



MEETING OF MINDS



EUROPEAN CITIZENS' DELIBERATION ON BRAIN SCIENCE

For the first time, 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, or ECD. This ambitious and innovative process of citizen participation, begun in 2004, represents an unprecedented opportunity to give ordinary people a role in guiding the EU in the earliest stages of policy development in a complex scientific field. By bringing together citizens of nine countries, of differing cultural and linguistic backgrounds, ECD marks a breakthrough in participatory governance that holds promise for policy development in many other fields and levels of government.



Brain science: the topic

The subject is central to humankind: the magnificent, complex and extraordinary human brain. Rapid advances in brain research not only raise the hope of new cures for brain disease, but profound questions of what it means to be human and how we retain our sense of self. New technologies and drugs that can alter, enhance or control our brains go right to the core of our identity. How will we respond to these extraordinary advances? Simply stated: How are we going to use our newfound knowledge of the brain?

The question is all the more critical in light of predicted growth in the spread of brain disease in an aging European society. By the year 2030, it is estimated that roughly half of the population will suffer from some form of brain disease. Finding new methods of prevention and treatment and possible cures thus becomes an urgent priority.

Yet for all their promise, new forms of brain imaging and the ability to alter brain function raise serious ethical, legal and social questions. These issues have long been discussed among experts in the field, whether brain researchers, philosophers, ethicists or politicians. Now, more than ever, it is essential to involve ordinary citizens in these debates and the decisions that are made, for it is their lives that will be most affected.



Research implications: the European perspective

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

For the European Union to truly represent all its citizens, it is crucial that Europeans develop a sense of ownership in policies affecting their daily lives. The ECD approach is a powerful response to EU efforts towards greater public involvement, as an exciting new method of transnational public discussion over future research, technological decision-making and governmental oversight.

The EU strongly supports brain research through its 7th Research Framework. Yet beyond funding for basic science, many other brain science issues, including regulation of procedures and drugs and impacts on health care systems, may be best addressed at a European level. For this reason, brain science is an ideal candidate for this first, pioneering effort in transnational deliberation.



Getting deliberations going: the drivers

A consortium of 12 technology assessment bodies, science museums, academic institutions and public foundations from nine European countries launched the initiative in 2004 with the support of the European Commission. These internationally renowned organizations, with long experience in drawing citizens into discussions over emerging technologies, have brought the precise mix of policy and methodological expertise required to traverse the uncharted territory of cross-national European conversation.

A chance to participate: the process

The ECD panel is composed of 126 citizens from nine countries: Belgium, Denmark, France, Germany, Greece, Hungary, Italy, the Netherlands and the United Kingdom. In each country, 14 citizens were chosen at random, but selected to include a broad range of age, gender and profession. No professionals in the field of brain science were invited to sit on these citizen panels, but they were deeply involved as expert resources.

To help citizens begin assessing the complex matters of brain science, a set of 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 deve-



developments in brain research might affect ordinary lives. Panelists were introduced to a variety of brain afflictions, including stroke, Parkinson's disease, Alzheimer's and dementia, 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 medications to enhance natural abilities, brain implants, and the molding of infant minds.

At a first meeting within each country, the cases were presented for discussion and the results included a broad range of hopes, concerns, ideas, opinions and questions.



Working as Europeans: the 1st Convention

In June 2005, the citizens met in Brussels for a weekend of deliberation. The method applied was carefully developed to ensure that each citizen could fully participate, and that a genuine European dialogue could result. The European Citizens' Panel held a series of individual, round table and plenary discussions, supported by an extensive team of professionals, and panelists emerged with a common framework and sets of questions for further deliberation. These, in turn, were shared with a wide variety of interested stakeholders, including patient advocacy organizations, mental health associations, ethicists and scientists.

Brain science issues in depth: national assessments

The 1st European Convention provided the national groups with a common approach with which to explore brain science topics further. In the autumn of 2005, the national panels will each conduct two further sessions, first to gain a deeper understanding of brain science, by inviting experts in the field, and second, to develop their initial assessments further. These results, too, will be shared with the broader community of interested observers in each county.

The science goes European: 2nd European Convention

In January 2006, the 126 panelists will meet again in Brussels to review the national findings and develop a Europe-wide consensus on the issues and recommendations for action. The design will vary from the first convention but the basic features will remain: Professional facilitation to assure the widest-ranging dialogue possible among the participants.

The second convention will be open to the public. And, in keeping with the goal of policy consultation, the citizen panels will present and discuss their findings and recommendations with a wide array of policymakers and interested participants from civil society.



Listening to the public: next steps

Public presentation of the results of the European Citizens' Deliberations is only the first step in disseminating the findings. As the project comes full circle, its goal will be to engage all of Europe in the brain science issues raised in this Meeting of Minds. To accomplish this goal, organizers will make presentations to the European Union, its decision-makers and the media. Then, in April 2006, the project will convene a major policy seminar for all those concerned with brain science within government, the media, the sciences and civil society. The purpose is to ensure that this two-year deliberative process has a significant impact not just on European brain science policy, but on how European society uses the deliberative process itself.

ECD: A powerful public tool

The European Citizens' Deliberation is an important achievement, establishing that citizen participation is possible on a European scale. It demonstrates that it is not only possible, but desirable, to draw on citizens' intellectual and creative capital to shape a common future in which all can feel a part. The success of the ECD, moreover, shows that this exciting innovation can work across many countries and cultures, and can be adapted to other fields of research, putting a European public face on areas previously stamped 'experts only'.



This process is conducted with the support of the **European Commission**. The general coordination of the process lies with **King Baudouin-Foundation** (Brussels) www.kbf-rbf.be.

Partner organisations: **University of Westminster** (UoW, London) www.wmin.ac.uk, **Flemish Institute for Science and Technology Assessment** (Flemish Community, Belgium) www.viwwta.be, **Danish Board of Technology** (Denmark) www.tekno.dk, **Cité des Sciences et de l'Industrie** (France) www.cite-sciences.fr, **Stiftung Deutsches Hygiene-Museum** (Germany) www.dhmd.de, **Fondazione IDIS Città della Scienza** (Italy) www.cittadellascienza.it, **Rathenau Institute** (The Netherlands) www.rathenau.nl, **Science Museum's Dana Centre** (United Kingdom) www.sciencemuseum.org.uk, **University of Debrecen, Medical and Health Science Centre** (Hungary) www.ccebd.co.uk/ceed/un/hu/hu005.htm, **Eugenides Foundation** (Greece) www.eugenfound.edu.gr, **University of Liège, SPIRAL** (French Community, Belgium) www.ulg.ac.be/spiral.