

Meeting
of Minds

European Citizens' Deliberation on Brain Science

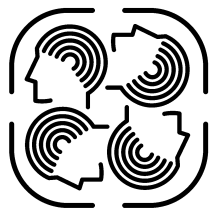


EP Interest Group Mental Health, Brussels

22/09/11

Tinne Vandensande

King Baudouin Foundation

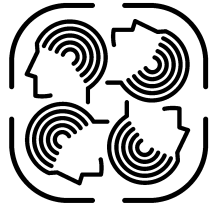


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European Citizens' Deliberation on Brain Science

Meeting of Minds: a pilot project

- **The first trans-national, multilingual public deliberation**
- **A panel of 126 citizens from 9 European countries**
- **“How are we going to use the new-found knowledge on the brain?”**

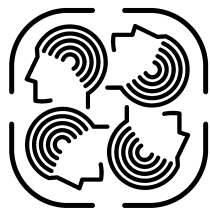


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Rationale

- **Brain sciences are rapidly gaining societal importance**
- **“The brain is much too important to leave the discussion to brain scientists”**
- **“ We hardly think of mind functions such as trust, love, or gratitude, let alone the stock market, the justice system, schools and social compliance. But these are all domains where neuroscience makes progress”**



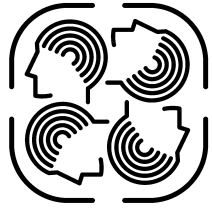
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Rationale

Governance of research

- **EU has become an important actor in research funding/policy**
- **Different stakeholders are organised at EU level (research organisations, interest groups, civil society organisations,...)**



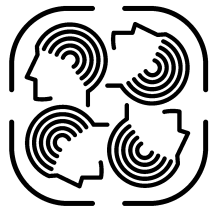
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Rationale

Society

- **The societal impacts of scientific developments are not confined to national borders**
- **The emergence of a European public sphere/debate**

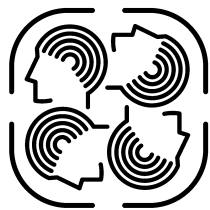


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Rationale

- **Public deliberation: also at EU level / on EU-related topics**
- **Closing the gap between the EU and its citizens:**
bringing the EU closer to citizens and citizens closer to the EU
- **EU as a laboratory for innovation in research**

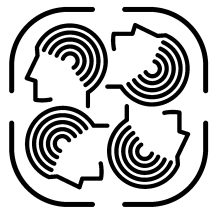


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Project characteristics

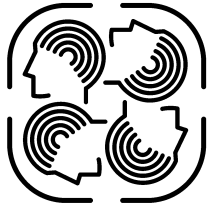
- **Initiative of a partner consortium of 12 organisations from 9 countries**
- **Running from 2004-2006**
- **With the support of the EC, DG Research, 6th FP, Science and Society Action Plan**
- **Project coordination and co-funding: King Baudouin Foundation**
- **Recommendations at national and European level**



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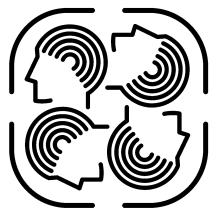
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Objectives

- **Content:**

A citizens' assessment of the societal and ethical aspects of brain sciences, considering the scientific and technological developments

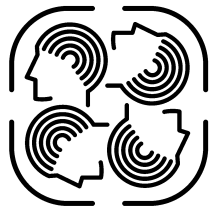


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Objectives

- **Policy-making/governance:**
 - **To set the issue of brain sciences on the (wider) political agenda**
 - **To come up with recommendations to the political, science and research community at European and national level**

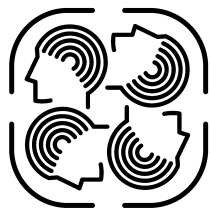


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Objectives

- **Method development:**
 - To set a standard for trans-national public deliberations in other policy areas**

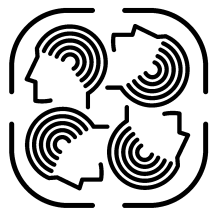


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Process

- **Learn about brain research**
- **Frame the issues from their own perspective**
- **Assess the scientific, technological, social, ethical and policy aspects**
- **Discuss questions and ideas with researchers, stakeholders and policy-makers**
- **Present recommendations to decision-makers and opinion leaders in the fields of brain research, (neuro)ethics and mental health in Europe**

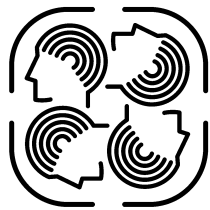


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ECD Method

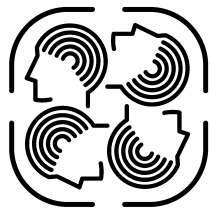
- 1. Issue-analysis by experts and citizens' information brochure**
- 2. First national citizens' meeting**
- 3. First European citizens' convention (Brussels, June 05)**
- 4. Parallel national citizens' assessments**
- 5. Second European citizens' convention & presentation of citizens' report (EP, 23 January 06)**
- 6. European and national policy advice & dissemination process (until June 07)**
- 7. Knowledge management and stakeholder & media communication**
- 8. Internal and external evaluation**



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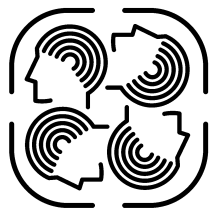
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Issue analysis by the experts

High-level workshop (Amsterdam, 2004) to explore developments and societal aspects of brain sciences

- **Medicalisation**
- **Enhancement and social justice**
- **Reductionism and personal identity**
- **Responsibility and free will**
- **Privacy and personal freedom**
- **Ethics of research and information exchange**



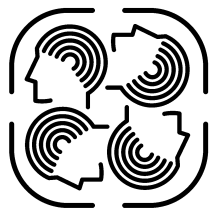
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Issue analysis by the citizens

European Citizens Convention (Brussels, 2005) to explore societal aspects of brain science

- **Normalcy vs. diversity**
- **Regulation and control of research**
- **Public information**
- **Pressure from economic interests**
- **Equal access to treatment**
- **Freedom of choice**

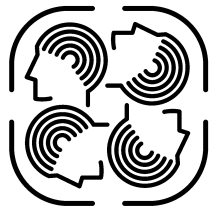


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Outcomes

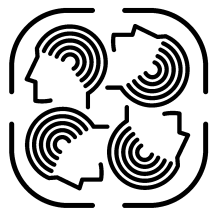
- **9 national assessment reports**
- **A European report with 37 recommendations**



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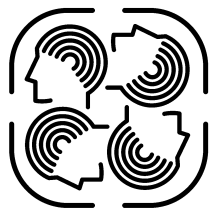


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7 EU policy dimensions

- **Ethics policy for science and technology**
- **Research policy**
- **Governance of science and technology**
- **Health care policy**
- **Pharmaceutical and medical devices policy**
- **Education and training policy**
- **Communication policy**

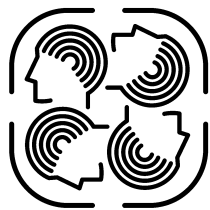


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Ethics of S&T

- **Establish mandatory informed consent procedures for brain imaging techniques. Prohibit use of brain imaging techniques by the police, the judiciary and the security services.**
- **Develop a EU procedure for nominating trusted representatives for persons with a mental handicap for mentally (“trusted persons”).**

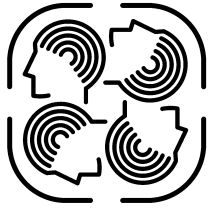


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Research and Development

- **Increase the EU funding of basic and fundamental research (both on healthy and impaired brains)**
- **Promote research to clarify the range of variations that exist within “normality” and what conditions should be labelled “abnormal”**

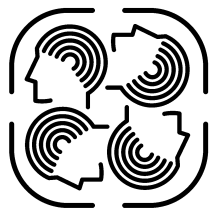


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Pharmaceutical and medical device development

- **Develop mechanisms to encourage pharmaceutical companies to undertake research on rare brain disorders and research into long-term consequences of medication and other treatments**
- **Organise the prompt evaluation at EU level of new treatments and technologies**

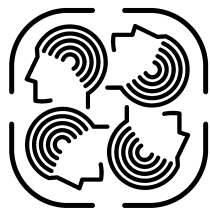


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Health care

- **Establish EU guidelines for MS medical assistance to ensure dignity of life for mentally ill**
- **Encourage MS to provide mentally ill patients with multi-disciplinary care in a family atmosphere or in their own home**

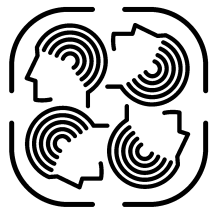


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Education and training

- **Provide publicly funded information brochures on the brain for prospective parents in maternity clinics and gynaecology departments**
- **Encourage the education and training system to take full advantage of the knowledge available from brain research to improve the learning process at all stages**

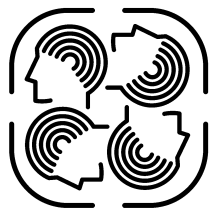


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Governance of S&T

- **Set up citizens' deliberative procedures at regional, national and EU level. Research institutions and pharmaceutical companies should initiate such consultation procedures in order to obtain feedback on their research**
- **Encourage common European methods for citizen participation organised by national democratic institutions**



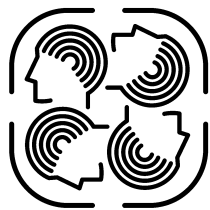
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Making waves

- **“Meeting of Minds demonstrated that citizen participation is possible on a European scale. Moreover, it shows that it is not only possible, but also desirable to draw on citizens’ intellectual and creative capital in shaping a common future of which we can all feel part”.**

Professor Ortwin Renn, University of Stuttgart,
external evaluator



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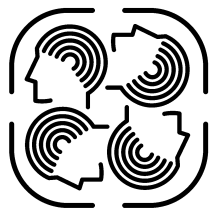
Making waves

“ The citizens have definitely installed the provocative claim needed to start a debate, amendments and resolutions to be taken by the EP”

Neuroscientist

“An excellent way of bridging the perceived gap between citizens and the EU in many areas”

Janez Potočnik, EU Commissioner

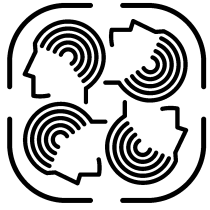


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Conclusions

- **MoM has laid the foundations for the public value of brain sciences**
- **A genuine transnational, multilingual deliberation is possible**
- **Public deliberation on research and technology is definitely possible and can lead to substantive results**
- **An inspiring and thrilling experience – most citizens, experts (and organisers) would like to do it again!**

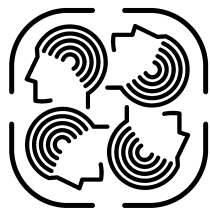


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4 years later...

- **MoM outcomes are quoted/discussed by ethical bodies, scientific associations, scientific literature**
- **European Citizens' Deliberation described/commented in literature on public deliberation and participatory technology assessment (a "benchmark" project)**

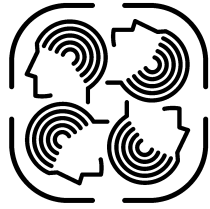


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4 years later...

- **EC code of conduct for responsible nanosciences and nanotechnologies research**
- **PER (public engagement in research)**
- **European Citizens' Consultations (1800 citizens from 27 member-states, 20 languages)**
- **Citizens' consultations to be included in the EC-toolbox for public consultation ?**



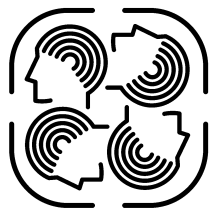
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4 years later...

**From the "Decade of the Brain"
to the "Decade of the Mind"?**

Time to revisit "Meeting of Minds"?



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www.meetingmindseurope.org

www.kbs-frb.be

vandensande.t@kbs-frb.be