



Meeting of Minds

European Citizens' Deliberation on Brain Science

New style of dialogue could let public set the agenda

Summary report of the workshop 'Connecting Brains and Society: Lessons learnt and future developments'. organised at ESOF on 18 July 2006

By Aisling Irwin

Meeting of Minds reached a climax earlier this year when over a hundred laypeople, speaking eight native tongues, reached verdicts on the new science of the brain. Now, for the first time, eleven key players in Meeting of Minds have met for a frank analysis of the project. What did it produce? What went wrong? Is it worth repeating? The meeting, which took the form of presentations, panel discussions and audience participation, was held at the EuroScience Open Forum (ESOF) 2006 in Munich.

What is to be done? In June a scientist claimed to have shown that intelligence has evolved at different rates in different races. In July, researchers announced that a chip inserted into the brain has enabled a man to control a distant object by thought alone.

With such news we should be worried, says **Michael Rogers**, a consultant (Risk, Ethics & Law) chairing the meeting. We need to think about where brain science is leading and what we should do about it.

Meeting of Minds was an attempt to do just that – to indicate to policy-makers and scientists how they might shape the course of brain science for the common good.

Meeting of Minds was an exercise in public consultation -- but no ordinary one. It was a grand experiment on an unprecedented scale. It mixed cultures and languages in the pursuit of the goal of a European, rather than a national, consensus on what should be done.

The organisers, funded largely by the European Commission and the King Baudouin Foundation, were gripped not just by brain science. They also perceived a need to pursue public dialogue on science to a new level that reflects the power that lies in Europe -- a relatively new seat of decision-making that is without much input from laypeople.

The project began with a meeting of experts from across Europe who outlined what is happening in areas such as brain scanning, implants and memory drugs. Then, after a random selection of participants from nine European countries, came a series of national and European meetings in which the laypeople passed through a brainstorming phase, chose which themes to explore and interviewed experts. At a final, pressured 72 hours in Brussels -- and with the help of swathes of support staff, including 48 translators -- they agreed their conclusions.

Now the frenzy is over, the insurmountable surmounted. The citizens have presented their views at the European Parliament and returned home.

The final recommendations of Meeting of Minds have been published, and were debated properly for the first time at a conference in Munich, where there was some hard scrutiny of the €2 million enterprise. Has it been an important step forward in the democratisation of science, injecting vital lay input into policy at a European level? Or was it just an odd experiment, too complex to repeat?

Delegates considered three issues at the ESOF meeting: did the method work? did it produce interesting, coherent recommendations? and can scientists and policy-makers be made to care about it? Debating the issues were the external evaluator of Meeting of Minds, three members of the steering committee (two key designers of the project and one of the chief organisers) two of the 126 lay participants, a neuroscientist, a mental illness advocate, a science and society specialist, and an ethicist.

The Method

Tumultuous as it was, the method, known as the European Citizens' Deliberation (ECD), seems, broadly, to have functioned well, according to the speakers. One of its creators, **Stef Steyaert**, of the Flemish Institute for Science and Technology Assessment, described it to the meeting.

The project was organised by 12 partner organisations in the nine countries. They included technology assessment bodies, science museums, academic institutions and public foundations.

Once the issue of "brain sciences" had been chosen, the first step was to gather leading experts to explore the subject, after which a citizens information brochure was produced.

Then, in each country, invitations went out to 4-5,000 people of whom those who accepted were selected according to age, gender and education.

In each country, nationals got to know each other at an introductory "brainstorming" session.

The first European meeting was inspired by the American 21st Century Town Hall Method with a few adaptations to reflect the multilingual environment. Most of the discussion happened at small, mixed-language tables. At this meeting the citizens chose the themes they wanted to pursue and the questions they would be asking themselves.

Computer networking, half-hourly updates fed to a central team for rapid digestion and circulation, keypad polling ... these kept thoughts progressing and the meeting under control.

Back in their home countries, the citizens held two meetings based on the "consensus conference" model, in which they hammered out reports on societal aspects of brain science which they then offered to their parliaments.

The second and final European meeting used a new method synthesised from different existing methods such as the Carousel and the World Café. The citizens moved between large and small tables according to a complex choreography that allowed them to hold their most intricate discussions with people of their own language, with an overlay of multilingual exchange. Deliberation, selection and prioritising were done mainly through dialogue and sometimes through voting.

“It’s no surprise that the complex process described above created problems,” Steyaert told the ESOF meeting. “For some of these problems it was impossible to find definite, satisfactory solutions.”

The biggest challenges, he said, were the breadth of the chosen subject, the melting pot of languages and cultures, and the step-change from national to European deliberations.

Breadth of subject

The question, "How should we deal with the newly acquired knowledge about the brain?" was so broad that the participants themselves needed to work out which of its many aspects they would select for study. This had benefits: the citizens felt more ownership of the results; the panel members and experts learned a lot. But it introduced an extra layer of complication that could have been avoided. The topic was "undoubtedly a factor that has strongly added to the complexity of the deliberation process," said Steyaert.

Profusion of languages and cultures

Nurturing dialogue is a subtle process even in a monolingual environment.

"Multilingual dialogue takes a lot of time and requires particular interpretation and facilitation skills," said Steyaert. Different cultures deliberate in different ways, language barriers are also filters on the expression of thought.

Helping citizens through the babel of languages and cultures towards a lucid exchange of ideas was a challenge for the designers -- and for the interpreters, writers and facilitators. At times the stress of it seemed almost too much. But, ultimately, the citizens rose to the challenge.

"It was a very delicate process, especially in the European meetings," **Tom Huigen**, member of the Dutch citizens' panel and member of the writers' group during the second citizens' convention, told the ESOF meeting. "It required strong motivation from everybody, but the combination of hard work and time-pressure resulted a couple of times in emotional outbursts. Having the flexibility and ability to handle these emotions was a critical factor for the success of this project."

Sometimes it was not even the language and culture that posed the problem ... just the sheer number of citizens.

“Naturally, if you have more persons taking part in discussions, the quantity of opinions grows,” said **Tamara Franke**, a member of the German citizens' panel. “Whereas a group discussion at national level would be taking 30 minutes to reach results, discussions at European level would need sometimes two hours and that would even not be sufficient. But this was not a problem. I think the supervisors of Meeting of Minds worked greatly, both on national, and on European levels.”

Not a national view, but a European one

Making the transition from national viewpoints to a common European one was the third great challenge, said Steyaert. On the one hand, the core rationale for the project was that Europe is an emerging public sphere with increasing policy relevance in the area of research. On the other hand, the national sphere remains the one in which people most comfortably function, and where many scientists, media and stakeholders are best organised.

Steyaert was adamant about the dream of the Meeting of Minds consortium -- attaining a truly European level of exchange -- but this attitude provoked some debate.

Rainer Gerold, formerly European Commission director for Science and Society, who was partly responsible for Meeting of Minds, said: "I was overwhelmed that 126 citizens working together in Europe for two years, apparently are all convinced Europeans. I think this is a very positive message in a Europe where not only Europe scepticism, but also Europe pessimism prevails. I think that this is a great success."

But he questioned whether such European feeling had been put to the best use, suggesting that it may have led to recommendations for action at a European level on matters that would be better left to nations.

"You forget the very simple rule of subsidiarity," he said. "You should only adopt rules or guidelines at European level if this can't be done better at national level."

For example, it may have been the European structure of Meeting of Minds that led the citizens to demand a pan-European ethics committee to set rules for member states. In fact, said Gerold, there is already a "very good system" of national ethical councils that periodically exchange views, plus a European group on ethics which advises the European Commission. Recommendations such as this were "over the top ... this will have a very negative reaction".

But the designers felt that "the European assessment represents an additional level of deliberation which has its own value and cannot be reduced to a simple addition of the national results," said Steyaert.

"The transnational dialogue gave citizens an intuitive sense of issues that need to be dealt with at European level instead of at national level."

The design team is looking forward to refining the process next time to make it articulate more smoothly between the national and European levels of debate. The team opted for a double-track process where some of the tasks were completed nationally and some supra-nationally. There was some interaction but "we were not good enough to use the results from each step as input into the next step," said Steyaert.

What is "random selection"?

The ESOF audience queried another aspect of the method. How can you lay claim to "randomness" of selection when the participants must, by definition, have been unusually well-endowed with time, confidence and an interest in the brain?

"I am sure the selected and accepted public is a kind of specific public," said audience member **Roland Pochet**, professor at the Université Libre de Bruxelles and member of the Dana Alliance for the Brain.

David Cope, an audience member from the Parliamentary Science Office in London, agreed. His office was involved in the first national consensus conference on genetically modified organisms (GMOs), in Britain, in 1994. He challenged the speakers to demonstrate that citizens such as those selected for Meeting of Minds "do in their deliberation embrace the full range of issues which subsequently come up in the entire legislative process."

It's an illusion that you can select a group that is a perfect microcosm of society, agreed **Ortwin Renn**, of the University of Stuttgart, whose group carried out the formal evaluation of Meeting of Minds.

Instead what you aim for is "diversity" rather than quantitative representation. To get the full scope of the arguments a small group of people is enough – provided diversity is assured. Indeed, methodologists generally agree that as few as 12-20 people are enough to generate 95% of the arguments on a given topic. "If you ask ten people and then you ask the eleventh one, very rarely will you get another perspective," said Renn. "If you have 120, then the chance that you miss an argument is extremely unlikely."

If, however, you want to know how many people on average agree or disagree with a specific argument, you need a representative sample, which is something different.

The external evaluation

Renn's external evaluation of Meeting of Minds was mostly positive. He was pleased with the diversity of opinions, backgrounds and national identities. He felt that the citizens accomplished well the task of showing "what kind of knowledge from our life experience we can impose in this debate". He had some reservations that, despite the best efforts of the organisers, the citizens were not given the time and space to develop their own thoughts but were over-mentored. And he felt that, though the process was mostly transparent, there were times when there was a descent into confusion, "where talk went backwards and forwards and nobody really knew what was going on".

In general, though, the process ticked his four boxes: it was fair, competent, mostly transparent, and efficient.

But perhaps the real test of the quality of the Meeting of Minds method comes from studying its findings.

The recommendations

These 37 prized recommendations -- teased out, developed, expressed, debated, refined, nurtured, written down, translated and voted on -- have now been published and can be found in full on the Meeting of Minds website.

First the citizens drew six themes from the tangle of issues presented to them. These were: defining the difference between normal and abnormal; controlling research; letting the public know what is happening; dealing with pressure from economic interests; equal access to treatment; and freedom of choice. From these they developed their recommendations.

Here is a taste of them.

Concerned about the fledgling ability of scientists to mind-read, or at least "look inside your head", the citizens want the use of brain imaging techniques prohibited by the police, the judiciary and the security services.

They want funding to be set aside for research into the interaction between the brain and the environment, in the hope of reducing the incidence of brain-related disorders.

They would like the labels "normal" and "abnormal" to be scrutinised, and possibly defined, as a way of halting the medicalisation of behaviour variation.

The citizens call for the selective lengthening of some patents to encourage drug companies to research rare brain disorders.

They want dialogue between the education and brain communities so that the former can benefit from the manifold new insights of the latter.

Perhaps predictably they want everyone -- regions, nations, drug companies, research institutions -- to hold citizens' consultations as a matter of course.

These were some of the recommendations that **Tinne Vandensande**, of the King Baudouin Foundation, highlighted at the ESOF meeting.

To Rogers, the dominating message from the recommendations was a demand for better communication, and better training in communication for scientists.

Huigen felt the most important recommendations were those where the citizens took fresh angles on problems, such as the patent issue. He was also proud of those recommendations that espoused fundamental principles that can become lost in day-to-day politics, such as the importance of patient dignity and freedom of choice.

Mostly Praise

Senior people, including Octavi Quintana Trias, director of the Health Directorate of DG Research in the European Commission, have praised what the citizens produced: "The report informs us of a number of new issues of which we had so far been unaware," he said.

And Rogers, who has now matched the recommendations to relevant EU policy areas so that campaigning can be finely targeted, told the meeting: "You can identify very large numbers of very useful policy recommendations".

Renn also praised the results: "These were not the usual trivial things you find out if you ask people in surveys. They were substantial and many stakeholders were quite astounded".

Raluca Nica, president of GAMIAN Europe, which is concerned with those who suffer from mental illnesses, said the recommendations were "full of substance and could be easily presented as recommendations coming from a mental health project, for example".

Inez de Beaufort, health care ethicist at Erasmus University in Rotterdam, reinforced this view: "There are very fundamental ethical notions all through the report and the recommendations. I don't think they missed anything ... They really do something with them." She was surprised, however, that one controversial aspect of brain technology that looms large – enhancement -- received virtually no attention.

So far, so impressive. But now the hard work really begins: drawing the attention of scientists, and overworked and possibly sceptical policy-makers, to the results.

Promoting the results

For Renn, dissemination poses a fundamental structural problem: "How do you link the results of these participative processes to the normal political process ... we need to find new institutional ways to make these kinds of recommendations become a part of the political culture within the political institutions".

"Since there is no explicit 'pull' for results the impact will mainly depend on how well they are 'pushed' into the political process," said Vandensande.

"Politicians are not always eager to listen" and "scientists are also very sceptical because they believe they know what they should do," said Gerold.

Indeed, some parliamentarians feel they already represent the people, without the need for input from consensus conferences, said Steyaert.

He described a recent debate, in the Flemish parliament, about one of the issues tackled during Meeting of Minds. When the MPs discussed the topic, they "missed lines of argumentation" that the citizens, in their discussions with stakeholders and experts, had uncovered. "And that's a pity. I really think that this can add value to parliamentary discussions," he said.

The daunting enterprise of dissemination is fraught with dangers, said de Beaufort. Pitfalls include "polite listening". This is when your target audience displays enthusiastic agreement ... then files your paper in the bin.

The Meeting of Minds results could even be damaging -- if they are mishandled or exploited. Ethicists are aware of stultification, where people "stop thinking because they know that the other members of the public have already discussed this in depth," said de Beaufort. "That would be the contrary effect to what you want."

"I think that citizens may be misused in the future like ethicists have been misused in the past," de Beaufort told the conference. One example of this misuse occurs if politicians seize on the results as a perfect representation of the public view, saying " 'This is what the public wants. We have consulted the public and the public agrees.' Well the citizen's panels are not a representation of the public."

Promoting the results will be extra hard because of the choice of subject, thought Steyaert. Brain science is an "emerging issue", something that has not yet been forced onto the political agenda and thus can be more easily ignored. Others, however, felt that the timing of the work was appropriate. Several made comparisons with the timing of GMO consensus conferences – some felt these were held too early, others that they were too late.

"Basically I think we are right on time because you see the debate coming up," said **Rinie Van Est**, of the Rathenau Institute in The Netherlands, another of the project's designers. "You have to remember that we started this project four years ago ... Actually our analysis was quite simple. For the last 20 or 30 years we actually discussed two basic key technologies: biotech and information technology. For the last five years two key technologies have come in extra: nanotechnology and brain sciences. What we thought was: it is really time to get social scientists, ethicists and the public involved in this development."

Bending the ears of scientists and policymakers is a task that has already begun; Meeting of Minds has identified the precise agencies, directorates and programme themes that correlate with each individual recommendation. They fall into seven EU policy dimensions. Recommendations to do with freedom of thought, for example, fall under Ethics of Science and Technology. The issue "connects with the safeguarding of Fundamental Rights in the Union and refers to the Charter of Fundamental Rights," said Vandensande. "Meeting of Minds welcomes the setting up of the new Fundamental Rights Agency, becoming operational in 2007, which will take into account the issues of mental health."

Eight recommendations fall into the category of Research and Development, where the European Commission is the hub. Some of the eight slot neatly into one or two of the health themes in the Seventh Framework Programme. Key players in brain research will be pulled together for an online discussion on this subject in September, said Vandensande.

Under the heading Pharmaceuticals and Medical Devices, the team found four relevant recommendations. It's a policy area concerned with working towards a better balance between market interests and the common good, said Vandensande. "The development of new legislation is a continuous process and thus it is important to discuss what is on the cards for

the near future with the European Medicines Agency (EMA) and DG Enterprise and Industry Directorate Consumer Goods.”

Meeting of Minds has already made a formal response to the Green Paper on Mental Health, which covers most of the seven recommendations that come under “healthcare”.

Education and Training is the next category – a broad one that touches on the work of no less than four different directorates. There is also the exciting OECD project "Learning Sciences and Brain Research", an operation that could make the OECD a significant player in this area.

After Communication, comes the final category of Governance, into which three of the recommendations fit. There is already an imperative, from the European Commission’s White Paper on EU governance, to carry out work in this area. Also, there is some overlap between what Meeting of Minds wants and what is called for in the Science in Society theme of the Seventh Framework Programme, said Vandensande.

So far, then, there was broad agreement that the method was pretty good, the standard of output was high, and that getting anyone to listen will be tough but some progress has been made.

So was it worth it?

The cost

Despite showering praise on the enterprise, Gerold has a major practical reservation. At that price -- €2 million -- replication on a wide scale is unthinkable.

Gerold's solution is to plunder the methodology for elements that can be used nationally, and then to network the results at a European level -- "which is of course lighter and much less expensive" but destroys the dream of a unifying, European sensibility.

Another fruitful, and cheaper, use for the method would be to insert citizen consultations into € multimillion programmes areas such as nanoscience and medical research. Here, said Gerold, the budgets are big and the questions are narrower -- perfect for citizen reflection.

Gerold's ideas provoked animated responses.

The idea of embedded consultations is already in place, said de Beaufort. It appears, tacked onto science programmes, under the title "Ethical, legal and social aspects". It is a troubled area, encountering, for example opposition from scientists.

Others questioned whether an ECD is genuinely costly if viewed over the long term.

Think of the debacle over the European constitution, said Renn -- undone after referenda in several countries rejected it. "Maybe if we had had something like this before we had the debate and the referenda, we might have got a different outcome."

"I think we'll save quite a bit of money if we do this in advance rather than paying for the conflict cost later on."

The impact

But this benefit is not to be seen in a crude side-stepping of controversy, he cautioned.

"If you think about the GMO debate, as one example, even if you had had a million citizens' panels beforehand, if there were value clashes in society and you can't reconcile them, then that controversy will exist, and co-exist, for the future."

De Beaufort agreed: "You tell your fellow citizens that because the others have been thinking about it, this is actually what they also want ... then you think you can prevent political discussions. But I think you can't. This is what happens to ethicists all the time. 'The ethicist gave his or her blessing, so it should be OK.' But no, of course, it's not OK.

Nevertheless, said Renn, there are subtle advantages to having debated the issue beforehand.

"The impact of such a process is that in advance you know where these conflicts will arise and, secondly, if there are modifications that are available from the beginning that can help you to take into account the concerns and maybe the visions that people have."

So there is an element of "disaster preparedness" to be found in the value of citizens' conferences. An important part of this preparedness comes from the connections fostered by a project such as Meeting of Minds.

"This network is not only a citizen's network, but also one of politicians and experts ... people can find each other and add to the value," said audience member **Josée van Eindhoven**, of Erasmus University, a former director of the Rathenau Institute.

Van Est agreed: "it is about setting up and linking the various actors: citizens, experts, policy makers ... that was central in this topic and that is a kind of basis to build this further debate".

Connections for **Balázs Gulyás**, neuroscientist at the Karolinska Institute in Sweden, lay in one important direction: the opportunity to drum up public support for brain research: "I found great richness in this initiative, because I am convinced that this way we can indeed motivate people in Europe to focus on brain research."

So where does this type of deliberation fit in?

If these are the strengths of a European Citizens' Deliberation, what can it be used for in the future?

For Huigen it has a very specific role: "It cannot replace other democratic processes. It should be used as an additional tool, where communication between politicians and citizens is complex, the feelings of the general public are not very clear and the impact of decisions on everyday life is high".

For de Beaufort, too, the ECD is a very specific tool. It should not be, for example, a tool for generating consensus.

“What do you sacrifice for consensus? Consensus may be wonderful, but it also requires sacrifices. That is one of the dangers of the pan-European citizens’ committee ... What you get is a consensus on very basic things where you leave out the ideals. I am very much in favour of the idea of consulting citizens, which is a different role. But not in laying down the ethics rules. That would be bypassing democratic policies that we need.”

So was it worth it?

Let’s leave the final word on the worth of this extraordinary undertaking to one academic and one citizen.

For Van Est, its worth lies simply in its existence. “I would say: ‘we *did* this project. It was the first time it was done. That is already a big impact. Learning by doing – that’s the only way to go about it.

And for Franke: "The most important outcome is that such a meeting has taken place at all, and led to results. More than a hundred completely different people, with eight languages, found common ground with one another and developed common ideas -- that strikes me as something great."

ENDS