge of the brain to improve the information reaching the public (children, teenagers and adults of all ages) and various targets groups (e.g. medical students, nurses, doctors) and to keep them up to date with the latest developments in the field.

- **We recommend supporting or revising health (care) education programmes at all learning levels so that they take account of the most recent developments in our knowledge about the brain.** An important topic in these programmes could be the influence of life style and diet on the brain.

4. Constantly adapt the education system to new knowledge of the brain

There is a big gap between the scientific knowledge on how the brain learns and how it is used in practice in the education system.

- **We recommend strongly encouraging both the education and the training system to take constant advantage of the knowledge available in order to improve the learning process in all stages.**

5. Engage the responsibility of knowledge producers

It is also important that both public and private research institutes and the (pharmaceutical) industry share and disseminate their research results, both positive and negative, with each other, the general public and relevant target groups.

- **We recommend organising more communication activities.**

6. The role of NGOs

- **We recommend supporting NGOs in their role to educate the public on brain sciences.**

Tom Huigen from the Dutch panel presented the recommendations for the fourth of the six themes: Pressure from economic interests. Our debates were very fruitful and, although I may run the risk of oversimplification, I will try to be brief.

On the first issue discussed, balancing public and private funding for research, we made the following recommendations:

1. Incentives for pharmaceutical industries

A way to achieve this is to stimulate pharmaceutical industries to invest more in research which initially they might not find very promising. For example, in the case of rare diseases the potential group of buyers of drugs will be too small to guarantee much profit. Also, pharmaceutical industries will not easily take up fundamental research, because it takes a long time for this type of research to bear fruit financially. This is a problem for society. A way to tackle this problem is to make this type of research, be it fundamental or applied, financially more attractive to pharmaceutical industries. This could be done by incentives for pharmaceutical companies taking up this type of research. Therefore:

- **Apply additional incentives for pharmaceutical companies to encourage them to take up appropriate research. This research could be fundamental or applied or research into rare diseases.**

On the second issue discussed, the risk of company's economic interests conflicting with public interests, we made the following recommendations:

1. Research for the common good

We want research that is governed by the health needs of individuals, and not by the profit motives of the industry. Therefore we recommend that the EU sets aside money for research in the whole area of brain science. This specifically includes non-pharmaceutical solutions for problems related to the brain as well.

To safeguard this, we want it to be studied where in the field of brain science funds for research are lacking although the public interest is high. Priorities for where EU money is set should also be based on this knowledge. Politicians, NGO's, or other public bodies should consequently take steps to ensure that money is directed to these important but neglected research-topics.

- **We recommend balancing the pressure exerted by the pharmaceutical industries by taking initiatives which are in the interests of the common good. These initiatives should come from politicians, NGO's, or other public bodies which have the common good in mind.**

2. New ways to stimulate pharmaceutical research with low profit-potential

As said before, we would like pharmaceutical industries to take up research, for example into rare brain disorders. Perhaps we could encourage them to engage in research that is possibly not highly profitable by changing the existing rules a bit. For example: one could lengthen the patents on drugs for rare diseases, so pharmaceutical companies will have longer returns on their investments in this particular research. We want the EU to explore the variable length of patents and other incentives for pharmaceutical industries to invest in this type of research.

- **We recommend examining ways of encouraging pharmaceutical companies to undertake brain research with low profit-potential as well as research into long-term consequences of medication and other treatments.** For instance, patent rules must be revised and linked to the turnover generated by a given drug. Thus, the length of a patent may be significantly extended in the case of a rare condition, whereas in other cases it may even be reduced.

Anno Giebels from the Belgian panel presented the recommendations for the fifth of the six themes: Equal access to treatment.

On the first issue discussed, equal access to treatment options across Europe, we made the following recommendations:

1. Equal access to treatment

It is a fundamental right of the person to have equal access to treatment regardless of his or her age, sex, origin or social status. Even if we don't know how this can be reached (this is beyond our knowledge), we think that it is a duty of EU to find a way of guaranteeing this equal access to everyone with reference to cost-effectiveness. Ideally, we should even guarantee the upgrading of quality of life, and not just guarantee quality of life.

- **We recommend that the EU should look into long-term priorities on how all European citizens can have equal access to equal treatment within brain science, also with reference to cost-effectiveness without discrimination (age, sex, origin, etc).**

2. Priority to research into brain disorders

- **We recommend that the EU prioritises research into brain disorders in the 7th framework programme and strategically allocates research funds in order to save costs in the future.**

3. Evaluation of the effectiveness of new treatments

New treatments and technologies need to be objectively evaluated for their effectiveness. These assessments should be communicated widely in order to inform patients as rapidly as possible about their existence. Information generated by research should be used.

- **We recommend that a European body evaluates and communicates throughout Europe the effectiveness of new treatments and technologies so that they can be used as quickly as possible, giving patients access to them.**

On the second issue discussed, acute versus chronic and long-term treatments needs, we made the following recommendations:

1. Enabling families to provide long-term care

Long term care is vitally important. Some chronic patients can come back to normal life after having suffered for years, if they receive the right treatment and decent and adapted housing. Nevertheless the impact of a chronic disease on a family can be very heavy. The person is not productive and care costs a lot. Often, there seem to be much more resources for acute problems while chronically ill patients suffer from limited availability of treatments.

- **We recommend that families and private carers should receive financial support so that they are able to provide care. This support should be a proportion of the amount it would cost to keep the patient in an institution.** Subsidies should be given directly to families, if they can give care. These should cover the considerable cost of certain diseases; including drugs; physiotherapy etc. Where families are no longer in a position to provide the care, they should be enabled to pay a carer. This could be facilitated through special social security schemes or dedicated insurances. A control system in case of abuse of subsidies must be developed.

2. Providing professional multi-disciplinary care teams

We believe it is important for patients to be able to live in a family environment. Old people, chronically ill people should be looked after at home, where possible, because institutional care cannot always give the affection and loving care of a family. If they can live by themselves, professional care should be provided at patients' homes by professional multidisciplinary teams. We think it is important to improve the image of all the professionals working in this field. Day care centres are an important alternative but they often have long waiting lists.

- **We recommend that the EU urges national governments to provide patients with a professional multi-disciplinary care in a family atmosphere or in their own home. Where patients are hospitalised conditions should be comparable.** This should include care and associated services, and they should be delivered through small and medium sized structures which are more human to live in. Patients should be provided with equipment, hospital beds, and help with rearranging homes so that they are able to stay there.

3. Ensuring dignity and quality of life for chronically ill patients

We find that long-term patients are often not given the best possible treatment, including the most up-to-date drugs. Expensive treatments for chronic disease are under pressure because of more risks are falling out of health insurances. This affects our societies as a whole. Therefore, we strongly believe there should be no discrimination between acute and chronic phases.

- **We recommend that the EU should establish a guideline for national-level medical assistance to ensure dignity of life for chronically ill patients.** This guideline should pay particular attention to improving care levels in hospitals but also minimum standards for non medical treatment. It should establish a quality control system for medical and non medical treatment within the national health care systems.

4. Helping in the acute phase to enable long-term quality of life

If you can provide excellent help in the acute phase of a mental or brain related disease, you can give the patient more chances to get back to an enjoyable quality of life. You shouldn't wait till the disease has become too severe even if the person will never recover. They should be given a chance to live a normal life in society. It also means that you invest in the human being by giving a chance to that person to be integrated in society. This doesn't necessarily mean the working society, because, for instance, old persons can have an important role without working (e.g. babysitting their grandchildren). This would also save long-term costs.

- **We recommend that the EU urges member states to provide excellent help for the acute phases of chronic mental illnesses in order to increase the eventual chances of that person to lead a “quality life” and to be integrated in society.**

5. Preventing mental illnesses and psychological problems

Prevention programs can sometimes prevent people from falling into a vicious circle. They need to be directed at the family level where they are most important. We need more channels for prevention, for instance directed at school children's problems. Given that age-related diseases are a large part of chronic diseases, and ever more important in the context of the ageing population, funding for prevention in this area would also be wisely spent.

- **We recommend that the EU encourages programs for prevention in family and education tasks to minimise mental health issues.** This should include educational programmes directed at families helping them prevent mental health issues. Also, schools, sports and music should be included.

Guillaume Le Royer from the French panel presented the recommendations for the last of the six themes: Freedom of choice.

On the first issue discussed, helping impaired people to make a good, informed choice, we made the following recommendations:

1. Choosing a trusted person

We saw a need to discuss who could be of help in situations where people, due to their brain problems, can't make a proper choice for themselves. We came up with the idea of a 'trusted person'. By a trusted person we mean someone who takes decisions for you in case you yourself cannot do so anymore. Because this trusted person might become so vital later on in your life, we think you should be able to choose this person at a moment when you still have all your faculties. It is also important to be able to make a living will when you still have all your faculties. It should be possible to give this choice a more formal status, along the lines of a written explicit wish. Therefore,

- **We recommend devising a procedure on European level for choosing one or several trusted persons.**

2. Guidelines for trusted persons

Of course, the position of this trusted person is a very delicate one. Their task may well become very heavy, so there should be local systems of support for these persons. On a EU level however, we see the need for broad guidelines concerning these trusted persons. Here the focus should be on the interests of the patients. The guidelines should regard the legal

responsibility of trusted persons – and the limits of their responsibility. Guidelines should also include criteria to determine who qualifies as an appropriate trusted person. A body of experts could look at regulations in other countries to set up a framework for these guidelines.

- **We recommend to install guidelines for trusted persons**

3. Information for people with brain conditions

In the field of brain-sciences, information is particularly complex and hard to come by. Therefore we think EU parliament should create an independent body responsible for impartial information, advice and mediation for those with brain conditions. This body should function like an ombudsman, which means: it should be impartial and informed, and have the power to work on behalf of citizens. This body should also be sufficiently culturally diverse, accessible, and within anyone's financial means.

- **We recommend to install a body which ensures impartial information and mediation for people with brain conditions**

On the second issue discussed, guaranteeing the dignity and quality of life, we made the following recommendations:

1. Choice for early diagnosis

A special dilemma is laid bare by the growing possibilities to have an early diagnosis. By an early diagnosis we mean: a diagnosis stating one could develop a life-threatening disease later in life, for example Alzheimer's disease. This knowledge may have tremendous negative personal consequences for an individual citizen; it might spoil their life when they are still healthy. If given a choice, they might not want to know this diagnosis. For other citizens an early diagnosis may be positive, because it may lead to better treatment of this person. Therefore we believe it should be possible for citizens to choose, or refuse, early testing and diagnosis. Doctors should only be able to disclose information based on early diagnosis if the patient consents.

- **We ask for the explicit right of citizens to choose whether or not they want to receive early testing or be informed of an early diagnosis.**

The challenges of multi-lingual communication

Stathis Athanassoglou. As regards the difficulties of communication, I feel quite confident that all of us can now deal with such communication challenges and that we can probably write a thesis on the subject. So, if anyone needs any information and communication, we are in a good position to provide it. I am not going to talk about brain sciences, but instead I will talk about the European experience in which I have shared. The report which you have received a copy of now is like an iceberg, it represents maybe 1% or 1/1000 of the efforts that went into this entire exercise and that is what is so great about willowing down. The procedure was quite a difficult one. There were some beautiful moments, such as listening to music until 3 a.m., but also difficult moments. I remember a time in the deliberations which could have proved fateful for the outcome of entire exercise, but fortunately, and I think this is a source of hope, there was a kind of European will for communication, as if the morning sun had broken, scattering the clouds of misunderstanding which had prevailed until that moment.

I think that all of us here are aware of the fact that if we want to see Europe being built, it is only through such procedures that this can happen. These procedures are not easy, they are certainly not straight-forward, nor is there a ready-made blue print guaranteeing success. That is why I was very happy to hear the Commissioner and our chairwoman this morning stress the fact that this is a procedure that will be repeated in future on other questions. I can assure them as a simple 'informed' citizen, that the European Union would have much fewer problems and headaches today and much fewer failures in its record if it had followed this sort of exercise in more areas.

Stathis Athanassoglou. I would like to recall the great Greek poet Kavafis and to paraphrase him in saying that we are not afraid of the Cyclops or of the enraged Poseidon. We do not need to fear any gods or monsters of the sea if we have good feelings and good will and if we know that Ithaca, the homeland of Ulysses, is there and will continue to guide us in our search.

The commitment of the citizens

Anthony Goody. I will now echo some of the things that have been mentioned before. It is important to recognise that there is a lot of commitment behind this process and this report. Citizens have been working through five long weekends spread over almost a year and have also informally been working between events doing their own research, reading documents, researching on the Internet and sharing their ideas.

A lot of thought and effort has gone into this report and there is a lot behind it, beyond just the written word. It has been the work of citizens with a great level of participation and the result of cooperation between the different nations involved. The process has been a great model for sharing ideas and for public participation and it can definitely be used for other European consultations. Such public participation can only help Europe to deal with the important decisions it has in the future. It has been said a few times this weekend that democracy can be a messy process and delicate at times. However, such citizen deliberations can only help to bring people closer to the European institutions that take decisions for them and can only enhance the legitimacy of decisions that are taken in the future. I would like to thank you very much for listening to what we have had to say today and I hope you will find the report useful and will find time to read all of it.

Andrea Fischer. I am sure that on the basis of what we have heard so far, it is clear that one of the main aims of this report is to provide stimulus for public discussion and more activities in the field of brain research. That is why we are very happy to be able to welcome representatives of decision-makers as well as those who have been actively participating in the entire discussion process over the last year. So, I would to very warmly welcome to Mr Octavi Quintana Trias, the Director of the Directorate of Health at DG Research and MEP Philippe Busquin, the Chair of STOA (Scientific and Technological Options Assessment) and a former EU Commissioner for Research. I would like to invite them now to take the floor in order to respond to many of the points raised by our panel members this morning.

Handing over the European Citizens' Assessment Report to:

The Director of the Directorate of Health at DG Research, **Octavi Quintana Trias**, commented on the report. Thank you very much for the report that we have been following for all this time and from which we expect to draw a number of lessons. First of all, we need to understand the use of the recommendations and all this work for us. In our deliberation process, which is rather complicated, the point of view of the citizens is not usually incorporated because there is no mechanism for this. We are now starting experiences working with citizens, namely patients, and having them as an input for our decisions. Our decisions are mainly related to the construction of the research programme, in this case the Seventh Research Programme.

The importance of regulation and communication for the citizens

The first thing that strikes us is that we see that the recommendations and questions focus on two major issues. The first issue relates to legal aspects, regulations and communication of research. I say that it strikes us because we were certainly not aware that the legal issues i.e. setting the limits, regulations and a legislative framework were so important for the citizens. That is a first lesson that has a lot to do with communication in both directions, i.e. from science to the citizens and from the citizens to science, with us as policy makers acting as a bit of a go-between in this dialogue.

The second thing relates much more to the content and here I think that major issues were basic research on everything related to health. Here, the point of view of the patients is very important because they very often realise that it is very difficult, if not impossible, to cure diseases but a crucial issue is to improve the quality of life. I think that when one deals with scientists, this is something that is often disregarded. New therapies and new technologies will considerably change the way that health care is provided in all our countries and we certainly need to keep a close eye on it.

Implementing the recommendations

So, how are we going to incorporate these thoughts into our programme which is currently being discussed in the Parliament and the Council? I would like to highlight a number of important points.

Firstly, the recommendation on basic research or what is referred to as blue sky research, i.e. research that in principle will have no obligations. I think that neuroscience and brain science is maybe the prime line of this research. The brain is the only organ for which we will fund not only the study of diseases but also research about how it works and develops. We know nothing, or very little, about how the brain really works and how the brain develops. We want to focus on these issues and accord it a high priority.

One of the initiatives that some of you may have heard of is the creation of the European Research Council which is a new body. It will have three features that are completely different to what is currently researched at Commission level. The first feature is that

individual citizens will be able to submit proposals, which is currently not the case since they need to be on consortia. The second one is that the topics will not be decided by the Commission, but it will be investigatory driven research so anyone will be able to apply to any topic. The third one is that the only criteria used to evaluate these proposals will be scientific excellence. This is a fundamental step in a completely different direction to that which was previously taken by the European Commission in the framework programmes. I think that we will respond to a very important demand of society, at least scientific society.

We also want to give priority to the simplification of our procedure. This was already started when the Commission of Philippe Busquin was in power and we are trying to continue this simplification process.

One of your recommendations fits perfectly with what we want to do, that is to say provide incentives to industry. Of course, we want to work much closer with the industry and for this reason, we will launch the innovative medicines initiative which aims to respond to scientific problems that the European industry has in Europe. For this, we have already developed quite an extensive research agenda which we expect to fund in the next framework programme. This will depend on the funds we have available, but it is more or less already budgeted for at over 400 million euros per year. It will try to respond to major issues on drug development and will be funded half by us and half by the industry.

The third example is that we are opening up a completely new area that we did not have in the previous framework programmes that deals with what research really works and tries to understand the best ways to deliver health to citizens. It does not just deal with research at fundamental level or clinical research, but it also deals with how these research outcomes are translated into clinical practice and how health care systems are organised and which are the best and worst examples.

We have a major interest in brain diseases and a long history of funding rare disease. We were the first funders in Europe of rare diseases. This is certainly an area where the European dimension is essential because we need big numbers and with the regulators in the Commission we have succeeded in providing good incentives for the industry.

As regards incorporating citizens into our policies and regulation, we will do this by including citizens, and especially patients, in our decision process. We want them to be in at least two main areas. One is the advisory group, which advises us on how to build the programmes where there will be a lay person who will give us the point of view of a non- expert. The second is that we will also include citizens and patients in the evaluation stage to select which projects will be funded. This is an exciting new element which should also allow us to incorporate this point of view into our work

So, you can see that we take your recommendations very seriously and that we expect to keep this dialogue in the future during the whole duration of the framework programme.

"An example of how well Europe can work"

The chair of STOA, **Philippe Busquin MEP**, commented on the report. As a member of the European Parliament in the present term I would like to speak very briefly about methods and particularly stress that I am very happy, as I'm sure are many of my colleagues, to welcome you here in your house, because the Parliament is the house of Europe's citizens. Therefore, the initiative which was taken to hold this meeting here, to bring citizens here together and to host a meeting on this very complex and challenging question and then coming out with a final document of recommendation which needs to be put into practice is an excellent example of just how well Europe can work. I must say I was particularly struck by one of the points I found in reading through your report which said "This is the first time Europe has asked my opinion, today I feel entirely European". I think that was a Greek participant who had said that he had felt European because his opinion was being asked.

It was not easy to organise such an event. As you have seen yourselves this means that each of you must be personally committed to success. It is a very difficult organisation event and therefore I am happy to see foundations involved such as the King Baudouin Foundation, which is very close to my heart because it is a Belgian organisation. I was happy to see this institution take the very important initiative to establish a link between science and citizens and politicians. I was also very happy to see that scientific and technological evaluation is being taken on board here as well so that we really can build a bridge between science and citizens. This really should allow the debate to be organised at national level initially but to end up having a European dimension.

A timely event on a crucial issue

It is in this spirit that at European level we have been trying to work in the STOA, of which I am Chair, to set up a network of various national scientific evaluation bodies. You also have selected a very important subject, that of the mind, of the brain and of course in the Commission we look at research. I was responsible for research in the Commission so I have been involved in the whole background to this. But it is very important to involve the citizens in these deliberations as well. In fact, you might know that right now as we speak there is a meeting going on in the Albert Borschette centre, the building of the Commission, on the whole question of science and society. So, this is a very, very timely and crucial question.

We in Europe feel that we have a community of values, we also feel the need to develop quality research, enhanced research and to focus more of the actual meaning of scientific research and development. The whole theme of that other conference, science and society, really reflects that. Only by working in a complementary or supplementary fashion between people in research and in political posts can we get more research focused on rare diseases. It is in that way that we really can bring about better cooperation between scientists and decision-makers in the future.

So, thank you very much again for your work. I can assure you that I will give very serious follow-up to this report. I am a member of the Parliament and a member of the body I mentioned before, the STOA which is in charge of scientific options and assessment. We will be looking at the new research framework for research and development for the next period and we look forward to founding that on active cooperation and involvement of citizens. We will try to make sure that the results of your work will actually be put into practice in a way that European citizens can understand and which will be to their benefit.

Dialogue with European Citizens' Panel and European Policy-makers, Experts and Stakeholders

Congratulations!

Mary Baker from the European Federation of Neurological Associations (EFNA) and the European Brain Council. I would like to congratulate the meeting on what has been achieved and I do not think that anybody can disagree with any of the recommendations. However, the challenge now is how to change fine words into fine deeds. I think all of us have to take a responsibility for that. Certainly in my life in the non-governmental organisations, we have got a lot of work to do about educating the people we are trying to help, to get that information out to them and to engage them much more in the deliberations. That is a challenge because not everybody wants to. But you want to try to bring them into the decision making process because there is no doubt that people living with brain disease are experts in their same way. Nobody knows better what it is like to live with these illnesses and I certainly want to pick up on Dr Quintana Trias' point about it is not all about cures, it is all about improving the quality of life and managing the knowledge that they have to make a big impact not only on their own lives but on their family's. So, I think we have a responsibility there and it is something we want to take ahead.

The other thing I want to say is that we have to lay aside a number of prejudices that we all carry, the baggage that we carry in society. The pharmaceutical industry is not always greedy, it can be incredibly helpful. Doctors are not always patronising, they can make wonderful partners. Policy-makers do not always not listen, we are very fortunate I think at the moment because we have a Commissioner and a Director who do listen and who have been very instrumental in engaging with the patients. And patients are not always ignorant, they bring much to the table and they deserve the name of expert patients. I think it is a challenging time and I look forward to working with you and I really most sincerely congratulate the King Baudouin Foundation, very, very well done.

Good mental health policies and good mental health: key factors in today's society

Georgina Georgiou, Cabinet of the Commissioner for Health and Consumer Protection, European Commission. I would like to start by speaking a bit from the health perspective and by again congratulating the project and the report. Although, at a first glance, I have some comments that I would like to make, but I would rather keep them until the end of the speech.

Good mental health is essential for the quality of life of individuals and their ability to perform their social and economic roles. However, mental health problems are frequent. Recently, a study by the European Brain Council found that 27% of people in the EU experience a mental disorder in a year. The WHO estimates suggest that every fourth citizen undergoes a mental health problem at least once during his lifetime. Hence, it is clear that mental disorders are frequent and we know that the share of mental disorders in the burden of disease is high and increasing. Mental disorders have severe implications for individuals and societies. They create human tragedies firstly for those concerned and their families. Suicide, often a result of mental disorders, kills more people in the EU than normal car accidents which are estimated at around 50,000 per year, while suicides are estimated at 58,000 per year.

In addition to these, the social and economic implications are equally significant. Mental disorders cause a loss of about 3-4% of the EU's GDP, mainly through the loss of productivity and the risk of social exclusion for people with mental disorders. For instance, people with mental disorders are among the groups with the lowest access to employment. At the same time, the importance of it has been long under-recognised in the health sector and societal environments such as schools and in the workplace.

Under the current public health programme for the period 2003-2008 and previous programmes, the Commission's Health and Consumer Protection Directorate General has supported several European projects to get more information about the prevalence of mental disorders and about possibilities for the promotion and prevention of these disorders. We learn from this work that prevention can contribute to tackling disorders. The mental wellbeing of people is a consequence of many factors including genetic disposition but also their life experiences. It is necessary to make life environments, such as schools or the workplace more friendly so that people can adapt better to their societal expectations. From the various funded projects we also understood that these disorders are not just the problem for medical concerns but also a societal concern. For instance, the stigma around mental disorders creates a second suffering for the mentally ill. And social integration including good employment conditions can significantly improve the wellbeing of the mentally ill.

Last October, the Commission presented a Green Paper on mental health as a first step towards the development of a strategy on mental health. The focus of this paper is on the promotion and prevention social inclusion and fundamental rights as well as the need for indicators, information and research. The Commission launched this Green Paper in order to promote ownership in a possible strategy because it is a precondition for its proper implementation and impact. The consultation on this Green Paper is open until the end of May 2006.

All that I have just mentioned is interlinked with this project because we consider that brain research did lead to the development of new and better drugs and other forms of interventions. They drastically improve the quality of life of people with mental illnesses such as schizophrenia or Parkinson's disease. The prospects of brain research are indeed not just important but also very exciting. Medical intervention as the result of such research is a key element in tackling mental disorders. However there have been many discussions on the undesired effects of some drugs and whether some anti-depressants can increase the risk of

suicide in children and so on and so forth. There is also currently a discussion about whether drugs against attention deficit and hyperactivity disorders might be prescribed too often. Despite that, the overall effect of these possibilities for intervention is so positive that we could not wish to miss them.

Still, brain disorders and brain research and treatment involves important questions such as about our concepts of normality or how to enable people to function well, through drugs or changes in their environment. Brain research is clearly very important to society as a whole. The Meeting of Minds project is an excellent initiative bringing the citizens closer to policy makers on such important questions raised by brain science as well as bridging the gap between science and society. As the report rightly says, it is the lives of citizens that will be the most affected by the advances in brain science. Therefore, I very much welcome this report as a valuable contribution to the public debate about what is feasible and what is desirable in brain research. Thank you.

Bridging the gap between science and society

Philippe Galiay, Directorate Science and Society, Unit Governance, DG Research, European Commission. I would like to say that I am very happy to be here today because I think that the preliminary contact that we had between the Commission and the Foundation and Andrea dates back three years. So you already have a year and a half behind you, but, please bear in mind that this project has an incubation history that is quite long and rich. So, it is the product of these three years of efforts that I see here today. I think it is very positive for the King Baudouin Foundation and for me as well, personally.

So, I would like to thank all the citizens first who took part in this Meeting of Minds exercise and I would like to say that I am very grateful to them for having spent and dedicated so much time to this exercise, which is really an exercise that is quite extraordinary. I would like to thank the people who contributed to the achievement of this project, most importantly the King Baudouin Foundation but other partners as well, which have perhaps remained unnamed but which are important nonetheless. I would like to congratulate our American friends, Mr Daniel Stone and Caroline from AmericaSpeaks that brought a lot of know-how and a dynamic atmosphere to the process.

I am part of the Science and Society Directorate at DG Research and you heard Mr Baer on Friday who is the director of this Directorate General. It was created by Philippe Busquin who spoke to you a little earlier on and I am very grateful to him for that. The purpose of this Directorate is to promote the harmonious integration of science and technology in European society. So we kind of push people in the Commission to become closer to European society and we have several ways of doing so. Firstly scientific communication, also working on awakening the interest of young people in science, encouraging women to take part more significantly in the scientific world and we also work on the relations of science and governance. In terms of what I mentioned last, this covers mainly three aspects. One aspect is linked to risk in society, be they natural risks or risks that spring up from scientific progress. It also covers the best use of scientific advice in the political world and also to guarantee the optimal participation of citizens and civil society in research entities and research-based entities.

As regards the funding of the project of the Kind Baudouin Foundation, I am not going to go into detail about what we have done with the Foundation since 2001 but let it be known that it was the first time that the Commission invested close to 100 million euros between 2002 and 2006 and this is set to continue. During the 2007-13 period, more effort will be made on the issue of science and society. The Commission has earmarked five times more money for this which shows how important this issue is to the Commission.

No doubt you will have noticed some key words in my overview of our activities that reflect the concerns in the papers and the documents that I have been reading since the beginning of this project. I would like to make two additional comments on the document, on the national reports and on what the experts view is of the national reports and what you presented in terms of the final document. In concrete terms and to produce results, there comes a time when you have to get to work and one must underscore that your recommendations affect a large number of players according to the level of governance. So, the Commission can actually encourage initiatives at European level but you also say that Member States are perhaps in a better position to act in their own national framework. Regions and cities can also take part in this debate. This is the case for the dialogue on science and society between universities.

There are also issues that go beyond the mere European framework and that are more to do with international discussions. I do not think you can only regulate in a European framework nowadays, you have to have a global vision. So, each level of governance has a certain amount of relevance depending on the issues addressed and you have to bear that in mind if you want to reach concrete results. There is a second aspect to your suggestions and that is more theme based. Some of these suggestions deal with the brain itself and solely the brain, for instance the prevention of brain conditions. Others deal with the governance on health, you talked about health care systems at European level. Others touch on governance in terms of research, more basic research, the ethical control of research. Finally, others touch on governance in general, day-to-day political life, democracy. That springs to mind when I read some of the things you wrote on information. I think that it is important to bear this complexity in mind in order to be more effective afterwards.

So, in terms of the Commission and our future action, you heard Mr Quintana Trias speak a little earlier on, he gave a certain amount of answers that I am not going to go into now. But in terms of the issue of governance in research, we want to step up our action on the basis of what we have learnt by means of the Meeting of Minds project, that is going to teach us a lot about civil society participation. Thank you.

Public consultation and ethics

Michael Rogers, Adviser Science and Ethics, Bureau of European Policy Advisers, European Commission. Having been involved in two of your meetings, I know just how hard you work and therefore I am sure you do not want another speech. So, I will restrain myself and just make a few comments if I may. First and the most important of all, having read your conclusions and having being present in some of the early confusion, I think you are to be whole-heartedly congratulated as citizens on the clarity of the results. It is really most impressive. I have spent my life, more or less, as a technological optimist as I think I described myself at the introduction of your last weekends' meeting. I have worked in both the physical sciences and the life sciences in a fairly random career path and in the last two years, I have been running this so-called European Group on Ethics. That is the reason why I am particularly fascinated by your project because the European Group on Ethics, which advises the Commission on the ethics of sciences and new technologies, has, in fact, addressed some of the aspects of brain science and we do try to involve the public but it is in a rather linear fashion. My committee is a committee of experts and we then consult citizens through a round table meeting.

The suggestions which you have made for an alternative approach will be of considerable interest to the European Group on Ethics and I will bring it to their attention at a very early stage. One other thing on the opinions which the European Group on Ethics issues and one of your recommendations, the opinions are not, of course, set in stone. Science not only moves on but so do ethical standards and so we revisit some subjects from time to time. One subject which we will clearly need to address in the next two or three years is the issue of brain science. What you have been concerned with is essentially the governance of expertise. What you do with scientific advice, how you involve citizens and the transparency and all the other criteria which we have talked about over the last few weeks. There I can say the Commission, of which I am a minor official, is wholly committed to improving the way in which we govern expertise, wholly committed to improving transparency and you can see that through our communications and through our actions.

But, and there is always a but, to get involved in this sort of thing, is not easy. It requires an incredible amount of effort in order to learn the basis on which scientists and experts might make their presentations, to learn the basis of what is here now and what might be here tomorrow. That sort of involvement is not cheap, it takes a lot of your time and that is another reason why you are to be very much congratulated. We are interested in increasing the training, particularly in ethical principles, which come out of some of the opinions we have issued in the last few years and I think that the training, in the public also, of what we mean by European values and European ethics is critically important.

It has been for me, in my small involvement watching and advising your project, an incredible experience. I cannot say it often enough, I am impressed by people coming from diverse backgrounds from across Europe working in nine languages and communicating effectively one to another and then coming to some sort of conclusion. It goes through hard work, commitment and dare I say it confusion. When I was there on Friday afternoon in the group looking at ethics and regulation and control there was at one point incredible confusion in the

room. Yet out of that confusion came some very interesting and very nice conclusions. So, it was very successful, you are to be congratulated and I am very grateful to have been involved in a small way. Thank you.

Raising awareness

Pierre Magistretti, University of Lausanne and the European DANA Alliance for the Brain (EDAB). The first thing I would like to say is how really pleased and impressed I was to be present at this weekend and the deliberations and discussions which took place and in which I occasionally took part as a resource person. I have to say that it has been a really very enlightening experience. As a neuroscientist and also as someone who is really committed to the public understanding of science, for example by being part of the EDAB, the European DANA Alliance for the Brain, which is an organisation very much committed to promoting public understanding, I can only stress how important we think it is to establish not only a line of information for the public but also a dialogue. I think that really what happened over the weekend and actually over the other four weekends that you had either here or in your countries, had all the characteristics of a dialogue and not only an information line.

I think initiatives such as this have to be encouraged. I think that is what has been done over the last seven or eight years through the brain awareness week, this is one example. I think that what has been done under aegis of the King Baudouin Foundation is simply phenomenal and we see the result here today, a result that I am sure, from what we all heard from the European Commission officials, will have an impact.

I also think that when you go back to your countries, even if we are dealing here only with 126 citizens, I really believe that there will be a snowball effect. Everyone of you will talk to maybe ten other people who then will talk to ten other people and then soon 100,000 people will be involved in this awareness raising. So, I think we should also look at this aspect, which is a very positive aspect. I would like to underscore the impressive amount of energy that has been put into this effort and, of course, the first to be commended are you, who have been doing this with a lot of commitment.

The focus on basic brain research

The second point I would like to make as a neuroscientist is that I was really very impressed that amongst the recommendations that emanated from the citizens, one was to increase support for basic brain research. I am the former President of the Federation of European Neuroscience Societies, which is very strongly committed to basic brain research, and I think it is key even when one is looking at treatment, which is all we have here as a commitment. Basic brain research is fundamental because one never knows what comes out of basic brain research, maybe something unexpected that would be useful in the treatment in a different field of brain research may emerge.

So, I was very impressed and happy to hear from the Director Quintana Trias that there will be an initiative to foster investigatory-based projects which I think complement very positively the notion of networks and consortia which has been supported by the European community. I think that this new dimension, which is very active at the national level and to

which the European community can make a very significant contribution, is to encourage individual scientists who sometimes have good ideas that can achieve appropriate results perhaps relevant to diseases. One of the topics that was discussed during the weekend was the notion of normalcy and diversity and I think these investigatory research projects are actually a sign of diversity which we would all like to encourage.

The importance of interdisciplinarity

Finally, something that has been mentioned briefly today, but was certainly mentioned in the carousels that I participated in was the notion of interdisciplinarity. I think that scientists and science, of course, are the leaders in promoting basic research and clinical research but that interactions with other scientists, particularly when the implications of research for society is concerned, is very important. So this means people from the humanities, from theology, from law, from sociology, from economics. I think that often actually major progress comes at the frontier of disciplines. I think interdisciplinarity between basic scientists, basic biological and medical scientists and other disciplines is a very important dimension.

This brings me to another aspect related to communication and dialogue between the scientists and the public. I think that embedding some of this dialogue within art and culture is something very positive because art and culture is a language we all share. Everyone is on an equal footing on this and one can actually access what could initially seem to be complex dimensions of science through art. I would just like to give you an example, when you listen to a play by Shakespeare, you have a panel of brain disorders that you can relate to very easily through this cultural dimension and then one can work from there on a more scientific basis.

Again, I feel privileged to have been part of this adventure and I would like to thank you all for your attention.

A medicalised or alternative approach?

Dorette Corbey, MEP. Thank you for your invitation to be present here today. Last year in the autumn, I was there at the presentation at the Dutch part of the Meeting of Minds and I have to say that I was very impressed indeed. I attended a discussion about topics that were covered under Meeting of Minds and I thought that the brochures that came out of it and the way in which the dilemmas were discussed were fascinating. I complemented the whole Meeting of Minds project and the recommendations and I would like to repeat that, I think it is really good that citizens are involved in such a way in such a project and it should serve as an example for other issues as well.

Political decisions are made in a very specific way, so as a Social Democrat, I have my views on employer representation etc. But, when it comes to the brain sciences, it is a little more difficult to have a clear-cut opinion. So it is very important for us as MEPs to talk with experts, to talk with patient organisations and with citizens as well. This goes one step further. I think it is important that citizens are involved so directly in the dilemma that involve us all. These are explorations on what it means to be human. The previous speaker talked about Shakespeare and the cultural aspect and the explorations made there. The contemporary

French writer, Michel Houlebec, is actually carrying out some research right now as well and I think it is fascinating that it gives an insight in the future in a form of humanity that has become the same and this begs the question whether we are all heading in that direction.

One of the biggest dilemmas is what you can reach with chemical substances and people. The temptation is to treat undesirable behaviour to treat it and to give it a medical, scientific explanation and to help the problem by giving someone a pill or injection or treatment of some sort. These have become more chemical and this is something that we should be very concerned about. I think that it is very important that this group which has come from different countries, has actually considered and discussed this.

Mental health is a subject that is increasingly on our agenda. As you know, there is a Green Paper. No doubt you have heard about it. It is also part of the framework of research programmes. I think that there should be much more research on mental health, on mental conditions and brain sciences and not to forget the social aspects that accompany this.

Just very briefly, to broaden the perspective a little bit. In the last few days, I looked into the work of previous UN Secretary General, Dag Hammarskjöld. He was a very impressive leader and he also focused on the mental health of the population. The discussion was entirely different at the time, it was in the 1950s and 1960s. He was very attached to the notion of making your mind mature and he thought that there should be a considerable investment in maturing our mental behaviour and he thought that one should deal with things with an adult perspective should not necessarily be combated at a medical level but at a human level. I thought that he was very inspirational and when we talk about brain sciences and mental health, we have to bring in this dimension because spiritual leadership is also important.

It is a pity I was not able to be here a little earlier on. I remember the discussion in the Hague mainly involving access to health care etc. I think that access to mental health care and honest access to treatment has to be one of the core points on our political agenda. In parallel to that, I think that we should not forget an adult approach to mental health and should pay continuous heed to that.

I shall try to bring in this project in the discussions on the Seventh Framework Programme and I think that this model should be replicated. The involvement of citizens and the bringing closer of the citizens to political decision making is very important at European level, and at every other level. I would like to thank the organisations and the participants for all the results that have been delivered here. Thank you for your attention.

Andrea Fischer. I am very grateful to all the experts who have come to our event today and who have made it very clear that this report does represent the formal end of this stage in the exercise but it really will just constitute one step towards the general effort to involve citizens in decision to be taken on brain research in Europe in the future. It is a very encouraging sign for everyone involved I am sure. Our original thought was to have an exchange of views between the people in the plenary and people here at the top table but unfortunately we are not going to have time for that. We do all have to get ready to go back home, there are planes to catch, trains to catch and, of course, we do not want to delay anyone. So I will just leave it by saying that I am very grateful to everyone who has come here today and for having made your

contribution to this excellent result. We are going to hear from Gerrit Rauws and Ms Koch-Mehrin, our host here in the European Parliament.

Closing remarks

Gerrit Rauws. Thank you to Andrea Fischer and thank you to the members of the panel for your very supportive comments.

Ladies and gentlemen,

I looked it up in my diary and on 21 September 2001, I met with Professor Simon Joss from the Centre of the Study of Democracy of Westminster University for the first time. We discussed an ambitious, not to say a crazy, idea: Is it possible to organise something like a citizens conference, which is a Danish invention by the Danish Board of Technology, on a European scale?

As one of Europe's leading experts in participatory technology assessment, Professor Joss has been involved in citizens conferences in several countries. But, despite the inherent international dimension of scientific developments and the gradual formation of a European civil society, no European public deliberation on science has ever been attempted until recently.

Today, more than four years later since that first lunch meeting and together with the Flemish Institute for Science and Technology Assessment, the University of Liège, the Danish Board of Technology, the Cité des Sciences et de l'Industrie, das Hygienische Museum, the Eugenides Foundation in Athens, the University of Debrecen, the Fondazione IDIS Città della Scienza, the Rathenau Institute and the Science Museum's Dana Centre, we can answer the question affirmatively. A European public deliberation on a complex research topic is feasible, and what's more: we've just accomplished it!

Thanks to the creativity, the expertise and the commitment of many, many people, we have written a new chapter in the book of science and technology assessment, and even in a more general book on the interaction between science and society. And I sincerely believe that we have laid the foundations for a new form of participatory governance in the European Union.

In the Meeting of Minds project, we worked with, and I just mentioned them, the most experienced partner organisations in nine countries, the best facilitators, the most creative interpretation bureau and the most skilled science writers that I forgot to thank yesterday, we brought in expertise from the United States, we used advanced technology, we had the support and collaboration of Europe's top experts in brain science, we received additional funding from the European Commission and my own organisation, the King Baudouin Foundation invested considerable financial and human resources. I think it is no exaggeration to say that this combination of expertise and resources is unprecedented in the area of science and technology assessment in Europe.

But, and there is always a but I heard, despite all this, Meeting of Minds was certainly not perfect. Due to its innovative character, we learned by doing, and we learned a lot. But we did it in the most open and transparent way possible, with internal and external evaluation processes and with transparent communication to all stakeholders. Also, in the coming weeks we would certainly welcome your feedback and comments because today is as much a start as the end of a process.

This afternoon at 2 p.m., there is a press conference in the Hotel Renaissance, just two minutes walk from here and I invite all journalists to join us there.

Ladies and gentlemen, it has been said before, but it is certainly true, the most heart-warming aspect of the Meeting of Minds project, was the meeting of minds of 126 extraordinary people, randomly selected in nine countries. They spent more than five weekends working on an issue in which they have no vested interests. They showed great intellectual curiosity, a tremendous amount of energy and brain power and a great sense of European citizenship. Thank you very much.

Silvana Koch-Mehrin. I have the pleasant task of closing this conference. I would like to thank the speakers, I would like to thank Gerrit Rauws. I am convinced that you and your work have left a great imprint on the European institutions. The way in which you have dealt with such a complex topic, your manner of work and the fact that you have reached results has been fantastic. So often in the Parliament and in the Commission, we speak about becoming closer to the citizens and about involving the citizens. I have often forgotten that we are citizens as well, every MEP is a citizen, every Commission official is a citizen, and they have been entrusted with a certain assignment and elected by the citizens.

I think that it is very good to have a view of someone's' daily working life, it is beneficial to you, it will help mutual understanding and no doubt you have learnt a lot from it. There has been a lot of talk about there being a crisis in Europe and that a lot of things do not have a solution to it but I think you have reached a milestone in the way that you have worked and the way you have reached results because if it works for such a highly scientific issue like brain sciences, which is a very challenging topic, then it should work for other subjects as the future of Europe. This is the only way forward, a Europe of citizens where everybody feels good and well and which everyone wants to contribute to the configuration of. So, I think you have made an important step. Thank you for your commitment, thank you for coming to the Parliament today to have a closer look at the representation of the people in Europe.

I would like to close now. I am going to give you a little bit of an English expression here: 'Great minds think alike and fools never differ' and I think that will give us a good introduction to lunch. Thank you for your work.