

37 Recommendations on Brain Science

European Citizens' Assessment Report

Complete Results



Meeting
of Minds
Europe



Public Presentation at the European Parliament, Brussels, 23rd January 2006

Colophon

The European Citizens' Assessment Report is a joint report of the Meeting of Minds European Citizens' Panel

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Table of Contents

Foreword	7
Introduction	9
I. Proceedings of Second European Convention	17
Programme Design	17
Getting started – input into the Second Convention	18
Core design principles	19
Dialogue formats	19
Process design	21
From themes to issues to recommendations	23
1. Theme Regulation and Control	23
1.1 Identification of issues and selection of two issues	23
1.2 Issue 1: Ethical Control	24
<i>Formulation of draft recommendations</i>	24
<i>Presentation of the draft recommendations in the European Cafés</i>	25
<i>Completion of report, reviewing the input received during the European Cafés</i>	25
<i>Plenary review of the recommendations: discussion and adoption of amendments</i>	26
1.3 Issue 2: Involve citizens in regulation and control	28
<i>Formulation of draft recommendations</i>	28
<i>Presentation of the draft recommendations in the European Cafés</i>	28
<i>Completion of report, reviewing the input received during the European Cafés</i>	29
<i>Plenary review of the recommendations: discussion and adoption of amendments</i>	30
2. Theme Normalcy vs. Diversity	32
2.1 Identification of issues and selection of two issues	32
2.2 Issue 1: Diversity as a source of richness in society	33
<i>Formulation of draft recommendations</i>	33
<i>Presentation of the draft recommendations in the European Cafés</i>	34
<i>Completion of report, reviewing the input received during the European Cafés</i>	35
<i>Plenary review of the recommendations: discussion and adoption of amendments</i>	36
2.3 Issue 2: Promote Brain Research	37
<i>Formulation of draft recommendations</i>	37
<i>Presentation of the draft recommendations in the European Cafés</i>	38
<i>Completion of report, reviewing the input received during the European Cafés</i>	38
<i>Plenary review of the recommendations: discussion and adoption of amendments</i>	40
3. Theme Public Information and Communication	41
3.1 Identification of issues and selection of two issues	41
3.2 Issue 1: Bridging the gap between science and society	42
<i>Formulation of draft recommendations</i>	42
<i>Presentation of the draft recommendations in the European Cafés</i>	43
<i>Completion of report, reviewing the input received during the European Cafés</i>	44
<i>Plenary review of the recommendations: discussion and adoption of amendments</i>	44
3.3 Issue 2: Improving education curricula	45
<i>Formulation of draft recommendations</i>	45
<i>Completion of report, reviewing the input received during the European Cafés</i>	46
<i>Presentation of the draft recommendations in the European Cafés</i>	46
<i>Plenary review of the recommendations: discussion and adoption of amendments</i>	48
4. Theme Pressure from Economic Interests	50
4.1 Identification of issues and selection of two issues	50
4.2 Issue 1: Research: the balance of public and private funding	51
<i>Formulation of draft recommendations</i>	51
<i>Presentation of the draft recommendations in the European Cafés</i>	52

<i>Completion of report, reviewing the input received during the European Cafés</i>	52
<i>Plenary review of the recommendations: discussion and adoption of amendments</i>	53
4.3 Issue 2: Economic interest of companies might conflict with public interests	56
<i>Formulation of draft recommendations</i>	56
<i>Presentation of the draft recommendations in the European Cafés</i>	57
<i>Completion of report, reviewing the input received during the European Cafés</i>	57
<i>Plenary review of the recommendations: discussion and adoption of amendments</i>	58
5. Theme Equal Access to Treatment	60
5.1 Identification of issues and selection of two issues	60
5.2 Issue 1: Equal access to treatment options across Europe	61
<i>Formulation of draft recommendations</i>	61
<i>Presentation of the draft recommendations in the European Cafés</i>	62
<i>Completion of report, reviewing the input received during the European Cafés</i>	62
<i>Plenary review of the recommendations: discussion and adoption of amendments</i>	63
5.3 Issue 2: Acute versus chronic and long-term treatment needs	65
<i>Formulation of draft recommendations</i>	65
<i>Presentation of the draft recommendations in the European Cafés</i>	66
<i>Completion of report, reviewing the input received during the European Cafés</i>	66
<i>Plenary review of the recommendations: discussion and adoption of amendments</i>	67
6. Theme Freedom of Choice	69
6.1 Identification of issues and selection of two issues	69
6.2 Issue 1: Helping impaired people to make a good informed choice	70
<i>Formulation of draft recommendations</i>	70
<i>Presentation of the draft recommendations in the European Cafés</i>	70
<i>Completion of report, reviewing the input received during the European Cafés</i>	71
<i>Plenary review of the recommendations: discussion and adoption of amendments</i>	72
6.3 Issue 2: Guaranteeing the dignity and quality of life	73
<i>Formulation of draft recommendations</i>	73
<i>Presentation of the draft recommendations in the European Cafés</i>	74
<i>Completion of report, reviewing the input received during the European Cafés</i>	75
<i>Plenary review of the recommendations: discussion and adoption of amendments</i>	75
Plenary review of recommendations:	
Summary of Sunday 22 January discussion and approval of amendments	77
II. The 37 recommendations on Brain Science	83
1. Regulation and Control	85
2. Normalcy vs. Diversity	87
3. Public Information and Communication	89
4. Pressure from Economic Interests	92
5. Equal Access to Treatment	94
6. Freedom of Choice	97
III. Summary of the Public Presentation of the European Citizens' Assessment Report at the European Parliament, 23 January 2006	99
Appendixes	105
1 Members of the European Citizens' Panel	
2 Synthesis Report on National Assessments	
3 Experts' Views on the Synthesis Report	
4 List of Resource Persons	
5 The Partner Consortium	

Foreword

The extraordinary pace of developments in brain science is challenging society on every level, from defining what it is to be normal to whether drugs can help children achieve at school. Research is moving so fast that it threatens to leave the public behind.

Meeting of Minds – European Citizens’ deliberation on Brain Science is a new, ambitious and lively way of involving the general public in debates about issues of cutting-edge science. Over the past year, 126 citizens from nine European countries have immersed themselves in a melting pot of ideas and discoveries about the brain. They have quizzed leading scientists, heard from interest groups and debated with each other during national and European meetings. The citizens, who came from a wide variety of countries and cultures, had to overcome their differences in order to discover their similarities as regards our new-found knowledge of the brain.

In January 2006, the final phase of the first European Citizens’ Deliberation on Brain Science took place. After a second three-day Meeting of Minds Convention in Brussels, the European citizens’ panel ended their deliberations and formulated recommendations that they compiled in a European Citizens’ Assessment report. On 23 January 2006 the citizens presented their recommendations at the European Parliament and handed over their report to important decision makers in the European Union.

Unlike the European Citizens’ Assessment Report presented on 23 January 2006 in the European Parliament, the present report integrates the results from the different rounds of dialogue used to arrive at the final recommendations. It shows how the citizens went from six themes, to issues and then to the final recommendations. The aim of the report is to make the deliberation process more transparent and to present the recommendations that were discussed by the citizens but that were not included in the final report.

The partner organisations of the Meeting of Minds project, wish to thank the European citizens’ panel for the tremendous work they put into the deliberation process, as well as all the people and organisations that contributed to the process and helped achieve these results. We would particularly like to thank the European Commission for the support it has given to the Meeting of Minds project.

Gerrit Rauws
Director
King Baudouin Foundation
On behalf of the Meeting of Minds Partner Consortium



Introduction

For the first time citizens from across Europe have come together, with international experts, to discuss and compare their views on how upcoming developments in brain science will change our lives. Their recommendations will aid European and national policy makers.

What is Meeting of Minds?

In Meeting of Minds, citizens of the European Union are in the driver's seat in debates that are shaping public policy. The field is brain science, an issue of such importance that it has inspired a unique two-year initiative known as the European Citizens' Deliberation on Brain Science (ECD), or Meeting of Minds. This ambitious and innovative process of citizen participation, presented ordinary people with an unprecedented opportunity to guide the EU in the earliest stages of policy development in a complex scientific field. The Second European Convention in January 2006 was the culminating event in this endeavour. The complete results of this Convention are reproduced in the present report.

The initiative comes from a consortium of 12 technology assessment bodies, science museums, academic institutions and public foundations from nine European countries. They launched the Meeting of Minds initiative in 2004 with the support of the European Commission. These internationally renowned organisations, with long-standing experience in involving citizens in discussions about emerging technologies, have helped to create the precise mix of policy and methodological expertise required to traverse the uncharted territory of cross-national European conversation. Together, they developed the ECD process to provide the opportunity for citizens to hold such dialogue and come up with a truly European citizens' deliberation on an area of science.

At the end of the process Meeting of Minds has:

- provided new insights and specific recommendations from European citizens on the political and societal dimension of brain sciences
- proven that it is not only possible, but also desirable, to draw on citizens' intellectual and creative capital to put a public face on areas previously stamped 'experts only'
- demonstrated that informed and substantive debate between citizens on a European scale is possible, across different cultural and linguistic backgrounds
- pioneered a new participatory governance format that holds promise for policy development in many other fields and levels of government.

Why brain science?

The subject is central to humankind: the magnificent, complex and extraordinary human brain. Brain science today is on the verge of a revolution. It offers us hope, for it is science that will provide primary solutions to brain disorders. This will, of course, be beneficial to patients, but the means and possibilities offered by brain sciences may also help to improve our quality of life. However, concerns also exist.



The breakthroughs in the world of brain science raise fundamental questions on what it means to be human and how we retain our sense of self. New technologies that would alter, enhance or control our brains go right to the core of our identity. How are we going to respond to these extraordinary advances? How are we going to use our newfound knowledge of the brain?

The brain and the perception of its function and meaning are of universal concern. Though policies will affect all European citizens, attitudes towards the implications of brain science tend to differ from country to country due to differences in culture and heritage. The ECD - Meeting of Minds project is the first to incorporate these varying national approaches and provides a unique opportunity to develop a common European perspective.

Why do we need a citizens' deliberation?

A citizens' deliberation is a form of public participation in consultation about science policy. The recommendations of the citizens give policy-makers and stakeholders information on the responses an informed public has to various policy options. For complex and controversial issues, it is the best method available for engaging in the deep conversation necessary between experts and citizens and achieving constructive outcomes.

The ethical, legal and social questions raised by brain science are already being discussed among experts - brain researchers, ethicists or philosophers - in the field. Now, more than ever, it is essential to involve citizens in these debates and the decisions that are made, since it is their lives that will be most affected by the advances in brain science. Creating a forum like Meeting of Minds where scientists and other stakeholders can interact with citizens will result in more informed and wider accepted ideas.

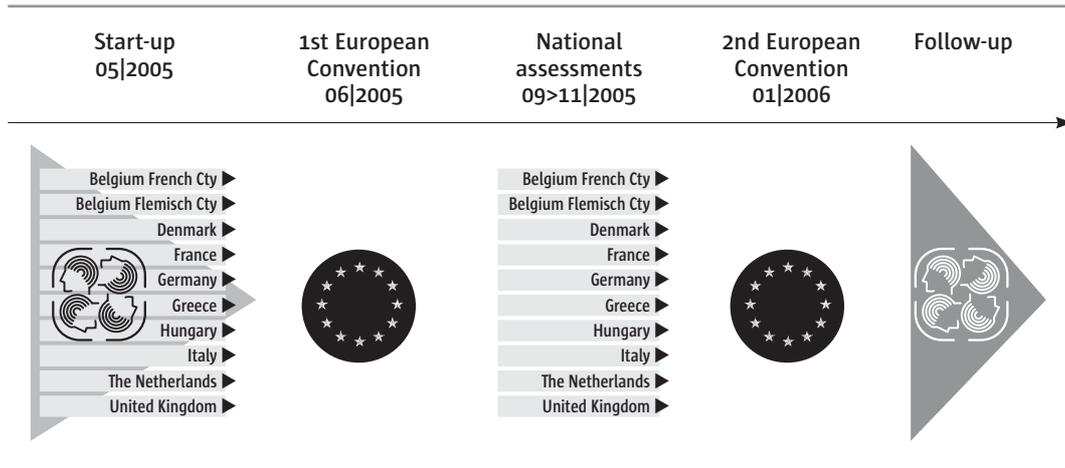
Who are the citizens?

The Meeting of Minds panel is composed of 126 citizens¹ from nine countries: Belgium, Denmark, France, Germany, Greece, Hungary, Italy, the Netherlands and the United Kingdom. In each country², 14 citizens were randomly selected to receive invitations to participate in the project. Panelists were selected from among the people who expressed an interest and in such a way as to ensure that each national group represents the diversity of their country, reflecting a broad range of age, gender and educational backgrounds. No professionals in the field of brain science were invited to sit on the citizen panel, but they were involved at all stages of the process as advisors and expert resources.

- 1 Although at the start the panel was composed of 126 citizens, there were 121 citizens present at the Second European Convention (see Appendix 1).
- 2 In Belgium, there were two panels: one from the Flemish community and one from the French speaking community, each composed of 14 citizens. They met in parallel at national level but merged at European level, where 14 Belgian citizens were selected to take part in voting sessions in the two European Conventions.



How did Meeting of Minds work?



The project consisted of three national meetings in each participating country and two European meetings held in 2005 and early 2006. At the start, the 126 citizens from across Europe were invited to explore the issue of brain science. During the First European Citizens' Convention held in June 2005, a common framework and an agreed set of questions were established, which set out those aspects of brain science that needed to be examined further and discussed in greater depth. National panels took these proposals home and continued working on them at two national assessment meetings. Each panel produced its own conclusions on the desirability and potential of brain science. In January 2006, the Second European Citizens' Convention collected the national conclusions and recommendations and developed them further, producing a European assessment report on brain research issues. This report was delivered to high-level European officials and representatives of the European scientific and research community at a public ceremony on 23 January 2006.

Start-Up: Approaching the challenge

At the start of the process, and to help the panel members begin assessing the complex matters of brain science, a set of provocative case studies was developed, with the aim of encouraging them to think, reflect and contemplate - without stumbling over technical and scientific hurdles. These cases vividly illustrate how new developments in brain research might affect ordinary lives. Panelists were introduced to a variety of brain disorders, including Parkinson's disease, Alzheimer's, depression, ADHD (attention deficit hyperactivity disorder) and brain patterns associated with criminal behaviour. They were also presented with challenging questions such as the use of medication to enhance natural abilities, brain implants, and the moulding of infant minds.

At a first meeting in each country, the cases were presented for discussion. The outcomes of the discussions included a wide range of hopes, concerns, ideas, opinions and questions.



The First European Convention: Understanding the issues and setting the agenda

“ *This is the first time Europe has asked my opinion. Today, I feel truly European.*”

GREEK PARTICIPANT AT MEETING OF MINDS, BRUSSELS, JUNE 2005

In June 2005, the panel members met in Brussels for their first weekend of deliberation at European level. The six case studies served as the starting point for deliberation at this Convention. The method applied was developed to ensure that each panellist could participate fully and to foster the development of genuine European dialogue. The European Citizens’ Panel held a series of individual, round table and plenary discussions, which were supported by an extensive team of professionals. They reviewed their national group’s initial ideas about the case studies and shared them with other panel members to get a truly European view of the issues. By means of dialogue and voting, the European Citizens’ Panel established a common framework and a common set of questions for further deliberation at national level. These were then shared with a wide variety of interested stakeholders, including patient advocacy organisations, mental health associations, ethicists and scientists. The closing session of the First European Convention was open to the public.

The First European Citizens’ Convention provided the national groups with six broader, cross-cutting themes that they could use as a basis to explore brain science topics further.

Regulation and Control: How and by whom can research on the brain and developments in brain science be regulated and information be disseminated at European and national levels so that it is ethically, economically and socially acceptable to citizens, governments and scientists?

Normalcy vs. Diversity: How can normalcy be defined whilst taking into account the diversity of people so that none are stigmatised? Sub-questions included: What kind of mental diseases do medical science consider abnormal? How can we guarantee that a person who is sick has the same possibilities and opportunities in society?

Public Information: How can we ensure that reliable, comprehensive, transparent, unbiased and up-to-date information on all aspects of brain science is available to everybody?

Pressure from Economic Interests: How can we make sure that the economic interests of pharmaceutical companies and laboratories meet the common interests without creating additional unnecessary consumption and treatment needs, whilst taking into account health education, the contribution of alternative treatments and avoiding animal suffering?

Equal Access to Treatment: How can we ensure that all (European) citizens have equal access to adequate facilities, information and financial means?

Freedom of Choice: How can we safeguard patients’ right to choose treatment? Should a brain treatment ever be imposed on an individual? What does a patient need to be able to make a choice?



How did the First Citizens' Convention give all citizens a voice?

To make a genuine European dialogue possible across language and cultural barriers, the Convention used a wide array of innovative methods and technology to support the citizens in their deliberations. Professionally facilitated discussions around small tables of 8 to 10 participants made sure that every panellist had a voice. Each small group included citizens from different countries so that a better exchange of ideas could take place between the countries.

Every table sent its results through a wireless computer network to a central 'theme team', which synthesised the results in real time. At key points during the weekend, the panelists used electronic keypads to vote on results synthesised by the theme team. Interpreters at the tables and in booths during the plenary ensured that at each stage of the process, every panellist could participate fully, regardless of language. In total, eight languages were spoken throughout the Convention.

At the end of the Convention, the participants agreed that they had not only witnessed an intensive and substantial debate on the topics, but also an extraordinary European experience that left them feeling empowered as citizens.

National assessments: Developing opinions and recommendations

In the autumn of 2005, the national panels each conducted two further sessions to gain a deeper understanding of brain science and develop their initial assessments. Experts in the field were invited to these meetings. The citizens were asked to compile national reports containing the results of the deliberations for each of the six themes. The national panels outlined their understanding of the topic and the resources they used (e.g. experts, publications) as well as their findings, recommendations and any questions left unresolved.

“For quite a number of years I have been interested in the creative potential of the brain. There are also a number of brain science issues (mental health, degenerative brain disorders) that have affected my immediate family. I have been very impressed by the structure of this process. It has enabled the perspectives of a great variety of people to be represented in a balanced yet powerful way.”

ROBERT, FROM THE UK PANEL, IS 34 AND WORKS AS A CREATIVE DIRECTOR.

On the basis of the national assessments, a **synthesis report** was created as a common foundation for the Second European Convention (see Appendix 2). The synthesis report identifies the topics that were discussed during the national deliberations. Among the topics that were discussed across all six themes were: improving public awareness and information; emphasising patients' autonomy and individuality; balancing societal and individual demands; strengthening prevention; fostering interdisciplinary cooperation and holistic approaches; addressing the challenge of a long-term increase in neurodegenerative diseases; safeguarding the independence of basic and niche research; aligning treatments and health systems on a European level; and giving a stronger voice to citizens and laypersons. The analysis of the national assessment reports also revealed that sometimes terms, such as 'alternative treatments', can be interpreted differently in the different countries.



The following topics, presented in detail and grouped by theme, emerged from the national assessments:

Regulation and Control

- Strengthening the role of citizens in policy and regulation
- Improving transparency and ethical control of research
- Funding fundamental and blue-sky research
- Broadening the understanding of covered treatment
- Tackling discrimination against mental diseases
- Reforming European health systems
- Extending patients' rights

Normalcy vs. Diversity

- Living with diversity
- Improving treatment of mental diseases
- Strengthening brain research
- Connecting brain science and society
- Enhancing brains and capacities
- Dealing with disease and non-normal behaviour

Public information

- Bridging the gap between science and society
- Making information reliable
- Coordinating new sources of information
- Encouraging information flow between experts
- Improving education curricula
- Linking environment and brain disease
- Determining the role of the media
- Balancing mainstream and alternative information

Pressure from economic interests

- Increasing feasibility of research with little commercial appeal
- Promoting alternative treatments and prevention
- Drawing the line between drugs and consumer products
- Fighting misuse of academic platforms for product marketing
- Acting against over-treatment and medicalisation

Equal access to treatment

- Promoting equal access
- Balancing limited resources in health care
- Defining the quality of health care
- Establishing a common European approach
- Strengthening the public health care system
- Giving priority to helping people with neurodegenerative diseases
- Increasing funding of public health care
- Achieving justice by differentiating

Freedom of choice

- Making informed choice possible
- Making informed consent possible



- Ensuring a variety of treatments
- Create awareness for financial burdens
- Ensuring diversity of research
- Drawing the lines of individual responsibility
- Balancing demands
- Tightening public monitoring
- Balancing individual freedom and public security
- Assessing national law and free will
- Judging “healthy” and “ill”

As an additional supporting step for the deliberations at the Second European Convention, leading international experts were interviewed about the synthesis report topics. They were asked to identify the topics they thought most relevant and fruitful for discussion at the Second Convention and to reveal additional aspects that citizens might want to explore. This expert feedback was summarised into a separate report entitled ‘**Experts’ Views on the Synthesis Report**’ (see Appendix 3).

The experts were impressed by the scope and the depth of the deliberations. They commended the citizens for tackling complex issues and for coming to fairly substantial and creative recommendations. Some of the experts particularly appreciated the fact that citizens had thought about quite far-reaching consequences that go beyond the current political discussions. Most experts commended the citizens for paying special attention to prevention, complementary medicine and alternatives to drug-based treatments. They also noted the focus on the treatment of diseases as opposed to capacity enhancement and other issues. However, they also thought that many topics were not highly specific to brain sciences and actually applied to all sciences or to health systems in general. The experts also thought the citizens should be aware that some of the possibilities they had discussed would not be available in the near future.

Second European Convention: Creating shared results of European citizens

From 20 to 23 January 2006, the 126 panelists met again in Brussels to review the national findings and develop a Europe-wide consensus on the issues and recommendations for action. The second convention was open to the public, and many stakeholders used the opportunity to see democracy in action for themselves.

How did the Second Citizens’ Convention produce joint European recommendations?

The design was different to that of the First Convention but the basic features remained the same: Professional facilitation to assure the widest-ranging dialogue possible among the participants; innovative dialogue formats, including three so-called carousels each containing approximately 40 citizens representing all nine countries; and a European Café setting, where the citizens were able to rotate informally to the two other carousels to learn what had been discussed and to give their input and feedback. During the Convention, the language barriers were overcome with the help of interpreters, and by combining nationalities in different settings to facilitate multi-language interaction. A group of citizens and writer-editors worked together during the Convention to draft the interim and final results of the discussions. During a final plenary session, amendments were introduced and voted on to finalise the weekend's recommendations.



At the end of the Second and last European Convention, the citizens presented their results in the European Parliament on 23 January 2006. They handed over their ‘European citizens’ Assessment Report’ to high-level European officials, representatives of the European scientific and research community and other stakeholders.

“ I consider the whole process important, as the citizens do not own the problems of brain research, but the places and the results of research have an impact on the whole society. This is why the initiative - that people chosen from all walks of life have an opportunity to ask questions relating to scientific problems they are concerned about, express ideas, put forward proposals that could be thought-provoking, creative for researchers, specialists and politicians as well - is so good. This project could, because of its organization, serve as a model for other initiatives with different topics that aim at shaping political decision making on a European level.,,

MAGDOLNA IS A TEACHER FROM HUNGARY. SHE TEACHES REMEDIAL CLASSES.

Follow-Up: disseminating results and policy advice

The end of the deliberation phase and the presentation of the results of the Second Convention in the European Parliament also marked the beginning of the final and crucial step in the ECD process, i.e. the dissemination of the findings and recommendations to policymakers.

In keeping with the goal of policy consultation, in 2006, the citizen panels will present and discuss their findings and recommendations with a wide variety of policymakers and interested parties from civil society.

The challenge of this phase is to maximise the impact of the outcomes of the Meeting of Minds project in relevant EU and national decision-making processes. This will be achieved using different means, such as policy advice workshops, events and other forms of input into policy processes throughout 2006. A list of events can be found on the project website: www.meetingmindseurope.org



Proceedings of Second European Convention

Programme Design

The Second European Citizens' Convention, held between 20 and 23 January 2006, was the culminating event in the ECD process. The result was a European Citizens' Assessment Report on brain science, which provided the European citizens panel's collective response to the developments in brain science. The report covers the findings and recommendations within the agenda set by the six key themes that were identified at the first European Citizens' Convention in June 2005 and serves as an input into policy making.

On 23 January 2006, the report was presented in the European Parliament to high-level European officials and representatives of the European scientific and research community, and civil society organisations with an interest in brain-related issues.

Every day, an average of 260 people attended the Second European Citizens' Convention. This figure includes the European citizens' panel, support staff, resource persons and the general public.

Key roles during the Second Convention

- **121 citizens** – the European citizens' panel – took part in dialogue with a view to reaching a common European perspective on brain sciences and then developing specific recommendations on the six key themes
- **Facilitators:** A **lead facilitator** facilitated dialogue during the group plenary sessions. Three **carousel lead facilitators** guided the discussions in each carousel. They were responsible for the team working within their carousel, they guided the dialogues towards conclusions and they supported the overall lead facilitator during the group plenary sessions as required. In addition, a total of **11 support facilitators** helped the carousel lead facilitators within their assigned carousel. Their tasks included keeping track of time, grouping together and synthesising recommendations, assisting citizens when required - both within the carousels and at other points during Convention - and taking notes during carousel discussions. They organised the 'stay behind' sessions of the European Cafés, moderated these sessions, and facilitated table group discussions during plenary sessions, if required
- **The writers' group:** There was one overall writers' group, which was composed of three sub-writers' groups. Each of the sub-writers' groups was responsible for two themes and was composed of two citizens from the relevant carousel, a member of the steering committee, a writer-editor (providing general writing and editorial assistance and helping with the preparation of the final report for presentation in the European Parliament) and a support facilitator. The overall writers' group was responsible for keeping track of, summarising, writing up and presenting draft texts of the assessments of the issues



- 12 **resource persons** (scientists, policy-makers, patient organisations, civil society associations) provided input into the discussions during the carousel sessions and the European Cafés, thereby helping the citizens to decide what issues to focus on during the sessions (see list of resource persons in Appendix 4)
- Two **producers** were responsible for facilitating the process and keeping a general eye on the design in the three carousels. They provided support to the lead facilitators as and when needed and ensured the general coordination of all the activities
- The **Executive Committee** composed of a number of members of the Steering Committee and lead facilitators, had primary responsibility for the design of the Convention and considered adjustments to the design during the Convention if necessary
- 48 **Interpreters**, coordinated by a representative from CII, provided simultaneous interpretation into eight languages in the three carousels, European cafés and plenary sessions. They translated the carousel results for the plenary session on Sunday
- **Stakeholders** and members of the **public**, including journalists and students, participated in the European Cafés, providing input into the draft assessments. They also observed specific elements of the programme
- **Observers/evaluators** gathered information with a view to writing an impartial assessment and evaluation of the ECD process
- The **Steering Committee**, made up of representatives of each of the 12 consortium partner organizations, is chiefly responsible for the development and implementation of the methodological and participatory elements of the ECD Meeting of Minds initiative. The members, including project managers and observers, provided assistance to the writers' groups, the European Cafés, the translators and the national panels as and when needed during the Convention (see Appendix 5)
- **Project managers** provided logistical support. Oversaw the technical aspects of what happened on the stage (PowerPoints, etc) and the content of the information being presented, ensured that all the relevant material was in the right place at the right time and provided other technical support when required

Getting started – input into the Second Convention

Prior to the Second Convention, the European citizens' panel members received a **synthesis report** of the national assessment reports. The document, based on an analysis of the national reports, summarised the major findings, including the core similarities and differences between the different national groups. As such, it gave the citizens an idea of the results of the national meetings that had taken place in each of the nine countries. The synthesis report was a primary tool during the Second Convention and parts of it were used as inspiration for discussion on several occasions. See Appendix 2.

The citizens also received a copy of the **Expert's views on the synthesis report**. This report included the thoughts and comments of a group of designated experts that had reviewed the outcomes of the national assessments. For each of the themes, they identified the major issues relevant at European level. See Appendix 3.



Core design principles

The method used in the Second Convention, incorporated a number of core principles:

- Ensuring direct integration of the results of the national assessments as the primary input into the design of the Second Convention
- Dividing the group of citizens into workable sub-groups so that the most efficient use could be made of the time available whilst maintaining a sense of unity amongst the entire group
- Allowing for a pace that encourages a sufficient and satisfactory level of thought and dialogue, appropriate to the complex nature of the subject matter
- Involving citizens extensively on the stage during plenary sessions to give a sense of ownership of the overall process
- Providing the opportunity for periodic reflection on the process and making adjustments as needed
- Providing the opportunity to speak in the citizens' own languages throughout the process, either by using monolingual table groups or simultaneous interpretation. Simultaneous interpretation is provided in all eight languages for centre table and plenary discussions in the carousels and European Cafés, and in the plenary sessions of the entire citizen's panel.
- Ensuring that citizens are adequately prepared from their national assessments to come to the Second Convention and that they are receptive and open to people challenging their national findings, thereby allowing the national findings to evolve further into European findings.

Dialogue formats

The Second Convention made extensive use of a variety of methods. Dialogue took place in a range of different settings:

Plenary sessions: meetings of the entire citizens' panel that included both full plenary dialogue and facilitated table group discussions, which were shared with the entire group in some way or another.

Carousel sessions: meetings involving approximately 40 citizens representing all nine countries, two resource persons, support staff and observers. Each Carousel was led by a lead facilitator, assisted by three or four support facilitators.

The basic idea behind the carousel method is that all the citizens are able to make contributions in their own language. There were three stages in the process:

- In each carousel, the citizens start off by discussing in small '**monolingual**' table groups, with 3 to 7 participants who all speak the same language. So, for example, Dutch and Belgian Flemish citizens can be seated at the same table, as can French and Belgian French speaking citizens. It is also possible for citizens who are fluent in another language, to sit at a language table where their mother tongue is not spoken.
- Subsequently, representatives of these tables meet at the '**central table**' to continue the discussion. Different members can participate in these 'central table' discussions in different rounds. Here, simultaneous interpretation in the eight languages is provided.
- The process ends with a '**plenary discussion**' in which all citizens are involved. Again, simultaneous interpretation in the eight languages is provided.



Three carousel meetings were run simultaneously and were the primary working sessions of the Convention. The main function of the carousels was to prepare draft assessments of the six key themes. Each carousel was assigned two of the six themes as their primary focus. Prior to the Convention, the citizens indicated which carousel they wanted to join. They were then seated in the carousel of their choice for the duration of the Convention.

The distribution of themes per carousel was as follows:

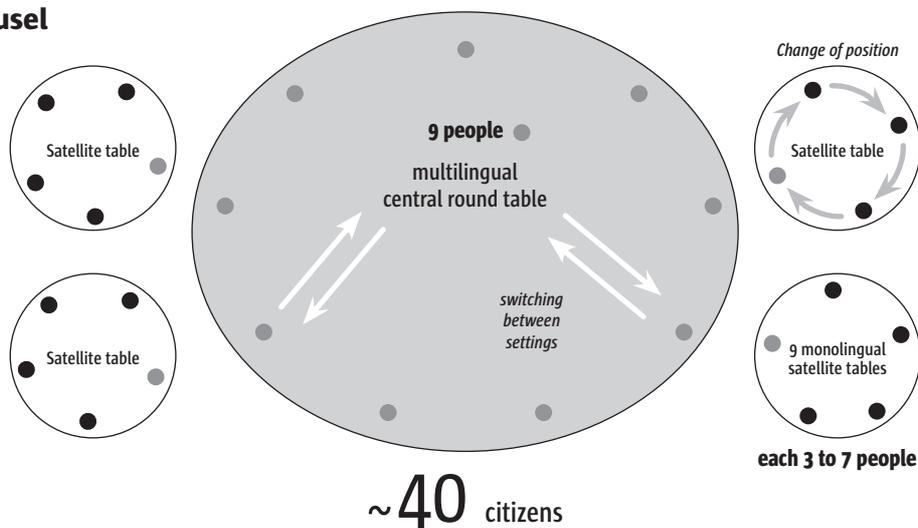
Carousel 1: Freedom of Choice & Pressure from Economic Interests

Carousel 2: Regulation and Control & Equal Access to Treatment

Carousel 3: Public Information & Normalcy vs. Diversity

In each carousel, there were nine small monolingual tables and a main round table in the centre for use at certain points during the carousel session.

Carousel



The small tables were arranged in a circle to enable the whole group to switch focus easily between the small group discussions and the centre table dialogue.

European Café : This set-up is a variation on the World Café. It enables citizens to rotate informally to the other two carousels to find out what they have discussed and to give input and feedback.

In a European Café set-up, there were two rotations. Each rotation was organised as follows: In each carousel, one member of each monolingual table 'stayed behind' whilst the rest of the carousel members 'visited' the other carousels.

The European Café began with a presentation of the carousel's recommendations by an overall presenter (one of the 'stay behinders' in the carousel). Then, the visiting members, seated at monolingual tables, were given the opportunity to consider the recommendations and provide additional input and opinions to the 'stay behinder' on their monolingual table. The 'stay behinder' noted down the feedback so that they could then present it back to their original carousel after the two European Café sessions. Once the first rotation was complete, the visiting members rotated to the final carousel to repeat the process on another theme.



Resource persons and the public were also invited to participate in the European Cafés and to give comments on the draft recommendations. A separate group, led by the members of the Steering Committee, was organised in each carousel rotation session for this purpose.

Process design

The outcome of the process was a set of recommendations for the two issues chosen for each of the six themes.

A good European recommendation is one that is:

- Linked to brain sciences
- Linked to the main Question: how are we going to use the new-found knowledge of the brain?
- Demands action at European level, and/or at national or regional level
- Clear about whom it is addressed to; it should contain an addressee
- Including a rationale: formulate the target, what you want to change, reach: ‘in order to...’
- Potency, significance; power of recommendation: potential impact, innovativeness, what is the impact of not doing this
- Contains an action verb

This section outlines how the European Citizens’ Panel came to their final recommendations.

The following table presents the overall flow of design

STAGE	TASK	OUTPUT
1	The citizens assemble in plenary to be briefed on their tasks in the Second Convention and to set the European tone for the event	Each carousel is assigned two of the six themes to develop draft findings and confirm writers group
2	The citizens assemble in their respective carousel to review the two themes they have been assigned and meet their sub-writers’ group	
3	Theme I: the citizens explore the first theme with their resource persons and agree on the two issues they want to address, which focus on the European dimension of the theme	In each carousel, two issues are identified and selected for the first theme assigned
4	The citizens develop a set of draft recommendations on the two selected issues relating to their first theme	Draft recommendations on first theme assigned
5	The citizens rotate to the other two carousels to review the draft recommendations that these carousels have made on their first themes (European Café)	Input from all citizens, resource persons, and public on the first three themes
6	The citizens return to their original carousel to review the input that has been generated on their first theme and to revise their recommendations	Revised recommendations on the first theme, incorporating input from all the citizens

STAGE	TASK	OUTPUT
7	Theme II: the citizens explore the second theme with their resource persons, focusing primarily on the selected issues they have identified	Input from resource persons about the selected issues
8	The citizens develop a set of draft recommendations on the two selected issues relating their second theme	Draft recommendations on second theme assigned
9	The citizens rotate to the other two carousels to review the draft recommendations that these carousels have made on their second themes (European Café)	Input from all citizens, resource persons, and public on the last three themes
10	The citizens return to their original carousel to review the input that has been generated on their first theme and to revise their recommendations	Revised recommendations on the second theme, incorporating input from all the citizens
11	Sub-writers' group in each carousel drafts the findings on both themes for presentation in the plenary	Draft reports on each of the six themes
12	The citizens assemble in the plenary and review each of the drafts of the six themes, national groups submit amendments	Final confirmation of the six theme reports, vote on amendments
13	Writers' group makes the final edit of the amended theme reports and compiles them in a final report	Final report compiling amended and edited reports of all six themes
14	The citizens present their findings to the European Parliament, media, public and other stakeholders	Final report handed over to policymakers and the public

There were two 'assessment' rounds per carousel. Each carousel considered the two themes that were assigned to it in two separate rounds.

So, in short, the method used to obtain the final recommendations for a given theme consisted of the following steps: identifying the issues and selecting two issues per theme (in carousels); formulating the draft recommendations for each of the selected issues in the carousel; presenting the draft recommendations in the European Café; reviewing (in the original carousel) the input on the draft recommendations received during the two European Cafés; amending (if necessary) and voting on amendments to the recommendations in the plenary. The adopted recommendations were then edited by the writers' group prior to the final presentation in the European Parliament.



From themes to issues to recommendations

Below is an overview per theme of the results from the different steps towards the formulation of the final recommendations, which are reproduced under II.

1. Theme Regulation and Control

1.1 Identification of issues and selection of two issues

The citizens began by identifying for this theme the issues they considered to be of major importance to them and for which they would go on to formulate recommendations for action. They remained constantly mindful of the central question ‘How are we going to use our new-found knowledge of the brain’ during the reflection process. The panelists used the synthesis report, and the comments from resource persons (the experts’ views on the synthesis report and the experts present in the carousel) as a basis for their discussions.

Per theme, two resource persons were present in each carousel. At the start of the carousel, they were invited to comment on each theme, present their views on the synthesis report of the national assessments and draw the citizens’ attention to the topics they considered to be the most relevant for brain sciences and European policy-making. The resource persons were also able to briefly comment on the citizens’ draft recommendations and provide additional information if requested by the panellists.

The resource persons for this theme were Mr Michael Rogers and Prof. Steven Rose.

A list of issues to be discussed further was compiled based on the following criteria:

- the relevance to brain science
- the relevance to policy making at European level
- the extent of impact on citizens

To focus the discussions and ensure that the process during the Convention was workable, the citizens prioritised the issues and chose two for further assessment.

Regulation and control

Issues identified	Issues chosen and argumentation
<ul style="list-style-type: none"> • Ethics: pan-European ethical regulation to strengthen control • Basic research: (potentially for specific groups) • Involvement of citizens • Drugs to enhance or control antisocial people 	<ul style="list-style-type: none"> • Ethical Control <i>How can one be sure that research is implemented in an ethical way? More and more clinical studies are being done in new EC countries because regulations are less sharp there. Moreover, not all Member States have a national ethical committee. We need to strengthen the ethical control at European level - not only for brain science and harmonise it across all member states. We need more transparency in the research for every country but also for the persons who come into contact with experimental treatment. We want to be sure that we can maintain the quality of life for patients enrolled in such treatment. The human being should be central to ethics, and not the economy</i>



- Harmonisation of research funding, specifically for the ageing (or it will cost more later on)

- **Involve citizens in regulation and control**

Regulation of brain research and treatment must be independent of political and economic interests. We citizens are essentially concerned with this because the brain represents our identity, personality and mind. Therefore, we want to be involved at the different levels of decision through various forms of participation. More involvement of citizens in ethical panels should help increase public confidence in research. The organisation of research in Europe should not only accept the dialogue with citizens, but also encourage it. Scientists will benefit from hearing the opinions of lay people

The citizens then assessed the two issues chosen. For each issue, recommendations were formulated for final presentation in the plenary session on Sunday 22 January. It should be noted that in each phase of the process, the draft recommendations were always dealt with consecutively for each of the two issues. This section gives an overview of the recommendation formulation process for the first and then the second so as to provide an account of the process that is as transparent and understandable as possible.

1.2 Issue 1: Ethical Control

Formulation of draft recommendations

The citizens started by clarifying what the issue was and why it was important. On the basis of the different elements mentioned above, they then formulated draft recommendations. In slight contrast to the other two carousels, this was done by using a support facilitator to capture citizens' ideas for recommendations in English live on a large screen, and then briefly discussing each idea and how it should be phrased (the same procedure was applied for theme 4). The two resource persons present in the carousel were invited to comment on the proposed recommendations.

Draft recommendation 1

Set up a pan-European ethical and legal advisory committee for the brain sciences which should include representatives of national ethical committees and representatives of European stakeholders organisations (health care, patients families, carers,...)

Draft recommendation 2

Do not create additional European-level committees at the moment but monitor developments in the sciences

Draft recommendation 3

Introduce a legislative differentiation between brain enhancements and other medical body enhancements

Draft recommendation 4

Prohibit brain-imaging procedures that abuse the privacy of the individual

Draft recommendation 5

Put or keep all drugs and technical manipulations which affect brain and behaviour under medical control with informed consent

Draft recommendation 6

Create a set of European guidelines establishing ethical and quality criteria for brain sciences



Draft recommendation 7

Create an independent European body monitoring the implementation of those European guidelines at national level

The citizens prioritised these draft recommendations. Numbers 1, 2, 4, 5 and 6 received a two-thirds majority and were therefore retained and elaborated further in preparation for the presentation in the European Cafés.

Presentation of the draft recommendations in the European Cafés

The next stage of the process consisted of the carousel 'stay behinders' presenting the draft recommendations in two **European Cafés**. The European Cafés gave the panelists from the other two carousels and the general public the opportunity to have an input, which would then be used to finalise the recommendations back in the initial carousel.

Draft recommendations 1, 2, 4, 5 and 6 were presented in following form:

Draft recommendation 1 (old 1)

Set up a pan-European ethical and legal advisory committee for the brain sciences which should include representatives of national ethical committees and representatives of European stakeholders organisations (health care, patients, patient families, carers,...)

Draft recommendation 2 (old 2)

Do NOT create additional European-level committees at the moment but monitor developments in the sciences

Draft recommendation 3 (old 4)

Prohibit brain imaging procedures that abuse the privacy of the individual

Draft recommendation 4 (old 5)

Put or keep all drugs and technical manipulations which affect brain and behaviour under medical control, with informed consent

Draft recommendation 5 (old 6)

Create a set of European guidelines establishing ethical and quality criteria for brain sciences

The additional thoughts raised during the European Café discussions were passed on to the initial carousel for further debate once it had reconvened.

Completion of report, reviewing the input received during the European Cafés

The carousel reviewed the input from the European Cafés. The review process also took account of the ideas raised by the general public during the European Cafés, which had been communicated to Steering Committee members present in these Cafés.

Subsequently, panelists established a final list of recommendations. Recommendations that received at least a two-thirds majority were included in the carousel's report that would be submitted to plenary for consideration by the entire citizens' panel (all three carousels together). As a result of the input from the European Café recommendation 2 was withdrawn, recommendation 4 was limited in scope and merged with 3 and recommendation 5 was subsumed under 1.



The chosen recommendations were presented in the plenary session on Sunday 22 January, worded as follows:

Pre-final recommendation 1 (previous 1 and 5)

Establishing ethical control

• **We recommend setting up a pan-European ethical and legal advisory committee**

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

Pre-final recommendation 2 (previous 3 and 4)

• **We recommend imposing an informed consent regulation for brain imaging techniques**

Plenary review of the recommendations: discussion and adoption of amendments

On Sunday 22 January, the European citizens' panel assembled in one plenary session to review the reports from each of the carousels in order to agree on a final report to be presented to the European Parliament on 23 January 2006.

The citizens received translations of the pre-final versions of the recommendations as concluded in the carousels and edited by the writers' group. At this point the recommendations already contained the input and represented the views of a large number of the panelists. The citizens were given a final chance to make adaptations to the recommendations. They were seated in their national panel groups for language reasons, but were asked to keep their focus European .

The national panel groups were allowed to make a maximum of two amendments: one on the first set of themes (Freedom of Choice, Regulation and Control, Public information and communication) and one on the second set (Pressure from economic interests, Equal access to treatment, Normalcy vs. diversity). The amendments proposed by each national table had to be accepted by at least two-thirds of the national panel group to merit consideration in the plenary and they had to refer to *very important* aspects that the national panelists felt absolutely needed to be added or amended in the text of the recommendation. This was to ensure that only significant amendments were submitted for vote in plenary.

The amendments were presented in the plenary and voted on by the entire European panel. Amendments were accepted if supported by a simple majority (half of all votes plus one). In total, 111 citizens were present when the voting took place. The final recommendations are reproduced under section II.

Three amendments were proposed, one of which was adopted.

■ **AMENDMENTS 1 AND 2**

On recommendation 1

From the French group

1 “Establishing ethical control”: replace ‘control’ by ‘questioning’



2 “Set up a pan-European ethical and legal advisory committee”: replace by ‘set up a network of national ethics committees’ because there is no common European ethics.

Rationale

“We think that it is not a good idea to speak about ‘ethical control’. Ethics is quite open-ended. For that reason we prefer ‘questioning’ as a word.

Second: since there is no such thing as common European ethics, we prefer a common European body or organisation of ethics, in other words: a ‘network’.”

Any rebuttals?

Belgian Flemish: “I understand that they want to change ‘control’ to ‘questioning’. A consequence of this change is: there is no pan-European ethics. So we do not have to vote twice: one is an offshoot of the other.”

Vote on the first part of amendment: 24 votes, not accepted.

Vote on the second part of amendment: 41 votes, not accepted.

■ **AMENDMENT 3**

On recommendation 2

From the Greek group

Add “These techniques should be prohibited for police or judicial investigations or for public security reasons” to the existing recommendation “impose an informed consent regulation for brain imaging techniques.”

Rationale

“We have heard explanations from experts in Athens and from Olivier that there is a great deal of confusion on the use to which brain imaging is put, particularly when it is being used outside of the laboratory. The extent of that kind of use is extremely vague.

Using this sort of vaguely defined techniques in a society which is overcome by hysteria of terrorism and crime, in a day and of age in which we are confronted with violations of human and civil rights (wire taping, tracking e-mails etc.). Even if there is a the slightest possibility that these techniques could be used in police or judicial investigations or for public security reasons, this would seriously compromise human rights, particularly as the police would be able to misuse this kind of information.”

Any rebuttals?

No

Vote: accepted by 80 votes.



1.3 Issue 2: Involve citizens in regulation and control

Formulation of draft recommendations

The citizens started by clarifying what the issue was and why it was important. On the basis of the different elements mentioned above, they then formulated draft recommendations, using the same procedure as with issue 1. The two resource persons present in the carousel were invited to comment on the proposed recommendations.

Draft recommendation 1

Citizen participation could be organised by universities who conduct research, co-organisations like the Dana centre and pharmaceutical companies. It would prevent science from going too far ahead. Either national or European level. Brain is a part of the individual identity, personality and soul, and it is a very fast moving field

Draft recommendation 2

We recommend using the information flow to reach and motivate people

Draft recommendation 3

A wide scope of information is desirable, using all kinds of channels (media, internet, questionnaires,...)

Draft recommendation 4

A European platform to allow citizens to publish their own opinion about priorities in research. There should be feedback, to see if things are changing or not

Draft recommendation 5

We recommend that regulation within brain science is done through scientific and legal experts and not through citizens

Draft recommendation 6

Citizens' voice should be heard, but they don't make the decisions. But we have to oblige Member States to listen to them. There has to be some kind of national organisation to achieve this. We recommend that European institutions oblige this. As for the method, there has to be debate and exchange about it, mutual learning. Respect for regional and cultural differences

Draft recommendation 7

Participation should be done through institutions at national levels (democratically elected) to take part in European decision making concerning direction and applications of brain science research

Draft recommendation 8

Citizens should take part in evaluating brain research. Patients groups, interest groups, families. We have to make a distinction between sick and healthy brain and this has to be controlled as well

The citizens prioritised these draft recommendations. Only number 1 received a two-thirds majority and was therefore retained and elaborated further in preparation for the presentation in the European Cafés.

Presentation of the draft recommendations in the European Cafés

The next stage of the process consisted of the carousel 'stay behinders' presenting the draft recommendations in two **European Cafés**. The European Cafés gave the pan-



elists from the other two carousels and the general public the opportunity to have an input, which would then be used to finalise the recommendations back in the initial carousel.

Draft recommendation 1 was presented in following form:

Draft recommendation 1

We recommend that research universities, science organisations and pharmaceuticals organise citizen participation on national and EU level, because the brain is part of the human personality and soul and brain science research is so fast moving

Since the carousel participants felt that important thoughts were contained in the rejected draft recommendations, they decided to discuss these ‘other draft recommendations’ in the European Café anyway.

Draft recommendation 2

We recommend to improve information flows to reach and motivate people

Draft recommendation 3

We recommend to the media that a wide scope of information is addressed using a large number of fora and channels (media, internet, questionnaires ...)

Draft recommendation 4

We recommend the creation of a European platform for the feedback of citizens setting priorities

Draft recommendation 5

We recommend that regulation within brain science is done through scientific and legal experts and not through citizens

Draft recommendation 6

We recommend to European institutions to oblige member states to involve citizens according to common methods of debates, exchange and mutual learning

Draft recommendation 7

We recommend that citizens should be encouraged to participate on the direction and application of brain sciences through national democratic institutions organising the participation. Decisions should be made by a European panel, respecting the regional and cultural differences

Draft recommendation 8

We recommend that patients groups and interest groups are brought into the evaluation of brain research on both the healthy and the ill brain

The additional thoughts raised during the European Café discussions were passed on to the initial carousel for further debate once it had reconvened.

Completion of report, reviewing the input received during the European Cafés

The carousel reviewed the input from the European Cafés. The review process also took account of the ideas raised by the general public during the European Cafés which had been communicated to Steering Committee members present in these Cafés.



Subsequently, panelists established a final list of recommendations. Recommendations that received at least a two-thirds majority were included in the carousel's report that would be submitted for consideration by the entire citizens' panel (all three carousels together) in the plenary.

On the basis of the additional input from the European Cafés on a number of the 'other draft recommendations', the initial carousel reconsidered its original assessment and decided by a two-thirds majority to reintroduce recommendations numbers 2, 6 and 7 for consideration in the plenary session on Sunday, along with recommendation 1. (NB: Draft recommendations 6 and 7 were merged to form pre-final recommendation 2.)

The chosen recommendations were presented in the plenary session on Sunday 22 January, worded as follows:

Pre-final recommendation 1 (previous 1)

• **We recommend organising advisory citizen participation on brain science on regional, national and EU levels**

We recommend that research universities, science organizations and pharmaceutical companies organise citizen participation on regional, national and EU level to give feedback on their research work

Pre-final recommendation 2 (previous 6 and 7)

Citizen participation should be 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. Citizens' voices should be heard, even if they don't make the final decisions, which have to respect the regional and cultural differences

• **We recommend establishing mandatory European guidelines for citizen participation organized by national democratic institutions**

Pre-final recommendation 3 (previous 2)

Enhance the confidence of people in science and motivate them to keep informed about the outcomes of research, about possibilities for prevention and about available treatments

• **We recommend improving transparency and information flows about research outcomes to motivate and empower citizens to participate**

Plenary review of the recommendations: discussion and adoption of amendments

On Sunday 22 January, the European citizens' panel assembled in one plenary session to review the reports from each of the carousels in order to agree on a final report to be presented to the European Parliament on 23 January 2006.

The citizens received translations of the pre-final versions of the recommendations as concluded in the carousels and edited by the writers' group. At this point the recommendations already contained the input and represented the views of a large number of the panelists. The citizens were given a final chance to make adaptations to the recommendations. They were seated in their national panel groups for language reasons, but were asked to keep their focus European.



The national panel groups were allowed to make a maximum of two amendments: one on the first set of themes (Freedom of Choice, Regulation and Control, Public information and communication) and one on the second set (Pressure from economic interests, Equal access to treatment, Normalcy vs. diversity). The amendments proposed by each national table had to be accepted by at least two-thirds of the national panel group to merit consideration in the plenary and they had to refer to *very important* aspects that the national panelists felt absolutely needed to be added or amended in the text of the recommendation. This was to ensure that only significant amendments were submitted for vote in plenary.

The amendments were presented in the plenary and voted on by the entire European panel. Amendments were accepted if supported by a simple majority (half of all votes plus one). In total, 111 citizens were present when the voting took place. The final recommendations are reproduced under section II.

There were no amendments.



2 Theme Normalcy vs. Diversity

2.1 Identification of issues and selection of two issues

The citizens began by identifying for this theme the issues they considered to be of major importance to them and for which they would go on to formulate recommendations for action. They remained constantly mindful of the central question ‘How are we going to use our new-found knowledge of the brain’ during the reflection process. The panellists used the synthesis report, and the comments from resource persons (the experts’ views on the synthesis report and the experts present in the carousel) as a basis for their discussions.

Per theme two resource persons were present in each carousel. At the start of the carousel, they were invited to comment on each theme, present their views on the synthesis report of the national assessments and draw the citizens' attention to the topics they considered to be the most relevant for brain sciences and European policy-making. The resource persons were also able to briefly comment on the citizens' draft recommendations and provide additional information if requested by the panelists.

The resource persons for this theme were Prof. Pierre Magistretti and Mr Didier Sicard.

A list of issues to be discussed further was compiled based on the following criteria:

- the relevance to brain science
- the relevance to policy making at European level
- the extent of impact on citizens

To focus the discussions and ensure that the process during the Convention was workable, the citizens prioritised the issues and chose two for further assessment.

Normalcy vs. Diversity

Issues identified	Issues chosen and argumentation
<ul style="list-style-type: none"> • Improve the quality of treatment • How society perceives normalcy and diversity; Diversity is a source of wealth for society; acceptance of diversity; understanding diversity to avoid stigmatisation in society • Promoting brain research as the foundation of everything • Distinction between healthy and sick people when speaking about normal or abnormal behaviour • How does society talk back to science? 	<ul style="list-style-type: none"> • Diversity as a source of richness in society <i>Diversity is a source of progress in society, in art and science. The suffering of people with mental disorders should be treated in a diverse way – but must avoid being discriminatory. Diversity is a source of wealth for society. It is very important and is much more a social than a scientific question. The acceptance of diversity makes a link between science and society. If people understand the issue of diversity we can help to avoid stigmatisation in society. It is a basic prerequisite for democracy and therefore a fundamental concern for us as citizens. Europe can move forward only if we accept diversity.</i> • Promote brain research <i>Europe wide, there is the problem that there are many people with brain disorders. We cannot simply sit back. The more people get targeted by treatments the better quality of life will be. There is a strong link between the quality of treatment and diversity. If you want to improve the quality you have to know at the first place what research can do for treatment. Brain research is the foundation of everything so we have to provide as much financial support to research as possible. More funding should go to brain research and we have to prevent brain drain – the moving of European researchers to the US. There is an exciting potential for Europe to increase learning potential and creativity by studying the brain.</i>



The citizens then assessed the two issues chosen. For each issue, recommendations were formulated for final presentation in the plenary session on Sunday 22 January. It should be noted that in each phase of the process, the draft recommendations were always dealt with consecutively for each of the two issues. This section gives an overview of the recommendation formulation process for the first and then the second so as to provide an account of the process that is as transparent and understandable as possible.

2.2 Issue 1: Diversity as a source of richness in society

Formulation of draft recommendations

The citizens started by clarifying what the issue was and why it was important. On the basis of the different elements mentioned above, they then formulated draft recommendations. The two resource persons present in the carousel were invited to comment on the proposed recommendations.

Draft recommendation 1

The importance of language and its critical nature. Instead of using abnormal, it would be much wiser to use the term unusual. You need citizens to avoid stigmatisation by talking about the terms. We need to develop common terms and classify them at the European level. A possibility is to talk about ‘normalcy’ and ‘diversity’. We only need to define definitions as far as they support people in positive treatment. They also must help doctors to communicate with each other. Citizens need to be able to have some definition that gives you some orientation. An active distinction in media and newspapers when it comes to normalcy and disease is necessary

Draft recommendation 2

Where diversity is accepted, it should not lead to discrimination. There should be legal protection

Draft recommendation 3

Diversity is a very positive element in society. It is not the world of science that questions diversity. It is the broader society that doubts if diversity is wealth. It should be a goal to educate the entire society through education at all levels. The EU parliament should make sure that diversity is taken into account in the school curriculum. A lifelong channel of education and information should be delivered so that people are aware of diversity. Press campaigns could be developed to provide people with better information to get rid of stigmatisation

Draft recommendation 4

In order to prevent stigmatisation and discrimination we need legislation for the prevention of disease. We must be sure that researchers are only working on prevention and treatment as opposed to enhancement

Draft recommendation 5

Grant the integration of sick children in the schools, adults in their jobs and both in their family or habitual environment. The government has to provide the necessary resources that it can be done in a constructive way. People have to be able to participate in their normal environments, where possible. When it is not possible to integrate, we should work on acceptance

Draft recommendation 6

Governments should take into account the perceptions around mental disorders. The level of tolerance in society should be increased



Draft recommendation 7

We should identify diseases which could be harmful for the society as a whole. Give treatment for these disorders in the very early stage of pregnancy may be of crucial importance. We cannot say that we want diversity on the one hand and say that we want pre-selection of children. Scientists are in the position to screen children, nobody can decide on that

Draft recommendation 8

We need improvements on the normal or healthy brain. We don't want to create an artificial idea of normalcy. We don't want a kind of normalcy like Barbie and Ken

Draft recommendation 9

We want to stimulate an active research on natural ways how to use the potential of the normal and healthy brain that is non-technical things and non-medical things

Draft recommendation 10

We have to do more research on underlying disorders. Initiative should be undertaken to create public awareness on the need for brain research

Draft recommendation 11

We want an active action in press and legislation and also among doctors as to what should be interpreted as a variation in a norm and towards what is a disease in order to prevent overmedicalisation

Draft recommendation 12

To act against social pressure both on parents and within the medical system to excessive medical treatment as often treatment is the easy way out. Society should stop putting that pressure on parents

Draft recommendation 13

Increasing the tolerance of society to psychiatric disorders

The citizens prioritised these draft recommendations. Numbers 3, 5 and 6 received a two-thirds majority and were therefore retained and elaborated further in preparation for the presentation in the European Cafés.

Presentation of the draft recommendations in the European Cafés

The next stage of the process consisted of the carousel 'stay behinders' presenting the draft recommendations in two **European Cafés**. The European Cafés gave the panelists from the other two carousels and the general public the opportunity to have an input, which would then be used to finalise the recommendations back in the initial carousel.

Draft recommendations 3, 5 and 6 were presented in following form:

Draft recommendation 1 (old 3)

Diversity is a very positive element in society. It is not the world of science that questions diversity but rather society at large that doubts whether diversity is wealth. One goal should be to educate all levels of society. The European Parliament should make sure that diversity is taken into account in the school curriculum. A lifelong method of providing education and information should be implemented so that people are aware of diversity. Press campaigns could be developed to provide people with better information in a bid to eliminate stigmatisation



Draft recommendation 2 (old 5)

Promote the integration of sick children in schools, of adults at work and of both in their family or habitual environment. The government has to provide the necessary resources so that this can be achieved in a constructive way. People have to be able to participate in their normal environments, where possible. When it is not possible to integrate, we should work on acceptance

Draft recommendation 3 (old 6)

Governments should take account of how mental disorders are perceived. The level of tolerance in society should be increased

The additional thoughts raised during the European Café discussions were passed on to the initial carousel for further debate once it had reconvened.

Completion of report, reviewing the input received during the European Cafés

The carousel reviewed the input from the European Cafés. The review process also took account of the ideas raised by the general public during the European Cafés which had been communicated to Steering Committee members present in these Cafés.

Subsequently, panellists established a final list of recommendations. Recommendations that received at least a two-thirds majority were included in the carousel's report that would be submitted to plenary for consideration by the entire citizens' panel (all three carousels together).

The chosen recommendations were presented in the plenary session on Sunday 22 January, worded as follows:

Pre-final recommendation 1 (previous 1)

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. This should be done in cooperation with teachers and health care practitioners. 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**

Pre-final recommendation 2 (including previous 2 and 3)

- **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**

Pre-final recommendation 3 (including parts of old 1 and 2)

- **We recommend clarifying which variations exist within 'normality' and what should be interpreted as a 'real' disease to avoid unnecessary treatment and unnecessary medicalisation**



Plenary review of the recommendations: discussion and adoption of amendments

On Sunday 22 January, the European citizens' panel assembled in one plenary session to review the reports from each of the carousels in order to agree on a final report to be presented to the European Parliament on 23 January 2006.

The citizens received translations of the pre-final versions of the recommendations as concluded in the carousels and edited by the writers' group. At this point the recommendations already contained the input and represented the views of a large number of the panellists. The citizens were given a final chance to make adaptations to the recommendations. They were seated in their national panel groups for language reasons, but were asked to keep their focus European.

The national panel groups were allowed to make a maximum of two amendments: one on the first set of themes (Freedom of Choice, Regulation and Control, Public information and communication) and one on the second set (Pressure from economic interests, Equal access to treatment, Normalcy vs. diversity). The amendments proposed by each national table had to be accepted by at least two-thirds of the national panel group to merit consideration in the plenary and they had to refer to *very important* aspects that the national panellists felt absolutely needed to be added or amended in the text of the recommendation. This was to ensure that only significant amendments were submitted for vote in plenary.

The amendments were presented in the plenary and voted on by the entire European panel. Amendments were accepted if supported by a simple majority (half of all votes plus one). In total, 111 citizens were present when the voting took place. The final recommendations are reproduced under section II.

One amendment was proposed and was adopted.

■ AMENDMENT 1

On recommendation 1

From the French group

Addition:

“We recommend implementing a lifelong method of providing education and information so that people are aware of diversity. This should be done in cooperation with teachers and health care practitioners. *Social workers should be sensitized and be able to sensitize the public to the question of diversity.* Public campaigns ...”

Rationale

“Awareness of people from the social sector should be raised during their training. They should be trained on diversity and then raise the awareness of the public.”

Facilitator: So the insertion should read as:

“Raise awareness of teachers, health care and social workers on diversity during their training so that they can raise the awareness of the people they meet in their professional lives.”

Any rebuttals?

One citizen asked to reduce the text to “This should be done integrating teachers, coaches, social workers and health care practitioners”.

Facilitator: “Editing on this should clearly be done. Let’s now vote on the ‘concept’. We can’t do the editing right now.”

Vote: accepted by 78 votes.



2.3 Issue 2: Promote Brain Research

Formulation of draft recommendations

The citizens started by clarifying what the issue was and why it was important. On the basis of the different elements mentioned above, they then formulated draft recommendations. The two resource persons present in the carousel were invited to comment on the proposed recommendations.

Draft recommendation 1

We need more funds to go to basic and fundamental research, because progress in society is based on research. There should be a European research society in order to create networking and funding possibilities for research. Through new knowledge and implementing them in educational programmes we can avoid stigmatisation. By making funds available we can avoid brain drain. The funding should not be exposed to the control of drug companies. More funding, more scientist and those we have should stay

Draft recommendation 2

We should promote brain research, we also want the authorities at the EU level to guarantee that this research is not setting up social standards and social control

Draft recommendation 3

We recognise that standardisation for research should be avoided. Although a minimal level of classification of diseases is needed for research. We are aware of the fact that in order to have a minimum set of criteria there is a need of screening system or common reference system. A threshold is needed. There is a certain need of standardisation

Draft recommendation 4

Part of the funding should be put on prevention. There is a need on research on rare diseases. They should get more attention

Draft recommendation 5

We agree we are all individuals with normalcy and diversity. We need professionals to recognise all kinds of mental diseases and translate them in treatment. We need money and skills to find out the best way to treat them.

Experts need to listen to patients carefully and to recognise their value as a crucial source of information in the understanding and treatment of their condition

Draft recommendation 6

We should add alternative medicine and economical resources and to have psychological backup support for families at both the European and national health level systems

Draft recommendation 7

The increasing knowledge should lead to research in other fields as learning, teaching and creativity. We could talk about financial and other assistance to be delivered to highly gifted children

Draft recommendation 8

Specialised efforts should be put on coming out with objective diagnostic methods on mental diseases and disorders. Measurement and diagnosing techniques should be objective so that we look to mental disorders in an objective way

Draft recommendation 9

A European policy is needed focused on quality treatment



Draft recommendation 10

Alternative treatments should be included in national health systems, so like psychiatric treatment

Draft recommendation 11

Through brain research we should create better opportunities for diagnosing and treating pathological conditions. This will help us to differentiate actively between normal variations and disease

Draft recommendation 12

Europe should actively address and support the need of researching the healthy brain, in order to study life quality, creativity and learning throughout life. It improves our society's competitiveness. This will never be an item for the medical industries, this must be supported by public means

The citizens prioritised these draft recommendations. Numbers 1, 2 and 4 received a two-thirds majority and were therefore retained and elaborated further in preparation for the presentation in the European Cafés.

Presentation of the draft recommendations in the European Cafés

The next stage of the process consisted of the carousel 'stay behinders' presenting the draft recommendations in two **European Cafés**. The European Cafés gave the panelists from the other two carousels and the general public the opportunity to have an input, which would then be used to finalise the recommendations back in the initial carousel.

Draft recommendations 1, 2 and 4 were presented in following form:

Draft recommendation 1 (old 1)

Basic and fundamental research should receive more funding because societal progress depends on research. A European research society should be established in order to create networking and funding possibilities for research. By implementing new knowledge in educational programmes we can avoid stigmatisation. By making funds available we can avoid the brain drain. Funding should be independent of the control of pharmaceutical companies. We need more funding and more scientists

Draft recommendation 2 (old 2)

We want the authorities at EU level to guarantee that brain research does not mean setting up social standards and social control

Draft recommendation 3 (old 4)

Part of the funding should be focused on prevention. Research needs to be conducted on rare diseases. They should get more attention

The additional thoughts raised during the European Café discussions were passed on to the initial carousel for further debate once it had reconvened.

Completion of report, reviewing the input received during the European Cafés

The carousel reviewed the input from the European Cafés. The review process also took account of the ideas raised by the general public during the European Cafés which had



been communicated to Steering Committee members present in these Cafés. Subsequently, panellists established a final list of recommendations. Recommendations that received at least a two-thirds majority were included in the carousel's report that would be submitted to plenary for consideration by the entire citizens' panel (all three carousels together). Recommendations 1 and 2 were further elaborated, recommendation 3 was adapted to include parts of old draft recommendation 4 and 12, and recommendation 4 was introduced containing elements of old recommendation 6.

The chosen recommendations were presented in the plenary session on Sunday 22 January, worded as follows:

Pre-final recommendation 1 (previous 1)

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 the 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**

Pre-final recommendation 2 (previous 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**

Pre-final recommendation 3 (previous 3 and old 12)

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**

Pre-final recommendation 4 (parts of old 6)

Increase research on prevention and alternative treatment³

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

- **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 diseases. In addition, more research should be conducted on alternative treatment techniques**

3 The wording 'Alternative treatments' covers all alternative forms of conventional medical treatments. On the one hand, the term is used in the sense of 'complementary medicine' as a non-evidence-based medicine of homeopathic or anthroposophist origin used in addition to conventional medical treatment. On the other hand, citizens referred to it as a substitute to conventional medicine like psychotherapy, music-therapy etc...



Part of the text was missing in the version of pre-final recommendation 4 that was presented in the plenary session on Sunday. During the European Cafés, the citizens had suggested including alternative treatment techniques and the need for funding these treatments. The funding aspect was omitted in the version presented in plenary and in the final report presented in the European Parliament on 23 January. This has been rectified in the present report under section II.

Plenary review of the recommendations: discussion and adoption of amendments

On Sunday 22 January, the European citizens' panel assembled in one plenary session to review the reports from each of the carousels in order to agree on a final report to be presented to the European Parliament on 23 January 2006.

The citizens received translations of the pre-final versions of the recommendations as concluded in the carousels and edited by the writers' group. At this point the recommendations already contained the input and represented the views of a large number of the panellists. The citizens were given a final chance to make adaptations to the recommendations. They were seated in their national panel groups for language reasons, but were asked to keep their focus European.

The national panel groups were allowed to make a maximum of two amendments: one on the first set of themes (Freedom of Choice, Regulation and Control, Public information and communication) and one on the second set (Pressure from economic interests, Equal access to treatment, Normalcy vs. diversity). The amendments proposed by each national table had to be accepted by at least two-thirds of the national panel group to merit consideration in the plenary and they had to refer to very important aspects that the national panellists felt absolutely needed to be added or amended in the text of the recommendation. This was to ensure that only significant amendments were submitted for vote in plenary.

The amendments were presented in the plenary and voted on by the entire European panel. Amendments were accepted if supported by a simple majority (half of all votes plus one). In total, 111 citizens were present when the voting took place. The final recommendations are reproduced under section II.

There were no amendments.



3. Theme Public Information and Communication

3.1 Identification of issues and selection of two issues

The citizens began by identifying for this theme the issues they considered to be of major importance to them and for which they would go on to formulate recommendations for action. They remained constantly mindful of the central question ‘How are we going to use our new-found knowledge of the brain’ during the reflection process. The panellists used the synthesis report, and the comments from resource persons (the experts’ views on the synthesis report and the experts present in the carousel) as a basis for their discussions.

Per theme, two resource persons were present in each carousel. At the start of the carousel, they were invited to comment on each theme, present their views on the synthesis report of the national assessments and draw the citizens' attention to the topics they considered to be the most relevant for brain sciences and European policy-making. The resource persons were also able to briefly comment on the citizens' draft recommendations and provide additional information if requested by the panelists.

The resource persons for this theme were Dr. György Bardos and Prof. Axel Cleeremans.

A list of issues to be discussed further was compiled based on the following criteria:

- the relevance to brain science
- the relevance to policy making at European level
- the extent of impact on citizens

To focus the discussions and ensure that the process during the Convention was workable, the citizens prioritised the issues and chose two for further assessment.

Public information and communication

Issues identified	Issues chosen and argumentation
<ul style="list-style-type: none"> • Bridging the gap between science and society • Making public information more reliable • Coordinating new sources of information • Improving education curricula • Linking environment and brain disease 	<ul style="list-style-type: none"> • Bridging the gap between science and society <i>Scientific information is available but only for people who can judge whether the information is accurate or reliable. Regular citizens are not always in a position to judge the quality of scientific information. We need to have same definitions when talking between citizens and scientists. It is important that a society, which is getting older can still understand the behaviour of people in the future. They will find it more acceptable if they know what is likely to happen and to do this they need information. Access to science by the community will benefit both science and society. We don't just need information from scientists but also to them, then everyone will gain. Better communication between scientists and society must deepen scientific research and increase public awareness so that citizens' involvement to influence the direction of science can be enhanced</i>



- Improving the quality of media reporting
- Encouraging citizens' initiative

- **Improving education curricula**

An overall approach to education is needed which embraces all members of society (all ages). Education is not just a matter for children and teachers, but also for doctors, nurses, parents and all kinds of care and treatment providers. They need to be provided with further education. People must be trained in processing the information. This can be done by starting at early age in school, children should learn about brain related issues, such as mental conditions to promote more tolerance and reduce stigmatisation. People must learn the skill of thinking critically and be aware of possible abuse and side effects of medicines for instance. Doctors need to be kept up to date with most recent scientific developments as well

The citizens then assessed the two issues chosen. For each issue, recommendations were formulated for final presentation in the plenary session on Sunday 22 January. It should be noted that in each phase of the process, the draft recommendations were always dealt with consecutively for each of the two issues. This section gives an overview of the recommendation formulation process for the first and then the second so as to provide an account of the process that is as transparent and understandable as possible.

3.2 Issue 1: Bridging the gap between science and society

Formulation of draft recommendations

The citizens started by clarifying what the issue was and why it was important. On the basis of the different elements mentioned above, they then formulated draft recommendations. The two resource persons present in the carousel were invited to comment on the proposed recommendations.

Draft recommendation 1

Interdisciplinary work between experts should be fostered

Draft recommendation 2

We need an overall vision at European level in order to make scientific information available to a wide public. This information must be easy to understand and presented in a pleasant way (through the media, Internet, schools, different kinds of organisations). We need to ensure that we have different sources of information so that every person has the ability to access that information

Draft recommendation 3

Create a European body to disseminate information and coordinate initiatives. This body should be active in the different European countries. There should be a place or a reliable resource where people can get classified information based on a compilation of scientific publications. In setting this body up we must use as many existing resources and institutions as possible. The body needs to cover both the sick and the healthy brain, both medical and non-medical methods. It is important that this information is free from economic and commercial interests. In addition to such an information centre, we also need a free flow of information



Draft recommendation 4

All scientists should have to translate 'brainy' results into common language, if necessary in collaboration with skilled people (e.g. science journalists). Scientists and science students should be coached from the very outset to use the simplest language when talking about their work

The citizens prioritised these draft recommendations. All 4 recommendations received a two-thirds majority and were elaborated further in preparation for the presentation in the European Cafés.

Presentation of the draft recommendations in the European Cafés

The next stage of the process consisted of the carousel 'stay behinders' presenting the draft recommendations in two **European Cafés**. The European Cafés gave the panelists from the other two carousels and the general public the opportunity to have an input, which would then be used to finalise the recommendations back in the initial carousel.

The draft recommendations were presented in the following form:

Draft recommendation 1. (old 1)

We recommend fostering interdisciplinary work between experts

Draft recommendation 2 (old 2)

We recommend developing an overall vision at European level in order to make scientific information available to a wide public. This information must be easy to understand and presented in a pleasant way (through the media, Internet, schools, different kinds of organisations). We need to ensure that we have different sources of information so that every person has the ability to access that information

Draft recommendation 3 (old 3)

We recommend creating a European body to disseminate information and coordinate initiatives. This body should be active in the different European countries. There should be a place or a reliable resource where people can get classified information based on a compilation of scientific publications. In setting this body up we must use as many existing resources and institutions as possible. The body needs to cover both the sick and the healthy brain, both medical and non-medical methods. It is important that this information is free from economic and commercial interests. In addition to such an information centre, we also need a free flow of information

Draft recommendation 4 (old 4)

We recommend that all scientists should have to translate 'brainy' results into common language, if necessary in collaboration with skilled people (e.g. science journalists). Scientists and science students should be coached from the very outset to use the simplest language when talking about their work

The additional thoughts raised during the European Café discussions were passed on to the initial carousel for further debate once it had reconvened.



Completion of report, reviewing the input received during the European Cafés

The carousel reviewed the input from the European Cafés. The review process also took account of the ideas raised by the general public during the European Cafés which had been communicated to Steering Committee members present in these Cafés.

Subsequently, panellists established a final list of recommendations. Recommendations that received at least a two-thirds majority were included in the carousel's report that would be submitted to plenary for consideration by the entire citizens' panel (all three carousels together).

The chosen recommendations were presented in the plenary session on Sunday 22 January, worded as follows:

Pre-final recommendation 1 (previous 2)

- **We recommend developing an overall European strategy to make information about brain science covering ethical, legal and social aspects available for 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 forced to publish annual reports which are made available to the public

Pre-final recommendation 2 (previous 3)

- **We recommend establishing a European body or network of existing European and national institutions to disseminate information and coordinate initiatives in Member States**

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 centralized database that brings articles on brain science together, to which all citizens have open access

Pre-final recommendation 3 (previous 4)

- **We recommend coaching science students to use common language in talking about their work, and encourage scientists to translate 'brainy' results and scientific texts into common language**

Pre-final recommendation 4 (previous 1)

- **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 publicised. Enough public funds should be made available for this**

Plenary review of the recommendations: discussion and adoption of amendments

On Sunday 22 January, the European citizens' panel assembled in one plenary session to review the reports from each of the carousels in order to agree on a final report to be presented to the European Parliament on 23 January 2006.



The citizens received translations of the pre-final versions of the recommendations as concluded in the carousels and edited by the writers' group. At this point the recommendations already contained the input and represented the views of a large number of the panellists. The citizens were given a final chance to make adaptations to the recommendations. They were seated in their national panel groups for language reasons, but were asked to keep their focus European.

The national panel groups were allowed to make a maximum of two amendments: one on the first set of themes (Freedom of Choice, Regulation and Control, Public information and communication) and one on the second set (Pressure from economic interests, Equal access to treatment, Normalcy vs. diversity). The amendments proposed by each national table had to be accepted by at least two-thirds of the national panel group to merit consideration in the plenary and they had to refer to very important aspects that the national panellists felt absolutely needed to be added or amended in the text of the recommendation. This was to ensure that only significant amendments were submitted for vote in plenary.

The amendments were presented in the plenary and voted on by the entire European panel. Amendments were accepted if supported by a simple majority (half of all votes plus one). In total, 111 citizens were present when the voting took place. The final recommendations are reproduced under section II.

There were no amendments.

3.3 Issue 2: Improving education curricula

Formulation of draft recommendations

The citizens started by clarifying what the issue was and why it was important. On the basis of the different elements mentioned above, they then formulated draft recommendations. The two resource persons present in the carousel were invited to comment on the proposed recommendations.

Draft recommendation 1

Prevention should be the main focus from an early age, even before that. Awareness should be raised about prevention through education and training to enable 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. Thought should be given to how the brain can be used creatively. Parents and society should play a role in this

Draft recommendation 2

Future parents should receive education on the potential risks for the unborn child's brain. Information should be made available in hospitals for future parents (for example, neuroscience brochures). The health system needs to provide more time to doctors in order to provide support and treatment

Draft recommendation 3

There is a need to develop health care education programmes at all learning levels (children, teenagers and adults of all ages) which take account of the most recent developments in our knowledge

Draft recommendation 4

Universities should conduct more communication programmes to share the results of their research with students and the general public

The citizens prioritised these draft recommendations. All four received a two-thirds majority and were therefore retained and elaborated further in preparation for the presentation in the European Cafés.

Presentation of the draft recommendations in the European Cafés

The next stage of the process consisted of the carousel 'stay behinders' presenting the draft recommendations in two **European Cafés**. The European Cafés gave the panelists from the other two carousels and the general public the opportunity to have an input, which would then be used to finalise the recommendations back in the initial carousel.

Draft recommendations were presented in the following form:

Draft recommendation 1 (old 1)

We recommend making prevention the main focus from an early age, even before that. Awareness should be raised about prevention through education and training to enable 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. Thought should be given to how the brain can be used creatively. Parents and society should play a role in this

Draft recommendation 2 (old 2)

We recommend providing future parents with education on the potential risks for the unborn child's brain. Information should be made available in hospitals for future parents (for example, neuroscience brochures). The health system needs to provide more time to doctors in order to provide support and treatment

Draft recommendation 3 (old 3)

We recommend developing health care education programmes at all learning levels (children, teenagers and adults of all ages) which take account of the most recent developments in our knowledge

Draft recommendation 4 (old 4)

We recommend that universities conduct more communication programmes to share the results of their research with students and the general public

The additional thoughts raised during the European Café discussions were passed on to the initial carousel for further debate once it had reconvened.

Completion of report, reviewing the input received during the European Cafés

The carousel reviewed the input from the European Cafés. The review process also took account of the ideas raised by the general public during the European Cafés which had been communicated to Steering Committee members present in these Cafés.

Subsequently, panellists established a final list of recommendations. Recommendations that received at least a two-thirds majority were included in the carousel's report that would be submitted to plenary for consideration by the entire citizens' panel (all three carousels together).



The draft recommendations and rationale, were presented in the plenary session on Sunday 22 January, worded as follows:

Pre-final recommendation 1 (previous 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

- **To achieve this, it is important that education and training raises awareness of prevention and stimulates learning potential (learning how to learn) starting from an early age and continuing 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**

Pre-final recommendation 2 (previous 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

- **Therefore, 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 hospitals and gynaecologists. Proactive measures should be taken to encourage parents who are likely to take less care of their children to make use of the information and opportunities available. In addition, the health system needs to provide more time to doctors, midwives and health visitors to provide support and treatment**

Pre-final recommendation 3 (previous 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

- **At all learning levels health (care) education programmes should be supported or revised that 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**

Pre-final recommendation 4 (new with a part of previous 3)

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

- **Both the education and the training system should be strongly encouraged to take constant advantage of the knowledge available in order to improve the learning process in all stages**

Pre-final recommendation 5 (part of previous 4)

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.

- **To this end, they should organise more communication activities**

Pre-final recommendation 6 (new)

- **Support NGOs in their role educating the public on brain sciences**

Plenary review of the recommendations: discussion and adoption of amendments

On Sunday 22 January, the European citizens' panel assembled in one plenary session to review the reports from each of the carousels in order to agree on a final report to be presented to the European Parliament on 23 January 2006.

The citizens received translations of the pre-final versions of the recommendations as concluded in the carousels and edited by the writers' group. At this point the recommendations already contained the input and represented the views of a large number of the panellists. The citizens were given a final chance to make adaptations to the recommendations. They were seated in their national panel groups for language reasons, but were asked to keep their focus European.

The national panel groups were allowed to make a maximum of two amendments: one on the first set of themes (Freedom of Choice, Regulation and Control, Public information and communication) and one on the second set (Pressure from economic interests, Equal access to treatment, Normalcy vs. diversity). The amendments proposed by each national table had to be accepted by at least two-thirds of the national panel group to merit consideration in the plenary and they had to refer to very important aspects that the national panellists felt absolutely needed to be added or amended in the text of the recommendation. This was to ensure that only significant amendments were submitted for vote in plenary.

The amendments were presented in the plenary and voted on by the entire European panel. Amendments were accepted if supported by a simple majority (half of all votes plus one). In total, 111 citizens were present when the voting took place. The final recommendations are reproduced under section II.



One amendment was proposed and adopted.

■ AMENDMENT 1

On recommendation 2

From the Belgian Flemish Community group

Add the part in italics: “Provide public funds to produce information brochures for future parents. These brochures could be made available in maternity hospitals and through gynaecologists. Proactive measures should be taken to encourage parents *who are likely to take less care of their children* to make use of the information and opportunities available”

Rationale

We think it is important that all parents are informed about prevention of brain conditions. The way it is now formulated is discriminatory. There is no definition of parents who are more likely not to look after their children.

Any rebuttals?

None

Vote: accepted by 94 votes.



4. Theme Pressure from Economic Interests

4.1 Identification of issues and selection of two issues

The citizens began by identifying for this theme the issues they considered to be of major importance to them and for which they would go on to formulate recommendations for action. They remained constantly mindful of the central question ‘How are we going to use our new-found knowledge of the brain’ during the reflection process. The panellists used the synthesis report, and the comments from resource persons (the experts’ views on the synthesis report and the experts present in the carousel) as a basis for their discussions.

Per theme, two resource persons were present in each carousel. At the start of the carousel, they were invited to comment on each theme, present their views on the synthesis report of the national assessments and draw the citizens' attention to the topics they considered to be the most relevant for brain sciences and European policy-making. The resource persons were also able to briefly comment on the citizens' draft recommendations and provide additional information if requested by the panelists.

The resource persons for this theme were: Mr. Olivier Ouillier and Dr. Ian Ragan.

A list of issues to be discussed further was compiled based on the following criteria:

- the relevance to brain science
- the relevance to policy making at European level
- the extent of impact on citizens

To focus the discussions and ensure that the process during the Convention was workable, the citizens prioritised the issues and chose two for further assessment.

Pressure from economic interests

Issues identified	Issues chosen and argumentation
<ul style="list-style-type: none"> • Low profit research: need to counterbalance research done by pharmaceutical companies • Alternatives to medical treatment, including holistic therapies and healthy brain research • Lifestyle drugs: avoid inappropriate use of brain drugs • Economic pressure exerted by companies: over-treatment, retention of information on adverse effects of drugs • The licences of patents, certification and approval regulations • Healthy brain research • Need for independent information for journals. 	<ul style="list-style-type: none"> • Research: the balance of (between) public and private funding <i>Most brain research is done by the pharmaceutical industry as compared to public institutions. The pharmaceutical companies look into fields of brain research which promises to yield quick returns on investment. This may lead to lack of attention for important brain research fields, for instance on rare diseases. We need to find the balance between profit making and the common good. The two ways of funding research should be balanced</i> • Economic interests of companies might conflict with public interests in the field of brain science <i>Pharmaceutical companies produce many drugs that people with psychiatric and neurological afflictions cannot do without. But the objective of these powerful companies is to make profit and this aim may not coincide with the common good and social needs. This creates tensions. Thereby we want to restrict the influence of companies on physicians</i>



The citizens then assessed the two issues chosen. For each issue, recommendations were formulated for final presentation in the plenary session on Sunday 22 January. It should be noted that in each phase of the process, the draft recommendations were always dealt with consecutively for each of the two issues. This section gives an overview of the recommendation formulation process for the first and then the second so as to provide an account of the process that is as transparent and understandable as possible.

4.2 Issue 1: Research: the balance of public and private funding

Formulation of draft recommendations

The citizens started by clarifying what the issue was and why it was important. On the basis of the different elements mentioned above, they then formulated draft recommendations. In slight contrast to the other two carousels, this was done by using a support facilitator to capture citizens' ideas for recommendations in English live on a large screen, and then briefly discussing each idea and how it should be phrased. The two resource persons present in the carousel were invited to comment on the proposed recommendations.

Draft recommendation 1

Taxes, investments, funding for brain sciences

Invest in a public pharmaceutical industry. In the interest of citizens, we need to maximise profit from applied research. It must become attractive for pharmaceutical companies to invest in this. On the other hand we must set a ceiling for income from applied research.

There is an important contrast between state and private funding channels. We need a supra national regulation to rationalise where state and private funding goes. We must invest in fundamental research

Draft recommendation 2

Scientific research objectives

Scientific research objectives need to be stronger at EU level

Draft recommendation 3

Rare Brain Diseases

Rare diseases— although they provide no financial benefit - need to be researched. If needed, we must provide tax breaks to achieve this. Who should fund the research on rare brain diseases?

We must change the criteria for distribution of funding, they are not clear-cut at the moment. Is it, for instance, to treat life threatening diseases, or to improve quality of life, etc? Pharmaceutical companies are not interested in the common good, but in economic survival. Therefore we should perhaps match national funds at European level. A society should value people above profit

Draft recommendation 4

Sharing results

We need to share results between research institutions – both successful and non successful results.

We need better cross-fertilisation between basic research (universities). Fundamental and applied research should work hand in hand, using each others' results



Draft recommendation 5

Non-pharmaceutical research funding

We need to spend money on non-pharmaceutical research

Draft recommendation 6

Generic medicine, i.e. copies of medicines. What are the advantages of generic medicine/counterfeit medicine for brain-diseases? We should not fall into trap of doing too much research. We must also look at rare diseases.

There is a trend to match research money by governments, this means there is no independent research anymore, we are concerned about that

The citizens prioritised these draft recommendations. Only recommendation 1 received a two-thirds majority and was therefore retained and elaborated further in preparation for the presentation in the European Cafés.

Presentation of the draft recommendations in the European Cafés

The next stage of the process consisted of the carousel 'stay behinders' presenting the draft recommendations in two **European Cafés**. The European Cafés gave the panelists from the other two carousels and the general public the opportunity to have an input, which would then be used to finalise the recommendations back in the initial carousel.

Draft recommendation 1 was presented in following form:

Draft recommendation 1 (old 1)

Invest in a public pharmaceutical industry. In the interest of citizens we need to maximise profit from applied research. It must become attractive for pharmaceutical companies to invest in this. On the other hand we must set a ceiling for income from applied research.

There is an important contrast between state and private funding channels. We need a supra national regulation to rationalise where state and private funding goes. We must invest in fundamental research

The additional thoughts raised during the European Café discussions were passed on to the initial carousel for further debate once it had reconvened.

Completion of report, reviewing the input received during the European Cafés

The carousel reviewed the input from the European Cafés. The review process also took account of the ideas raised by the general public during the European Cafés which had been communicated to Steering Committee members present in these Cafés.

Subsequently, panellists established a final list of recommendations. Recommendations that received at least a two-thirds majority were included in the carousel's report that would be submitted to plenary for consideration by the entire citizens' panel (all three carousels together).

The chosen recommendation was presented in the plenary session on Sunday 22 January, worded as follows:



Pre-final recommendation I (previous I)

- **Apply additional tax incentives for pharmaceutical companies to encourage them to take up appropriate research, be it fundamental or applied**

We have the feeling that private research funding is overwhelmingly bigger than public funding. This should be balanced. More research for the common good and not only issues that have an economic interest

Plenary review of the recommendations: discussion and adoption of amendments

On Sunday 22 January, the European citizens' panel assembled in one plenary session to review the reports from each of the carousels in order to agree on a final report to be presented to the European Parliament on 23 January 2006.

The citizens received translations of the pre-final versions of the recommendations as concluded in the carousels and edited by the writers' group. At this point the recommendations already contained the input and represented the views of a large number of the panellists. The citizens were given a final chance to make adaptations to the recommendations. They were seated in their national panel groups for language reasons, but were asked to keep their focus European.

The national panel groups were allowed to make a maximum of two amendments: one on the first set of themes (Freedom of Choice, Regulation and Control, Public information and communication) and one on the second set (Pressure from economic interests, Equal access to treatment, Normalcy vs. diversity). The amendments proposed by each national table had to be accepted by at least two-thirds of the national panel group to merit consideration in the plenary and they had to refer to very important aspects that the national panellists felt absolutely needed to be added or amended in the text of the recommendation. This was to ensure that only significant amendments were submitted for vote in plenary.

The amendments were presented in the plenary and voted on by the entire European panel. Amendments were accepted if supported by a simple majority (half of all votes plus one). In total, 111 citizens were present when the voting took place. The final recommendations are reproduced under section II.

Four amendments were submitted. They were presented in turn by the national panel tables before being voted on. The results of the votes are included at the end of the list. One amendment was approved.

■ **AMENDMENT 1**

From the Greek group

Add the text in italics: "Apply additional tax incentives for pharmaceutical companies to encourage them to take up appropriate research, be it fundamental or applied *as well into rare diseases.*" (eliminating the word 'tax' at the beginning.)



Rationale

“We wanted to say with this proposal: we shouldn’t just restrict our efforts to tax incentives. At the same time there should be some possibilities within the European Union for a choice to be made between incentives which could be provided to drug companies so that they can achieve these aims. It might not be tax incentives, but other measures as well. Tax measures would end up being paid out of citizen’s pockets.”

Facilitator: *“There are two aspects to this proposal*

- 1 elimination of the word ‘tax’ as the only kind of incentive;*
- 2 insertion of ‘as well as into rare diseases’.*”

Any rebuttals?

A citizen from the British group: “I would rather the word ‘tax’ stay in, because it is important. I’d prefer ‘tax and other incentives’.”

■ AMENDMENT 2

From the German group

Another alternative suggestion. Replace the sentence with:

“We recommend that instead of providing additional tax incentives for pharmaceutical companies, investments be made in public brain research that deals with rare disorders.”

Rationale

“Basically we think it would be a good idea to tax pharmaceutical companies and then use the tax revenues for this purpose. So that we do not have to pump more money into the drug companies but take advantage of the resources that are there and make them available for more independent research.”

Facilitator: *“we now have three alternatives.”*

Any rebuttals?

From a citizen: “I’d like to agree with the Germans. We’ve heard a lot about funding this, or that. But where is that funding going to come from if we just give money away to some of the most scandalous, profitable industries that exist, the drug industries? Are people on minimum wages going to foot the bill for them? “

■ AMENDMENT 3

From the Belgian French Community group

Change the text to:

“Apply additional incentives for pharmaceutical companies to encourage them to take up appropriate research, be it fundamental or applied, as long as the reduction of taxes be invested in research and that this investment is controlled.”

Rationale

“Experts explained to us that the public service pays these companies to carry out the research the public wants. I want this public money to be controlled and that the private sector carries out research that the public wants.”

Facilitator: *“So emphasis on control of the research. The Belgian proposal does include the notion of tax incentives.”*



■ AMENDMENT 4

From the Hungarian group

Change text to:

“We suggest limiting the acceptable profit of pharmaceutical industry. Their surplus profit should be channelled to basic research.”

Rationale

“We suggest a different way in order to generate resources for fundamental research. We think that drug companies are already quite lucrative. We can take part of their turnover and use it for better social purposes, particularly since society is aging and health related costs are constantly on the rise. Therefore we would like the profit of drug companies to be channelled into fundamental research into rare diseases above a certain threshold level.”

Any comments?

Greek group: “There has been a slight misunderstanding around the Greek proposal. The only thing that we are basically looking for is for the words ‘tax’ and ‘incentive’ not to be used in the same sentence. Because then there is a lot of emphasis on the word ‘tax’. Then it seems that it is just a proposal on taxing drug companies, and that is not the point at stake. We wanted to place more emphasis on the word ‘incentive’. We are not against the German or Hungarian proposals. Our proposal is straightforward: do not restrict measures to tax. We want it to be a broader suggestion.”

British group: “Commercial organisations and profit can help to drive research more quickly. Profit provides incentives to people to do this kind of research. There is a danger that overtaxing pharmaceutical companies or not providing incentives results in this research taking place outside the European Union. That could be a real problem” (some applause).

Greek group: “We never suggested that anyone should be overtaxed. That’s a different idea. But they should not be exempt of taxes.”

Facilitator: “We are going to vote. Some of these are compatible, others are exclusive. If they are exclusive, please make a choice which one you are going to vote for”:

The amendments were voted on in the following order:

4 Hungarian proposal (a replacement)

Vote: 25 votes, the proposal was not accepted

2 German proposal (a replacement)

Vote: 45 votes, the proposal was not accepted

3 Belgian proposal (a replacement)

Vote: 46 votes, the proposal was not accepted

1 Greek proposal

Vote: accepted by 76 votes.



4.3 Issue 2: Economic interests of companies might conflict with public interests

Formulation of draft recommendations

The citizens started by clarifying what the issue was and why it was important. On the basis of the different elements mentioned above, they then formulated draft recommendations. The two resource persons present in the carousel were invited to comment on the proposed recommendations.

Draft recommendation 1

We recommend that the pressure from pharmaceutical industries is balanced by initiatives of politicians which are in the interest of the public in general

Draft recommendation 2

We recommend citizens awareness-raising programs on the use of drugs for brain-diseases. If a doctor gives options, it is interesting to know if they are genuine options. For example: antibiotics (cut back on the use of it). Specific for brain-science? Ritalin prescriptions are excessive in the US. We recommend that patients should know the actual costs of drugs before treatment starts. This is about all brain-treatments, also implants, or alternative treatments

Draft recommendation 3

We recommend that all funds that pharmaceutical industries give to third parties (like congresses) should be public. Funds used for marketing should be public

Draft recommendation 4

We recommend creating an impartial body that ensures that drugs are correctly prescribed with a view to countering fashion-drugs – which can be used for wrong purposes. Making sure that doctors are not under pressure to prescribe fashion-drugs

Draft recommendation 5

We recommend that the public be informed (by doctors) about the agents used in drugs, so that cheaper (generic) drugs could be used instead, if possible

Draft recommendation 6

We recommend that the duration of the patent-protection should depend on specific properties of the medicine, and the financial turnover in order to motivate pharmaceutical industries to carry out more basic research. It does not necessarily mean lengthening patents, it could also mean shortening patents of profitable drugs. We should combine this with allocation of money that is earmarked, and compare this with money that is invested in basic research

Draft recommendation 7

We recommend that existing monitoring bodies really monitor critically what happens in brain research and pharmaceutical industry; so that the common good is taken into account

Draft recommendation 8

We recommend more research on long-term effects of treatments of brain-diseases

Draft recommendation 9

We recommend a mediator, who has an overview of what is going on, and who can give an impartial view on how a particular medicine might be of help for a sick person



Draft recommendation 10

We recommend to distinguish between consumer products (products sold in supermarkets or other stores 'over the counter') for the brain and medicinal products. During exam periods there are concentration-enhancers being sold. This recommendation is about cognitive enhancers

Draft recommendation 11

We recommend a body which controls/monitors the effects of drugs

Draft recommendation 12

We recommend simple explanations alongside technical and detailed information on drugs. It should be there in addition to technical information (instruction leaflet)

The citizens prioritised these draft recommendations. Numbers 1 and 6 received a two-thirds majority and were therefore retained and elaborated further in preparation for the presentation in the European Cafés.

Presentation of the draft recommendations in the European Cafés

The next stage of the process consisted of the carousel 'stay behinders' presenting the draft recommendations in two **European Cafés**. The European Cafés gave the panelists from the other two carousels and the general public the opportunity to have an input, which would then be used to finalise the recommendations back in the initial carousel.

Draft recommendations 1 and 6 were presented in following form:

Draft recommendation 1 (old 1)

We recommend that the pharmaceutical industry's pressure is balanced by initiatives of politicians which are in the interest of the public in general

Draft recommendation 2 (old 6)

We recommend that the duration of the patent-protection depends on the specific properties of the medicine and its financial turnover in order to motivate pharmaceutical industries to carry out more basic research. It does not necessarily mean lengthening of patent, it could also mean shortening of patent of profitable drugs. Money could be earmarked. Compare this with money that is invested in basic research

The additional thoughts raised during the European Café discussions were passed on to the initial carousel for further debate once it had reconvened.

Completion of report, reviewing the input received during the European Cafés

The carousel reviewed the input from the European Cafés. The review process also took account of the ideas raised by the general public during the European Cafés which had been communicated to Steering Committee members present in these Cafés.

Subsequently, panellists established a final list of recommendations. Recommendations that received at least a two-thirds majority were included in the carousel's report that would be submitted to plenary for consideration by the entire citizens' panel (all three carousels together).



The chosen recommendations were presented in the plenary session on Sunday 22 January, worded as follows:

Pre-final recommendation 1 (previous 1)

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**

Pre-final recommendation 2 (previous 2)

As said before, we would like pharmaceutical industries to take up research, for example into rare brain diseases. Perhaps we could stimulate 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 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. 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**

Plenary review of the recommendations: discussion and adoption of amendments

On Sunday 22 January, the European citizens' panel assembled in one plenary session to review the reports from each of the carousels in order to agree on a final report to be presented to the European Parliament on 23 January 2006.

The citizens received translations of the pre-final versions of the recommendations as concluded in the carousels and edited by the writers' group. At this point the recommendations already contained the input and represented the views of a large number of the panellists. The citizens were given a final chance to make adaptations to the recommendations. They were seated in their national panel groups for language reasons, but were asked to keep their focus European.

The national panel groups were allowed to make a maximum of two amendments: one on the first set of themes (Freedom of Choice, Regulation and Control, Public information and communication) and one on the second set (Pressure from economic interests, Equal access to treatment, Normalcy vs. diversity). The amendments proposed by each national table had to be accepted by at least two-thirds of the national



panel group to merit consideration in the plenary and they had to refer to *very important* aspects that the national panellists felt absolutely needed to be added or amended in the text of the recommendation. This was to ensure that only significant amendments were submitted for vote in plenary.

The amendments were presented in the plenary and voted on by the entire European panel. Amendments were accepted if supported by a simple majority (half of all votes plus one). In total, 111 citizens were present when the voting took place. The final recommendations are reproduced under section II.

One amendment was proposed and adopted

■ **AMENDMENT 1:**

On recommendation 2

From the Belgian Flemish Community group

Add text in italics

“We recommend examining ways of encouraging pharmaceutical companies to undertake brain research with low profit potential *and the long term consequences of medication and other treatment.*”

Rationale

“We think it is important that the consequences of taking medication and the application of certain forms of treatment are researched at long term. Of course, the companies will have to be encouraged to carry out this kind of research, even if it isn’t lucrative.”

Any rebuttals?

None.

Vote: accepted by 91 votes.



5. Theme Equal Access to Treatment

5.1 Identification of issues and selection of two issues

The citizens began by identifying for this theme the issues they considered to be of major importance to them and for which they would go on to formulate recommendations for action. They remained constantly mindful of the central question ‘How are we going to use our new-found knowledge of the brain’ during the reflection process. The panellists used the synthesis report, and the comments from resource persons (the experts’ views on the synthesis report and the experts present in the carousel) as a basis for their discussions.

Per theme, two resource persons were present in each carousel. At the start of the carousel, they were invited to comment on each theme, present their views on the synthesis report of the national assessments and draw the citizens' attention to the topics they considered to be the most relevant for brain sciences and European policy-making. The resource persons were also able to briefly comment on the citizens' draft recommendations and provide additional information if requested by the panelists.

The resource persons for this theme were Prof. Dirk de Wachter and Mrs Raluca Nica.

A list of issues to be discussed further was compiled based on the following criteria:

- the relevance to brain science
- the relevance to policy making at European level
- the extent of impact on citizens

To focus the discussions and ensure that the process during the Convention was workable, the citizens prioritised the issues and chose two for further assessment.

Equal access to treatment

Issues identified	Issues chosen and argumentation
<ul style="list-style-type: none"> • Equal access to as many treatment options as possible, across Europe • Integration and information about new methods as soon as they become available • Priority to treatment of neuro-degenerative diseases amongst young people • Financial limits to equal access • Better distribution of resources • Increase funding, capacity and quality of brain-related health care 	<ul style="list-style-type: none"> • Equal access to treatment options across Europe <i>European citizens have a right to get high quality treatment wherever they live in the EC. Poor countries should be upgraded and rich countries preserve their standards; they should not meet at the middle. Regulation should guarantee that sort of harmonisation across Europe. Equal access to treatment is a fundamental right regardless of the age, sex, origin or social status of a person. Even if we don't know how this can be reached (this is beyond our knowledge), we think that it is a duty of the 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</i>



- Treatment of acute vs. chronic diseases
 - Prevention of disease
 - Evaluating financial effects
- **Acute versus chronic and long-term treatment needs**
Chronically ill persons suffering from neurodegenerative diseases or chronic mental illnesses are often the poorest in society; they are considered as a burden and as less valuable persons. Therefore, it is important to guarantee equitable funding of treatment for long-term mental problems, including community services and non-medical treatments

The citizens then assessed the two issues chosen. For each issue, recommendations were formulated for final presentation in the plenary session on Sunday 22 January. It should be noted that in each phase of the process, the draft recommendations were always dealt with consecutively for each of the two issues. This section gives an overview of the recommendation formulation process for the first and then the second so as to provide an account of the process that is as transparent and understandable as possible.

5.2 Issue 1: Equal access to treatment options across Europe

Formulation of draft recommendations

The citizens started by clarifying what the issue was and why it was important. On the basis of the different elements mentioned above, they then formulated draft recommendations. The two resource persons present in the carousel were invited to comment on the proposed recommendations.

Draft recommendation 1

We recommend that information about treatment options and criteria for the quality of treatments, hospitals and doctors (methods and experiences) have to be published across Europe to enable patients to make optimal decisions

Draft recommendation 2

We recommend to the EU to prioritize research into brain and age-related diseases (including the 7th framework program), and to strategically allocate research funds

Draft recommendation 3

We recommend to the EU to invest to overcome the divergence between different health systems in Europe, and to set a target for national investments

Draft recommendation 4

We recommend that the EU redirects funds from agriculture to brain research

Draft Recommendation 5

We recommend that the well being of patients has priority in accessing modern and longer-term treatments

Draft recommendation 6

We recommend that a European body evaluate the effectiveness of new treatments and technologies so that they can be used as quickly as possible, giving patients access to them

Draft recommendation 7

We recommend that the EU finance a plan to share resources and options for the treatment of neurodegenerative diseases across Europe



Draft recommendation 8

We recommend to the EU to improve efficiency, management and distribution of available resources on a EU level rather than asking for more funding (evidence-based medicine)

Draft recommendation 9

We recommend to avoid excessive doctor's salaries, hierarchies and duplication of spending in hospitals

Draft recommendation 10

We recommend to the EU to limit unnecessary duplication of research funding while keeping the benefits of competition within the EU

The citizens prioritized these draft recommendations. Numbers 2, 5, 6 and 10 received a two-thirds majority and were therefore retained and elaborated further in preparation for the presentation in the European Cafés.

Presentation of the draft recommendations in the European Cafés

The next stage of the process consisted of the carousel 'stay behinders' presenting the draft recommendations in two **European Cafés**. The European Cafés gave the panelists from the other two carousels and the general public the opportunity to have an input, which would then be used to finalise the recommendations back in the initial carousel.

Draft recommendations 2, 5, 6 and 10 were presented in following form:

Draft recommendation 1 (old 2)

We recommend to the EU to prioritize research (including the 7th framework program) into brain and age-related diseases, and to strategically allocate research funds

Draft recommendation 2 (old 5)

We recommend that the well being of patients has priority in accessing modern and longer-term treatments

Draft recommendation 3 (old 6)

We recommend that a European body evaluate the effectiveness of new treatments and technologies so that they can be used as quickly as possible, giving patients access to them

Draft recommendation 4 (old 10)

We recommend to the EU to limit unnecessary duplication of research funding while keeping the benefits of competition within the EU

The additional thoughts raised during the European Café discussions were passed on to the initial carousel for further debate once it had reconvened.

Completion of report, reviewing the input received during the European Cafés

The carousel reviewed the input from the European Cafés. The review process also took account of the ideas raised by the general public during the European Cafés which had been communicated to Steering Committee members present in these Cafés.



Subsequently, panellists established a final list of recommendations. Recommendations that received at least a two-thirds majority were included in the carousel's report that would be submitted to plenary for consideration by the entire citizens' panel (all three carousels together).

The chosen recommendations were presented in the plenary session on Sunday 22 January, worded as follows:

Pre-final recommendation 1 (previous 2)

- **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, race, etc)**

Pre-final recommendation 2 (previous 1 and 4)

- **We recommend that the EU should prioritise research (including the 7th framework program) into brain and age-related diseases, and to strategically allocate research funds - in order to save costs in the future**

Pre-final recommendation 3 (previous 3)

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

Plenary review of the recommendations: discussion and adoption of amendments

On Sunday 22 January, the European citizens' panel assembled in one plenary session to review the reports from each of the carousels in order to agree on a final report to be presented to the European Parliament on 23 January 2006.

The citizens received translations of the pre-final versions of the recommendations as concluded in the carousels and edited by the writers' group. At this point the recommendations already contained the input and represented the views of a large number of the panellists. The citizens were given a final chance to make adaptations to the recommendations. They were seated in their national panel groups for language reasons, but were asked to keep their focus European.

The national panel groups were allowed to make a maximum of two amendments: one on the first set of themes (Freedom of Choice, Regulation and Control, Public information and communication) and one on the second set (Pressure from economic interests, Equal access to treatment, Normalcy vs. diversity). The amendments proposed by each national table had to be accepted by at least two-thirds of the national panel group to merit consideration in the plenary and they had to refer to very important aspects that the national panellists felt absolutely needed to be added or amended in the text of the recommendation. This was to ensure that only significant amendments were submitted for vote in plenary.

The amendments were presented in the plenary and voted on by the entire European panel. Amendments were accepted if supported by a simple majority (half of all votes plus one). In total, 111 citizens were present when the voting took place. The final recommendations are reproduced under section II.



Two amendments were proposed, of which one was adopted.

■ AMENDMENT 1

On recommendation 1

From the Italian group

Request to insert the words in italics:

“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 *and pay the same price for medicine throughout Europe*. Also with reference to cost effectiveness without discrimination (age, sex, race, etc.)”

Rationale

“We notice that for the same kind of medicine different prices are requested by pharmaceutical companies in different countries. For example in Italy some medicines are more expensive than in other countries. We don’t see why we should be charged more. If pharmaceutical companies have still a profit at lower prices in other countries, people no longer have the same treatment opportunities.”

Any rebuttals?

A citizen from the Hungarian group said he would agree if people’s incomes were the same in all countries. However, that was not currently the case. If all the prices were brought down to Hungarian level then there would be no problem whatsoever.

Vote: 16 votes, the proposal is not accepted.

■ AMENDMENT 2

On recommendation 2

From the German group

Request to delete the crossed out phrase:

“The EU should prioritize research in the 7th Framework Program into brain and age related diseases.”

Rationale

“Research into disease suffered by small children and children suffering from brain disorders who need treatment, should receive priority because they are going to live longer. We also would like to get rid of the word ‘disease’ because we want to include all sorts of minority groups.”

Any rebuttals?

A citizen from the Greek table responded: “I wasn’t clear about that. What do you mean with ‘age’? Do you mean only young children should be given priority as opposed to elderly people? Where exactly do you want the emphasis?”

Clarification by German citizen:

“The point is not to place priorities on age-related diseases, but on all diseases, including those which afflict young children, infants and all other diseased people.

The emphasis is on ‘overall brain disease’.”

Another citizen:

“It should be ‘ageing related’ diseases – in order to save costs in the future. We are going to have a big problem in the future.”

Facilitator: *“either you leave it as it is or you remove the modifiers ‘age related’. If you are in favour or removing ‘age-related’, vote with your green card.”*

Vote: accepted with 84 votes.



5.3 Issue 2: Acute versus chronic and long-term treatment needs

Formulation of draft recommendations

The citizens started by clarifying what the issue was and why it was important. On the basis of the different elements mentioned above, they then formulated draft recommendations. The two resource persons present in the carousel were invited to comment on the proposed recommendations.

Draft recommendation 1

We recommend that families and private carers should be enabled to provide care when they are able to do so (managed care) (e.g. through state subsidies or dedicated insurance)

Draft recommendation 2

We recommend that the EU urges national governments to provide patients with a professional multi-disciplinary team in a family atmosphere or in their own home

Draft recommendation 3

We recommend to the EU to support media and schools to help improve the image of professional carers and families of brain patients in society

Draft recommendation 4

We recommend to the EU to systematically identify the needs and demands of member states within brain science and the cost of brain diseases to societies, comparing the social and economical impact e.g. of inaction vs. optimal treatment

Draft recommendation 5

We recommend that the EU should establish a guideline for national-level medical assistance to ensure dignity of life for chronically ill patients

Draft recommendation 6

We recommend that funding for research into chronic/long-term diseases should be monitored at national level

Draft recommendation 7

We recommend that the EU should urge and help member states to establish networks of care beyond the national capitals

Draft recommendation 8

We recommend that the EU urges to Member States to provide excellent help for brain-related illnesses in the acute phases of chronic illnesses in order to increase the chances of that person leading a “quality life”

Draft recommendation 9

We recommend to the EU to urge the relevant Member States to lift legislation banning low-cost carers from Eastern Europe

Draft recommendation 10

We recommend that the EU encourages programs for prevention of mental illnesses

The citizens prioritized the amendments. Numbers 1, 2, 5, 8 and 10 were retained and further elaborated in preparation of the European Cafés.



Presentation of the draft recommendations in the European Cafés

The next stage of the process consisted of the carousel 'stay behinders' presenting the draft recommendations in two **European Cafés**. The European Cafés gave the panelists from the other two carousels and the general public the opportunity to have an input, which would then be used to finalise the recommendations back in the initial carousel.

Draft recommendations and were presented in following form:

Draft recommendation 1 (old 1)

We recommend that families and private carers should be enabled to provide care when they are able to do so (managed care) (e.g. through state subsidies or dedicated insurance)

Draft recommendation 2 (old 2)

We recommend that the EU urges national governments to provide patients with a professional multi-disciplinary team in a family atmosphere or in their own home

Draft recommendation 3 (old 5)

We recommend that the EU should establish a guideline for national-level medical assistance to ensure dignity of life for chronically ill patients

Draft recommendation 4 (old 8)

We recommend that the EU urges to Member States to provide excellent help for brain-related illnesses in the acute phases of chronic illnesses in order to increase the chances of that person leading a “quality life

Draft recommendation 5 (old 10)

We recommend that the EU encourages programs for prevention of mental illnesses

The additional thoughts raised during the European Café discussions were passed on to the initial carousel for further debate once it had reconvened.

Completion of report, reviewing the input received during the European Cafés

The carousel reviewed the input from the European Cafés. The review process also took account of the ideas raised by the general public during the European Cafés which had been communicated to Steering Committee members present in these Cafés.

Subsequently, panellists established a final list of recommendations. Recommendations that received at least a two-thirds majority were included in the carousel's report that would be submitted to plenary for consideration by the entire citizens' panel (all three carousels together).

The chosen recommendations were presented in the plenary session on Sunday 22 January, worded as follows:

Pre-final recommendation 1 (previous 1)

Subsidies should be given directly to families, if they can give care. These should cover the excessive 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.

- **We recommend that families and private carers should be enabled to provide care when they are able to do so, to the degree proportionate to an institution**

Pre-final recommendation 2 (previous 2)

- **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**

Pre-final recommendation 3 (previous 3)

- **We recommend that the EU establishes 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

Pre-final recommendation 4 (previous 4)

- **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**

Pre-final recommendation 5 (previous 5)

- **We recommend that the EU encourages programs for prevention in family and education tasks to minimise mental health issues**

This should include educational programs directed at families helping them prevent mental health issues. Also, schools, sports and music should be included

Plenary review of the recommendations: discussion and adoption of amendments

On Sunday 22 January, the European citizens’ panel assembled in one plenary session to review the reports from each of the carousels in order to agree on a final report to be presented to the European Parliament on 23 January 2006.

The citizens received translations of the pre-final versions of the recommendations as concluded in the carousels and edited by the writers' group. At this point the recommendations already contained the input and represented the views of a large number of the panellists. The citizens were given a final chance to make adaptations to the recommendations. They were seated in their national panel groups for language reasons, but were asked to keep their focus European.

The national panel groups were allowed to make a maximum of two amendments: one on the first set of themes (Freedom of Choice, Regulation and Control, Public information and communication) and one on the second set (Pressure from economic interests, Equal access to treatment, Normalcy vs. diversity). The amendments proposed by each national table had to be accepted by at least two-thirds of the national panel group to merit consideration in the plenary and they had to refer to very important aspects that the national panellists felt absolutely needed to be added or amended in the text of the recommendation. This was to ensure that only significant amendments were submitted for vote in plenary.



The amendments were presented in the plenary and voted on by the entire European panel. Amendments were accepted if supported by a simple majority (half of all votes plus one). In total, 111 citizens were present when the voting took place. The final recommendations are reproduced under section II.

There were no amendments.



6. Theme Freedom of Choice

6.1 Identification of issues and selection of two issues

The citizens began by identifying for this theme the issues they considered to be of major importance to them and for which they would go on to formulate recommendations for action. They remained constantly mindful of the central question ‘How are we going to use our new-found knowledge of the brain’ during the reflection process. The panellists used the synthesis report, and the comments from resource persons (the experts’ views on the synthesis report and the experts present in the carousel) as a basis for their discussions.

Per theme, two resource persons were present in each carousel. At the start of the carousel, they were invited to comment on each theme, present their views on the synthesis report of the national assessments and draw the citizens' attention to the topics they considered to be the most relevant for brain sciences and European policy-making. The resource persons were also able to briefly comment on the citizens' draft recommendations and provide additional information if requested by the panelists.

The resource persons for this theme were Prof. Marc Jeannerod and Prof. Elias Kouvelas.

A list of issues to be discussed further was compiled based on the following criteria:

- the relevance to brain science
- the relevance to policy making at European level
- the extent of impact on citizens in Europe

To focus the discussions and ensure that the process during the Convention was workable, the citizens prioritised the issues and chose two for further assessment.

Freedom of choice

Issues identified	Issues chosen and argumentation
<ul style="list-style-type: none"> • Research: authorise stem cell research for therapeutic research • Financial aspects: financial limits vs. unconditional safeguard of patient's voice • How to guarantee quality and dignity of life • Early diagnosis: having the choice whether or not to have early diagnosis • Preventive actions and measures which might influence brain-development • How to help people with a brain impairment to make a choice • Range of treatments should be as broad as possible: health care systems should guarantee a range of options to choose from, including some alternative treatments 	<ul style="list-style-type: none"> • Helping impaired people to make a good, informed choice <i>In order to make a good choice, access to reliable, extensive, clear and independent information is vital. This holds true for any choice to be made. But precisely because of their disorder, people with an impaired brain or a psychiatric affliction might have an extra problem in choosing well. They need help to make a choice</i> • Guaranteeing the dignity and quality of life <i>People afflicted by brain-disorders might think differently about what counts as ‘quality’ in their particular life than non-ill persons would expect. Our efforts should be directed to improve their quality of life in their own terms and to respect their decisions – including the decision to say ‘no’ to a treatment on offer</i>



The citizens then assessed the two issues chosen. For each issue, recommendations were formulated for presentation in the plenary session on Sunday 22 January. It should be noted that in each phase of the process, the draft recommendations were always dealt with consecutively. This section gives an overview of the recommendation formulation process for the first and then the second so as to provide an account of the process that is as transparent and understandable as possible.

6.2 Issue 1: Helping impaired people to make a good informed choice

Formulation of draft recommendations

The citizens started by clarifying what the issue was and why it was important. On the basis of the different elements mentioned above, they then formulated draft recommendations. The two resource persons present in the carousel were invited to comment on the proposed recommendations.

Draft recommendation 1

Establish practical guidelines for specialists, including a list of criteria, to check whether someone is capable of making a decision

Draft recommendation 2

Brain research should focus on finding procedures to enable us to help people who are not able to make choices. We should do more research to make it possible to find out what people are thinking (wanting)

Draft recommendation 3

Set up EU guidelines on who should be capable of making carer decisions; this may for instance be an institution such as a court that can focus on the interest of the patient. We recommend creating a body of experts to look at regulations from other countries

Draft recommendation 4

The designated trusted person can be revocable

Draft recommendation 5

Install at European level a procedure to choose the trusted person

Draft recommendation 6

The European Parliament should create a body responsible for impartial information, advice and mediation for persons with brain conditions, like an ombudsman. It should also provide clarity about legal responsibility

Draft recommendation 7

Establish an EU law on how to create multidisciplinary team to take difficult choices for impaired people. It must be clear about who bears the responsibility

The citizens prioritised these draft recommendations. Numbers 3, 5 and 6 received a two-thirds majority and were therefore retained and elaborated further in preparation for the presentation in the European Cafés.

Presentation of the draft recommendations in the European Cafés

The next stage of the process consisted of the carousel 'stay behinders' presenting the draft recommendations in two **European Cafés**. The European Cafés gave the panelists from the other two carousels and the general public the opportunity to have an



input, which would then be used to finalise the recommendations back in the initial carousel.

Draft recommendations 3, 5 and 6 were presented in following form:

Draft recommendation 1 (old 3)

Guidelines for assignment of carers

We ask for EU guidelines to look at who is capable of being an appropriate carer. This may be an institution or court, whose focus is on the interest of patients. This should include a body of experts to look at regulations from other countries. The guidelines should be clear about the legal responsibility of the carers, and the limits of this responsibility

Draft recommendation 2 (old 5)

Choice of trusted person

On the European level a procedure should be installed which allows citizens to indicate a trusted person when they still have all their faculties (i.e. a person who takes decisions for you in case you are not able to do so anymore)

Draft recommendation 3 (old 6)

Impartial information

EU parliament should create a body responsible for impartial information, advice and mediation for those with brain conditions (an ombudsman)

The additional thoughts raised during the European Café discussions were passed on to the initial carousel for further debate once it had reconvened.

Completion of report, reviewing the input received during the European Cafés

The carousel reviewed the input from the European Cafés. The review process also took account of the ideas raised by the general public during the European Cafés which had been communicated to Steering Committee members present in these Cafés.

Subsequently, panellists established a final list of recommendations. Recommendations that received at least a two-thirds majority were included in the carousel's report that would be submitted to plenary for consideration by the entire citizens' panel (all three carousels together).

The chosen recommendations were presented in the plenary session on Sunday 22 January, worded as follows:

Pre-final recommendation 1 (previous 2)

Choosing a trusted person

- **We recommend to devise a European procedure to choose a trusted person. We think the European Union could help to install a procedure for these people to choose a trusted person at a moment when they can still make a choice. A trusted person is someone who takes decisions for you when you can not do so anymore. A lot of things are regulated by law, but we insist that the person can choose a person he or she can trust (not necessarily family or any other automatism)**



Pre-final recommendation 2 (previous 1)

Guidelines for trusted person

- **We recommend to install guidelines to support these trusted persons. They have to be embedded in a framework and should be helped to fulfil this role. First an expert body should look at the regulations in all the countries involved to see what has an impact**

Pre-final recommendation 3 (previous 3)

Information for people with brain conditions

- **We recommend to ensure impartial information. The European Parliament should create an independent body with sufficient cultural diversity that is accessible and within anyone's financial means. This must supply information, advice and mediation. Like an 'ombudsman'**

Plenary review of the recommendations: discussion and adoption of amendments

On Sunday 22 January, the European citizens' panel assembled in one plenary session to review the reports from each of the carousels in order to agree on a final report to be presented to the European Parliament on 23 January 2006.

The citizens received translations of the pre-final versions of the recommendations as concluded in the carousels and edited by the writers' group. At this point the recommendations already contained the input and represented the views of a large number of the panellists. The citizens were given a final chance to make adaptations to the recommendations. They were seated in their national panel groups for language reasons, but were asked to keep their focus European.

The national panel groups were allowed to make a maximum of two amendments: one on the first set of themes (Freedom of Choice, Regulation and Control, Public information and communication) and one on the second set (Pressure from economic interests, Equal access to treatment, Normalcy vs. diversity). The amendments proposed by each national table had to be accepted by at least two-thirds of the national panel group to merit consideration in the plenary and they had to refer to very important aspects that the national panellists felt absolutely needed to be added or amended in the text of the recommendation. This was to ensure that only significant amendments were submitted for vote in plenary.

The amendments were presented in the plenary and voted on by the entire European panel. Amendments were accepted if supported by a simple majority (half of all votes plus one). In total, 111 citizens were present when the voting took place. The final recommendations are reproduced under section II.

Two amendments were proposed, both of which related to the first recommendation. Both amendments were adopted.



■ AMENDMENT 1

On recommendation 1

From Belgian - French Speaking Community group

Change: “a trusted person” into “one, two or three people”, depending on cultural differences.

Vote: accepted by 87 votes.

■ AMENDMENT 2

On recommendation 1

From the Italian group

“People should be able to choose this person *and establish their biological testament* at a moment when they still have all their faculties. It should be possible to give this choice a more formal status along the lines of a codicil.” (*italics* = addition to existing text)

Rationale

“We thought that every citizen should have the possibility to state who his or her trusted person is. This possibility has to be extended to what he or she thinks his ‘quality of life’ should be from the point of view of ‘dignity of life’. The person should be able to write down what he considers an acceptable quality of life. The trusted person should receive this will and respect it. It is a possibility, it should not be an obligation and one should be able to change it at any time, as long as one is able to think clearly.”

Any rebuttals?

Belgian table: “I think it should be ‘and/or’.”

Facilitator: “this is an ‘edit’ and will be given to the editors. I don’t want to vote on it.”

British table: “the phrase ‘biological testament’ does not make sense in English. It needs rephrasing. This is not a comment on the intent.⁴”

Vote: accepted by 62 votes.

6.3 Issue 2: Guaranteeing the dignity and quality of life

Formulation of draft recommendations

The citizens started by clarifying what the issue was and why it was important. On the basis of the different elements mentioned above, they then formulated draft recommendations. The two resource persons present in the carousel were invited to comment on the proposed recommendations.

Draft recommendation 1

Declaration of intent

EU should initiate a declaration of intent that every life has a value, that each person is unique, and that treatment of any patient with a brain condition should have the aim of maintaining or improving their present quality of life. Furthermore: this declaration should be adopted as best practice policy, which always includes the patient’s own perception, where possible, of quality of life and dignity

⁴ The wording was adapted in the final recommendation, see under II.



Draft recommendation 2

Early diagnosis

An EU law should be installed to secure individuals against knowledge they don't want

We believe it should be possible to choose or not to choose for an early diagnosis. It may have tremendous personal consequences to be told that you may develop a life-threatening disease later in life. For other people it may be positive, because it may lead to better treatment of this person. A law at EU-level should secure this

Draft recommendation 3

Variety of choices of treatment secured by law

It should be possible to choose or not to choose for a medical treatment or other evidence-based non-medical treatment

Draft recommendation 4

Sufficient economic resources / financial support

We need economic resources to provide quality of life in society. We should discourage people from choosing euthanasia and we need to make significant improvement to psychiatric hospitals to secure better care. Since financial resources are finite, it comes down to allocation: there are more just and less just methods

Draft recommendation 5

Minimal level of quality of life

We need to establish a definition of what minimal level of life and dignity are. This minimal level should be provided at any rate, even if the costs are high. The allocation factor should only come into play beyond this level

Draft recommendation 6

Patient support

Patients should be supported by a qualified member of the medical staff, even if he decides to stay at home. At EU-level, laws should be enacted to secure that

Draft recommendation 7

Dignity

The EU should promote medical training in communication and advising patients who are not able to make decisions for themselves

Draft recommendation 8

Free health system

We must ensure a health system at European level in order to secure free access to treatment

The citizens prioritised these draft recommendations. Numbers 1 and 2 received a two-thirds majority and were therefore retained and elaborated further in preparation for the presentation in the European Cafés.

Presentation of the draft recommendations in the European Cafés

The next stage of the process consisted of the carousel 'stay behinders' presenting the draft recommendations in two European Cafés. **The European Cafés** gave the panelists from the other two carousels and the general public the opportunity to have an input, which would then be used to finalise the recommendations back in the initial carousel.



Draft recommendations 1 and 2 were presented in following form:

Draft recommendation 1 (old 1)

Declaration of intent

EU should initiate a declaration of intent that every life has a value, that each person is unique, and that treatment of any patient with a brain condition should have the aim of maintaining or improving their present quality of life.

Furthermore: this declaration is adopted as best practice policy, which always includes the patient's own perception, where possible, of quality of life and dignity

Draft recommendation 2 (old 2)

Early diagnosis

We believe it should be possible to choose, or refuse, early diagnosis. A law at EU-level should be installed to secure individuals against knowledge they don't want. This is because it may have tremendous personal consequences to be told that you may develop a life-threatening disease later in life. For other people it may be positive, because it may lead to better treatment of this person

The additional thoughts raised during the European Café discussions were passed on to the initial carousel for further debate once it had reconvened.

Completion of report, reviewing the input received during the European Cafés

The carousel reviewed the input from the European Cafés. The review process also took account of the ideas raised by the general public during the European Cafés which had been communicated to Steering Committee members present in these Cafés.

Subsequently, panellists established a final list of recommendations. Recommendations that received at least a two-thirds majority were included in the carousel's report that would be submitted to plenary for consideration by the entire citizens' panel (all three carousels together).

The chosen recommendations were presented in the plenary session on Sunday 22 January, worded as follows:

Pre-final recommendation 1: (previous 2)

Choice for early diagnosis

- **Guarantee an explicit right of citizens to choose whether or not they want to be informed of an early diagnosis. It should be possible for citizens to choose, or refuse, an early diagnosis. Doctors should only be able to disclose information based on early diagnosis of the patient consents**

Plenary review of the recommendations: discussion and adoption of amendments

On Sunday 22 January, the European citizens' panel assembled in one plenary session to review the reports from each of the carousels in order to agree on a final report to be presented to the European Parliament on 23 January 2006.

The citizens received translations of the pre-final versions of the recommendations as concluded in the carousels and edited by the writers' group. At this point the recommendations already contained the input and represented the views of a large number



of the panellists. The citizens were given a final chance to make adaptations to the recommendations. They were seated in their national panel groups for language reasons, but were asked to keep their focus European.

The national panel groups were allowed to make a maximum of two amendments: one on the first set of themes (Freedom of Choice, Regulation and Control, Public information and communication) and one on the second set (Pressure from economic interests, Equal access to treatment, Normalcy vs. diversity). The amendments proposed by each national table had to be accepted by at least two-thirds of the national panel group to merit consideration in the plenary and they had to refer to very important aspects that the national panellists felt absolutely needed to be added or amended in the text of the recommendation. This was to ensure that only significant amendments were submitted for vote in plenary.

The amendments were presented in the plenary and voted on by the entire European panel. Amendments were accepted if supported by a simple majority (half of all votes plus one). In total, 111 citizens were present when the voting took place. The final recommendations are reproduced under section II.

One amendment was proposed, which related to the first recommendation. The amendment was adopted.

■ AMENDMENT 1

On recommendation I

From the Dutch group

“Guarantee an explicit right of citizens to choose whether or not they want to be informed of an early diagnosis” – should be changed to “for citizens to choose or *refuse early testing and diagnosis*”. (*italics* = addition to existing text)

Rationale

“We looked at this carefully and we thought that it should be necessary to include the step before the diagnosis. Citizens should have the right to reject tests if there is no need for them.”

Any rebuttals?

German table:

We should stick to fundamental considerations – these are minor details with which we should not occupy ourselves.

Vote: accepted by 78 votes.



Plenary review of recommendations: Summary of Sunday 22 January discussion and approval of amendments

On Sunday 22 January, the European citizens' panel assembled in one plenary session to review the reports from each of the carousels and agree on a final report to be presented to the European Parliament on 23 January 2006.

Daniel Stone, the lead facilitator, pointed out that at this point the recommendations already contained the input and represented the views of a large number of the panelists. The recommendations that were going to be presented were the pre-final recommendations drafted by the writers' group. This would be the citizens' final chance to modify the recommendations.

He explained that there were two rounds and each round would deal with three themes. One member from each carousel would present an overview of the recommendations (also projected on PowerPoint slides) and then the citizens would convene in national panels to decide what amendments, if any, they wanted to make. He stressed that the amendments proposed by each national table had to be accepted by at least two-thirds of the national panel group to merit consideration in the plenary and they had to refer to very important aspects. He asked the panels to focus on changes to the meaning of recommendations, not language matters since these could be discussed separately with the writers' group. He also asked the participants to keep the European focus in their national panel groups.

Sixteen amendments were presented in the plenary and voted on by the entire European panel. Amendments were accepted if supported by a simple majority (half of all votes plus one). In total, 111 citizens were present when the voting took place. The final recommendations are reproduced under section II.

a) Round one: the first three themes

The pre-final recommendations were presented on PowerPoint slides for themes I Regulation and control, III Public information and communication and VI Freedom of choice. The citizens' panel was then given the opportunity to propose one amendment per national panel group.

Amendment 1:

Theme VI, Issue 1, Recommendation I: the Belgian French Community panel proposed increasing the possible number of trusted persons.

The amendment was adopted with 87 votes.

Amendment 2:

Theme VI, Issue 1, Recommendation I: the Italian panel suggested including the ability to make a living will at a time when a person still has all their faculties.

The amendment was adopted with 62 votes.

Amendments 3 and 4:

Theme I, Issue 1, Recommendation I: the French panel preferred the term "ethical questioning" to the term "ethical control". The French table also wanted to refer to a



“network of national ethics committees” as opposed to a “pan-European ethical and legal advisory committee”.

Neither amendment was adopted.

Amendment 5

Theme VI, Issue 2, Recommendation 1: the Dutch panel thought that it was important to include the possibility of choosing or refusing early testing as well as an early diagnosis. The amendment was adopted with 78 votes.

Amendment 6

Theme I, Issue 1, Recommendation 2: the Greek panel wanted to mention that brain imaging techniques should be prohibited for use by the police or judicial investigations or for public security reasons.

The amendment was adopted with 80 votes.

Amendment 7

Theme III, Issue 2, Recommendation 2: the Belgian Flemish Community panel did not think that it was appropriate to say “parents who were likely to take less care of their children”.

The amendment was adopted with 94 votes.

The UK panel thought that the report should be more specific by using the term “brain science” instead of just “science” and also qualifying the term “prevention” by saying “prevention of brain dysfunctions”.

b) Round two: the last three themes

The pre-final recommendations were presented on PowerPoint slides for themes II Normalcy vs. diversity, IV Pressure from economic interests and V Equal access to treatment. The citizens' panel was then given the opportunity to propose one amendment per national panel group.

A member of the **French panel** pointed out that recommendation II.2.2⁵, as it had been displayed on the slide, was completely different to the recommendation he had seen when he was working as a member of the writers' group.

The writer-editor read out the pre-final recommendation as it was written on paper.

The French citizen said that that was different to what had been presented on the PowerPoint slide.⁶ He asked what the citizens were supposed to be voting on – the version being presented on the slide or the version contained in the writers' group's report. Were they the same or not.

A **member of the writers' group** said that the paper version was always more extensive but that the writer-editors had been asked to write a short version with the core recommendations to be presented to the plenary. In the final report there would always be more, never less, than what appeared on the slide.

Rinie van Est from the writers' group explained that the slides contained the whole text of the core recommendation. The rationale before the recommendation had not

⁵ The roman numeral refers to the theme, the next number refers to the issue within the theme and the final number refers to the recommendation.

⁶ Not all national panels had received translations of the full recommendations in time for their reflection before the final plenary session.



been included on the slides but it would be included in the final report. He admitted that a mistake had perhaps been made.

A **British citizen** said that he did not know where theme II.1.3 came from. A Dutch citizen said that important parts were missing from this recommendation.

The **French citizen** highlighted that there were translation problems with a number of recommendations. He expressed his annoyance that recommendation II.2.2 contained no reference to social control, despite the fact that it had received the support of an overwhelming majority of the citizens. He said that this recommendation did not make sense as it stood and it was not the only one.

A **Greek citizen** said that the reference to patents had been omitted from recommendation IV.2.2. This was a topic that had been discussed a great deal in carousel 1.

The **French citizen** said that he did not understand why the citizens were not told at the start that what was presented on the slides was not the whole report. This meant that the citizens could only make amendments to what was on the screen and not what was actually contained in the report. He pointed out that people may have had amendments to propose on the full text and that therefore the first round of voting was not valid.

Daniel Stone suggested breaking for a few minutes to decide how to proceed. He also asked the panels to discuss any changes or apparent omissions with the writers' group during the break. Any changes made would then be projected after the break.

After the break, Daniel explained that what had been contained in the PowerPoint slides was the core of each recommendation but not the full text contained in the report. However, during the national panel sessions, the panels had been provided with a paper copy of the full report, including the rationale. He asked the panels to submit any additional comments or corrections to the writers' group. He explained that the citizens' would soon be provided with the entire text, on which they would be free to make comments, corrections or amendments. He also commented that, in some cases, what the writers' group had chosen to present as the core recommendation did not correspond to the citizens' idea of the core recommendation. This would be changed.

The **French citizen** said that he only wanted to vote on a definitive text and not one with mistakes. He thought that the final document did not reflect what the citizens' had talked about and said that he would not vote on the text.

Daniel Stone explained that what the citizens' were now receiving was a draft text and that he wanted to receive the citizens' comments and amendments on that text. It was simply not practical to repeat the entire procedure for the first three themes and so an alternative solution had to be found.

A **Greek citizen** asked if all the citizens supported the French panel and asked that the position be recorded officially.

The **French citizen** said that he was not happy with the answer he had received because the citizens had *not* received the complete document and that they had *not* been able to make comments on the complete document. They had only received a partial



French translation, some recommendations were missing and there were some major differences between the French and English versions. The French panel was therefore unable to submit amendments on certain parts of the report.

Daniel Stone said that the dilemma everyone was facing was about the availability of time. He explained that a certain amount of work had been done to the citizens' satisfaction and there was a certain amount of work that was not yet available for comment and input and it was unlikely that this work would be ready in the next two hours. The intention was to have a process that was 'good enough' and which got the citizens close enough to a set of recommendations. He asked the citizens how they wanted to proceed, if they wanted to proceed.

There was general consensus in the room that the best approach was to continue with the last three themes using the complete draft text and for the citizens to submit any very important changes on the first three themes to the writers' group. The national panels then went on to consider the last three themes.

Amendments 1,2,3,4

Theme IV, Issue 1, Recommendation 1: the Greek panel thought it was important to refer to all kinds of incentives and not restrict the recommendation to tax incentives. It also wanted to mention research into rare diseases. The UK panel, however, was in favour of keeping the word tax in the recommendation. The German panel thought that no additional incentives should be provided to the pharmaceutical companies but that instead investment should be made in public brain research relating to rare disorders. The Belgian French Community panel thought it was important to qualify the statement by adding that the tax reductions should be invested in research but that these investments needed to be controlled. The Hungarian panel wanted to focus more on limiting the acceptable profit of the pharmaceutical industry and channelling any surplus profit into basic research.

The Greek amendment was adopted with 76 votes. The others were rejected.

Amendment 5

Theme V, Issue 1, Recommendation 1: the Italian panel thought that there should be a standard price for medicines throughout Europe. However, the Hungarian panel pointed out that salaries in all the European countries were not uniform and so this idea was not feasible.

The amendment was not adopted.

Amendment 6

Theme V, Issue 1, Recommendation 2: the German panel wanted to remove the reference to age-related diseases in the recommendation.

The amendment was adopted with 84 votes.

Amendment 7

Theme IV, Issue 2, Recommendation 2: the Belgian Flemish Community panel thought it was important to mention research into long-term consequences of medication and other treatments.

The amendment was adopted with 91 votes.

Amendment 8

Theme V, Issue 2, Recommendation 1: the Dutch panel wanted to introduce the idea of a control system to prevent subsidies from being abused.

The amendment was adopted with 81 votes.



Amendment 9

Theme II, Issue 1, Recommendation I: the French panel thought it was important for social workers to receive training about diversity so that they could then raise awareness of the people they come into contact with in their professional lives.

The amendment was adopted with 78 votes.

A **Hungarian citizen** asked if the citizens would receive the full set of documentation in their own language before or after the presentation in the Parliament.

Daniel Stone said that the documentation would be made available in two stages. The first stage would be the report for the European Parliament which would be finalised by the Writers' group that evening.⁷ The second stage would be a more comprehensive report which would be compiled later and would contain minority comments and the results of the votes. It was not possible to produce the latter before the presentation to the Parliament because of time constraints.

At the end of the plenary session, the Danish panel communicated in written form a number of observations on the final recommendations. They did this instead of submitting specific amendments on the individual recommendations. They stated that they appreciate that following issues are included in the final document:

- The focus on guaranteeing dignity and quality of life
- The focus on early diagnosis
- The focus on improving education curricula; although they think that education of children has too much priority over education in the whole society
- The issue of citizen participation in regulation and control
- The focus on research in prevention of brain related diseases
- Research in alternatives to medical treatment
- Equal access (regarding financing) to treatment for the acute and the chronically ill
- The focus of diversity as a source of richness in society

They noted that in general they think, that research in the healthy brain for the purpose of understanding and developing the positive potential of the brain has had too little focus, and that problems and disease were overemphasized.

⁷ The format of the recommendation language varied slightly between carousels, as a result it was up to the writers' group to make a distinction between the core recommendation (presented on screen) and the supporting rationale (not presented on screen).





The 37 recommendations on Brain Science

At the end of the plenary session on the afternoon of Sunday 22 January, the European citizens' panel had produced 37 recommendations on the six themes they had addressed during their deliberation on brain science. After the citizens had voted on the amendments in the plenary session on Sunday, the writers' group revised the texts, introduced the amendments and made a few linguistic changes so that the texts read better in English.

The following day, the European Citizens' panel presented their final assessment report to high-level European officials, representatives from the European scientific and research community and stakeholders in the field, during a closing session in the European Parliament.

The final recommendations for each of the six themes and corresponding two issues are set out below. They are preceded by a short text providing the rationale for the recommendation. The core of the recommendation is written in bold, preceded by a bullet point.



Overview of the recommendations

1. Regulation and Control

1. Pan-European ethical committee
2. Informed consent for brain-imaging techniques
3. Dialogue between citizens and science
4. Common methods for citizen participation
5. Transparency and information flows

2. Normalcy vs. Diversity

1. Promote diversity
2. Foster integration
3. Avoid medicalising society
4. Increase funding for brain research
5. Avoid social control
6. Focus on prevention and rare conditions
7. Increase research on prevention and alternative treatments

3. Public Information and Communication

1. Organise a European information strategy
2. Establish a European information and coordination structure
3. Translate results into common language
4. Stimulate interdisciplinary work
5. Focus education on prevention and learning how to learn
6. Raise awareness among future parents
7. Constantly adapt health (care) education programmes to new knowledge of the brain
8. Constantly adapt the education system to new knowledge of the brain
9. Engage the responsibility of knowledge producers
10. The role of NGOs

4. Pressure from Economic Interests

1. Incentives for pharmaceutical industries
2. Research for the common good
3. New ways to stimulate pharmaceutical research with low profit-potential

5. Equal Access to Treatment

1. Equal access to treatment
2. Priority to research into brain disorders
3. Evaluation of the effectiveness of new treatments
4. Enabling families to provide long-term care
5. Providing professional multi-disciplinary care teams
6. Ensuring dignity and quality of life for chronically ill patients
7. Helping in the acute phase to enable long-term quality of life
8. Preventing mental illnesses and psychological problems

6. Freedom of Choice

1. Choosing a trusted person
2. Guidelines for trusted persons
3. Information for people with brain conditions
4. Choice for early diagnosis



1. Regulation and Control

We felt that the issues about ‘ethical control’ and ‘involving citizens in regulation and control’ were the most important ones to discuss within the theme of Regulation and Control.

Ethical Control

We think there is a need to strengthen the control of ethical matters and harmonise it across all Member States. This is a particularly pertinent issue in the area of brain science because human identity is central to ‘brain ethics’. Every piece of research and every treatment should be designed to maintain the quality of life and dignity of the patients. This should be guaranteed.

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.**



Involve citizens in regulation and control

Regulation of brain research and treatment must be independent of political and economic interests. We citizens are essentially concerned with this because the brain represents our identity, personality and mind. Therefore, we want to be involved at the different levels of decision through various forms of participation.

3. 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.

4. 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.

5. 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**



2. Normalcy vs. Diversity

We felt that the issue of diversity as a source of richness for society and that of improving the quality of treatment and the importance of promoting and stimulating brain research were the most important issues to discuss on the theme of normalcy vs. diversity.

Diversity as a source of richness in society

We need to focus on the acceptance of diversity in order to prevent stigmatisation. Diversity should not be seen as a problem but instead needs to be viewed as a positive aspect, in fact European society can only move forward if we learn to accept diversity. Diversity is a basic prerequisite for democracy. It is therefore a fundamental concern for us as citizens.

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



Promote brain research

Mental problems are on the increase in Europe today. People need to have access to a range of high-quality treatments which can be tailored to their individual needs. This will help to enhance their quality of life and preserve their individuality. As regards the promotion of brain research, it is important to note that brain research is an important building block for our societies. Therefore as much financial support must be made available as possible, in order to foster progress in this field and to prevent the brain drain to the US.

4. 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**

5. 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**

6. 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**

7. Increase research on prevention and alternative treatments⁸

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**
- **We recommend conducting more research on and providing more funding for alternative treatment techniques**

8 The wording of this recommendation has been adapted in this report to include the term 'Prevention' in the title, and the inclusion of 'more funding' in a second part of the recommendation. These additions had been mistakenly omitted in the final assessment report presented in the European Parliament. The wording 'alternative treatments' covers all alternative forms of conventional medical treatments. On the one hand, this term is used in the sense of 'complementary medicine' as a non-evidence-based medicine of homeopathic or anthroposophist origin used in addition to conventional medical treatment. On the other hand, citizens referred to it as a substitute to conventional medicine like psychotherapy, music-therapy etc...



3. Public Information and Communication

We felt that the issue of bridging the gap between science and society and that of improving education curricula were the most important issues to discuss on the theme of public information and communication.

Bridging the gap between science and society

The problem is not that there is not enough information available but rather the accessibility of this information and the clarity and quality of the information. This needs to be made explicit because citizens are not always in a position to judge the quality of scientific information for themselves. It is important to emphasise that information is a two-way process; information should flow from scientists to citizens but also citizens to scientists. It is also important that information is made available in a way that the general public can understand.

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

Improving education curricula

Education is not just a matter for schools but should be extended to include all of society: parents, teachers, children, pregnant women, doctors and health care professionals. Education plays a key role in increasing responsibility amongst the population and can help people to process the information they receive by teaching them how to learn and how to think critically. It can also help professionals to apply knowledge and ensure that they are kept up to date with the most recent scientific developments in their area of expertise. It can also help to promote more tolerance thereby reducing stigmatisation.

5. 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

6. 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

7. 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 target 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

8. 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

9. 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

10. The role of NGOs

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



4. Pressure from Economic Interests

We decided to focus on the following two issues: ‘Research: the balance of public and private funding’, and ‘Economic interests of companies might conflict with public interests’.

Research: the balance of public and private funding

Brain research goes on in private enterprises as well as public institutions. Private industry has generally more money to spend, but looks into fields in brain-research which promises to yield quick returns on investment. This may lead to lack of attention for important brain research fields. We feel the two ways of funding should be balanced.

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**

Economic interests of companies might conflict with public interests

Pharmaceutical companies produce many drugs that people with psychiatric and neurological afflictions cannot do without. But the objective of these powerful companies is to make profit and this aim may not coincide with the common good and social needs. This creates tensions.

2. 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**



3. 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**



5. Equal Access to Treatment

We decided to focus our discussions about Equal Access to Treatment on the issues of ‘equal access to treatment options across Europe’ and ‘Acute versus chronic and long-term treatment needs’.

Equal access to treatment options across Europe

We think that European citizens have a right to get high quality treatment wherever they live in the EC. Poor countries should be upgraded and rich countries preserve their standards; they should not meet at the middle. Regulation should guarantee that sort of harmonisation across Europe.

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**

Acute versus chronic and long-term treatment needs

Chronically ill persons suffering from neurodegenerative diseases or chronic mental illnesses are often the poorest in society; they are considered as a burden and as less valuable persons. Therefore, it is important to guarantee equitable funding of treatment for long-term mental problems, including community services and non-medical treatments.



4. 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

5. 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

6. 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

7. 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**

8. 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 programs directed at families helping them prevent mental health issues. Also, schools, sports and music should be included



6. Freedom of Choice

We decided to focus on the following two issues: ‘Helping impaired people to make a good, informed choice’, and ‘Guaranteeing the dignity and quality of life’.

Helping impaired people to make a good, informed choice

In order to make a good choice, access to reliable, extensive, clear and independent information is vital. This holds true for any choice to be made. But precisely because of their disorder, people with an impaired brain or a psychiatric affliction might have an extra problem in choosing well.

1. Choosing a trusted person⁹

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.

Therefore,

- **We recommend devising a procedure on European level for choosing one or several trusted persons. It should be possible to give this choice a more formal status, along the lines of a written explicit wish**

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.

⁹ The presentation of this recommendation has been slightly adapted in this report, according to the amendment made by the Italian panel in the plenary session accepted by a majority of the European citizens’ panel. In the previous version, presented in the European Parliament on the 23rd of January the second sentence of the recommendation was part of the rationale.



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

Guaranteeing the dignity and quality of life

People afflicted by brain-disorders might think differently about what counts as ‘quality’ in their particular life than non-ill persons would expect. Our efforts should be directed to improve their quality of life in their own terms and to respect their decisions – including the decision to say ‘no’ to a treatment on offer.

4. 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

10 Janez Potočnik was unable to attend the closing session in the European Parliament in person, but had prepared a video message for the citizens' panel.



Summary of the Public Presentation of the European Citizens' Assessment Report at the European Parliament

On 23 January 2006, the European citizens' panel presented their Assessment Report at the European Parliament. Following a brief welcome speech by the host, Silvana Koch-Mehrin, six of the citizens gave an overview of the recommendations they had written during the weekend and a further four gave short presentations about their personal experiences and the importance of the ECD process. These citizens were: András Gelencsér (HU), Cornelia Dodt (DE), Herman Depré (BE), Gerda Hempel (DA), Isabella Somaglia (IT), Tom Huigen (NL), Arno Giebels (BE), Guillaume Le Royer (FR), Stathis Athanassoglou (GK) and Anthony Goody (UK). The presentations were followed by comments from eight people, including high-level European officials, representatives of the European scientific and research community and representatives of civil society organisations with an interest in brain-related issues.

The text below is a summary report providing an account of what happened during the session in the Parliament.

Silvana Koch-Mehrin opened the session and welcomed the participants to the European Parliament. She highlighted the importance of brain research in today's aging society which is increasingly affected by brain disorders. The Meeting of Minds project was therefore an extremely timely event on an important topic enabling ordinary people to engage with cutting-edge science in a unique and unprecedented way and helping them to shape public debate and policy making. She expressed the *“hope that this approach will be replicated in other areas of public interest in which the public has a right to greater involvement”*.

Janez Potočnik¹⁰, the EU Commissioner for Science and Research, hailed the process as an excellent way of bridging the perceived gap between European citizens and the European institutions in many areas and said that the project was an important step in establishing that citizen participation is *“not only possible but also highly desirable”*. It is desirable since it helps policy-makers at the European Parliament and the European Commission to better understand the views of the people. Moreover, it is essential to show that European policy can be steered in a new and inclusive way. He was convinced that this approach would lead to more robust policies and deepen people's understanding of science, which would benefit the relationship between research scientists and citizens in the future.



Ten citizens presented the recommendations contained in their final report to the European Parliament. They too mentioned how vital this type of citizen involvement was for Europe since it helps Europe to deal with the important decisions it has to make on behalf of the citizens and helps to bring citizens closer together to the European institutions thereby enhancing legitimacy. They also highlighted the large amount of thought and effort that had gone into the report.

Octavi Quintana Trias, the Director of the Directorate of Health at DG Research also referred to the importance of citizen participation but said that in their deliberation process the citizens' points of view are not usually incorporated since no mechanism is in place for this. The report was very interesting for his Directorate since it informed them of a number of new points of which they had so far been unaware, for example the importance that the citizens attached to legal aspects and regulation. This lack of awareness clearly highlighted the need for communication between all the players i.e. citizens, scientists, researchers and policy-makers.

Dr Quintana Trias then went on to mention some of the ways that the Directorate was planning on putting the citizens' recommendations into practice and some of the initiatives already taken by the Directorate that tied in with the recommendations.

- The Commission is committed to financing basic brain research. In fact, the brain is the only organ for which funding is provided for the study of diseases and the research into how the organ works and develops.
- An initiative has recently been launched to create a European Research Council. This body will have three features: individual citizens will be able to submit proposals; the topics will not be decided by the Commission, but there would be investigatory-driven research; and the only criterion used to evaluate proposals will be scientific excellence.
- Procedures need to be simplified in a bid to make bodies more accessible to the public and to improve communication with and involvement of citizens.
- One of the recommendations made by the citizens' panel tied in perfectly with one of the Directorate's aims, namely to provide incentives for industry. The Commission wants to foster cooperation with industry and will therefore launch the innovative medicines initiative which aims to respond to scientific problems faced by the industry and major issues on drug development in Europe. An extensive research agenda has already been developed for this and is due to be funded in the next framework programme. It will be half funded by the Commission and half by the industry.
- A completely new aspect had been introduced in the current framework programme that focuses on the best ways to deliver health to citizens and on how research outcomes are implemented in clinical practice.
- As regards involving citizens in policy-making and regulation, the aim is to include citizens and especially patients into the decision-making process in at least two main areas: firstly in the advisory group which advises the Directorate on how to construct the framework programmes; and secondly in the project evaluation stage in order to help select which projects will be funded.

He concluded by assuring the citizens that *“their recommendations will be taken very seriously”*.

Philippe Busquin MEP, the chair of STOA (Scientific and Technological Options Assessment) described the event as *“an excellent example of just how well European*



can work". He was pleased that the initiative had been taken to bring citizens closer to European policy makers and was glad that the topic chosen for this event was a science-related topic. This would help to bridge the gap between science and society. Science and society is an important matter for the Commission and for STOA and currently a meeting on the question of science and society was being held.

He highlighted the need for scientists/researchers and policy and decision-makers to work together and said that it was only in this way that more research could be undertaken into rare diseases (one of the recommendations made by the citizens' panel).

He concluded by thanking the citizens' panel for the report and recommendations and assured them that he would *"give very serious follow up to the report"*. The STOA will be looking at the new framework for research and development for the next period and was looking forward to founding that on active citizen involvement and cooperation. The STOA will try to ensure that the results of the citizens' panel will be implemented in a way that European citizens can understand and which will be to their benefit.

Mary Baker from the European Federation of Neurological Associations (EFNA) and the European Brain Council congratulated the King Baudouin Foundation and the citizens on the work achieved. She did not think that anybody could disagree with any of the recommendations that had been made. The challenge now was to change these words into action, which was not an easy task. She highlighted the role of the non-governmental organisations in educating, informing and involving the people they were trying to help since patients can often make extremely valuable contributions.

She also thought that a number of prejudices needed to be put aside, such as that the pharmaceutical industry is always greedy, doctors are always patronising, policy-makers do not listen and patients are ignorant, so that we could approach the challenges facing us with an open mind.

Georgina Georgiou from the Cabinet of the Commissioner for Health and Consumer Protection at the European Commission highlighted the importance of good mental health for quality of life. Mental health problems are frequent and on the increase in the European Union and they can have serious implications for individuals, societies and the economy. Despite this, the importance of good mental health has long been under-recognised in the health sector. However, now the Commission is acting to reduce and prevent mental illness. Under the current public health programme (2003-2008), the Commission's Health and Consumer Protection Directorate General has supported several European projects in a bid to get more information on mental disorders and to look into the possibilities for prevention. The Commission also presented a Green Paper on mental health last October which represents a first step towards establishing a European mental health strategy.

Brain disorders and research raise important issues such as our understanding of the concept of normality and whether treatment should be provided by means of drugs or by changes in a person's environment. These questions were discussed during the Meeting of Minds project which is an *"excellent initiative bringing citizens closer to policy-makers on such important questions raised by brain science"*. The final report represents a *"valuable contribution to the public debate about what is feasible and what is desirable in brain research"*.



Philippe Galiay from the Directorate Science and Society at DG Research started by extending his thanks to the citizens' panel for their efforts and dedication to the project and also to the King Baudouin Foundation. The purpose of his Directorate was to *“promote the harmonious integration of science and technology in European society”*. There were a number of ways of achieving this such as organising scientific communication, increasing the interest of young people in science, encouraging women to become more active in the world of science and conducting work on the relationship between science and governance. The latter deals with achieving the best use of scientific advice in the political sphere and also guaranteeing optimal participation of citizens and civil society in research entities.

He pointed out that the citizens' recommendations affected a large number of players depending on the level of governance in question. There were some issues that could be sensibly addressed at European level, however others were perhaps better dealt with at national or regional level, whilst others needed a truly global approach. It was important to bear in mind that each level of governance had a certain amount of relevance depending on the issues addressed. The recommendations also focused on a variety of different aspects of brain science, some related to the brain and only the brain, others dealt with governance on health, others referred to governance on research and yet others focused on governance in general. This diversity in terms of both the levels of governance and the range of issues needed to be considered when attempting to implement the recommendations.

Since Octavi Quintana Trias had already mentioned some of the future actions planned by the Commission, Mr Galiay just made a brief comment on the issue of governance in research and said that DG Research wanted to *“step up our action on the basis of what we have learnt by means of the Meeting of Minds project”*. Many lessons about civil society participation will be able to be drawn from the project.

Michael Rogers, a science and ethics adviser at the Bureau of European Policy Advisers, which advises the European Commission on the ethics of sciences and new technologies was extremely enthusiastic about the project, with high praise for the King Baudouin Foundation and the citizens' panel for their achievements and the clarity of the results produced. In his committee, attempts are made to involve citizens but this takes place exclusively through round table meetings. The recommendations made by the panel on alternative approaches will be *“of considerable interest to the European Group on Ethics”* and Mr Rogers would draw their attention to the recommendations in the very near future.

He pointed out that the citizens had essentially been concerned with the governance of expertise, the use of scientific advice and ways of ensuring citizen participation and transparency. He assured the citizens' panel that the Commission was “wholly committed to improving the way in which we govern expertise and wholly committed to improving transparency”.

Pierre Magistretti from the European DANA Alliance for the Brain (EDAB) said that his organisation was committed to promoting public understanding of the brain. He considered it vital that real dialogue was established between citizens and experts and not simply an information line. What had happened during the *“Meeting of Minds project certainly had all the characteristics of dialogue”*. Such initiatives should be encouraged and he thought that the impact of the Meeting of Minds initiative would increase dramatically in the near future as a result of what he described as 'the snowball effect'



(the citizens' panel would tell people about the project, who would then tell other people and so on). This was a very positive aspect.

He was very impressed by the fact that the citizens had made a recommendation on increasing support for basic brain research. He was the former President of the European Federation of Neuroscience Societies which is strongly committed to basic brain research. Basic brain research is something which is often overlooked but which is of fundamental importance since nobody ever knows what will come out of it.

He was pleased to hear from Dr Quintana Trias that there would be an initiative to foster investigatory-based projects and he thought that these projects were a sign of diversity, an important topic and one which was discussed in the citizens' panel over the weekend. He also highlighted the notion of interdisciplinarity as a key factor in research. Scientists are the leaders in promoting basic research but interactions with other scientists are vital, especially when the implications of research for society is concerned. After all, *“major progress often comes at the frontier of disciplines”*.

As regards communication and dialogue, he thought that it could be helpful to embed some of this dialogue within art and culture since it was a common 'language' that was easily accessible and that everyone could understand.

Dorette Corbey, MEP, said how impressed she was by the whole project and thought it was excellent that citizens were involved in such a project which should serve as an example for others. She noted that this approach was particularly important in a field such as brain science since people often have a very clear-cut opinion on pure political matters, but this was much less the case for scientific and ethical issues.

One of the biggest dilemmas is what can be achieved with drugs and what can be achieved with environmental factors. *“There is a temptation to treat undesirable behaviour and give it a medical or scientific explanation”*. This is something that we should be concerned about and something that the citizens' panel has discussed.

Mental health is a topic that is increasingly featuring on the European Union's agenda. More research should be undertaken on mental conditions and brain science and access to mental health care should be one of the core points on the political agenda. She concluded by informing the citizens that she would try to incorporate the project in discussions on the Seventh Framework Programme and by thanking the organisers and the citizens for the results they had presented.

Silvana Koch-Mehrin said that the project was a milestone in participatory processes because *“if it works for such a highly scientific issue like brain sciences... then it should work for other subjects too”*. These processes were the only way forward for Europe. She concluded by thanking the citizens for their contribution and commitment to the project.





Rapid headway is being made in the field of brain science. This offers us hope since it is science that will provide primary solutions to brain disorders. However, there are also concerns. The breakthroughs in the world of brain science raise many questions and a wide variety of answers that concern us all.

Meeting of Minds - European Citizens' Deliberation on Brain Science is a unique exercise involving the general public in a discussion on cutting-edge science. For the first time, citizens of the European Union are leading debates that shape public policy. The ECD method enables citizens to hold an open, constructive and pro-active debate on the future of brain science in the earliest stages before opinions become strongly divided. It is a powerful response to the EU's efforts towards greater public involvement and is an exciting new method of transnational public discussion about future research, technological decision-making and government oversight.

Throughout 2005 and 2006, 126 citizens from nine European countries have held intense dialogues and debates on what they think should be done with our new-found knowledge of the brain. They debated the ethical, legal, social and economic implications with international experts.

23 January marked the end of the deliberation process of the first European Citizens' Deliberation on Brain Science. The European citizens' panel presented their recommendations at the European Parliament and handed over their European Citizens' Assessment Report to important decision makers in the European Union.

This report gives the complete results from the deliberation process at the Second European Citizens' Convention. It shows how the citizens went from themes, to issues to final recommendations.

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