

EBC Position Paper on its relationship with its member organisations and National Brain Councils

When the European Brain Council was being formed, one of the primary concerns was how such an organisation would maintain its focus and governing principles. As a coalition of other organisations with their own membership, rules and objectives, there were several issues to be considered.

The first of these was to decide which of the many European organisations whose aims are compatible with those of the EBC should become members. If the membership were open to all, the organisation could become unwieldy and inappropriately balanced between the disciplines - with neurological organisations outnumbering psychiatric ones, for example. The goal was also to achieve a healthy balance between organisations representing basic and clinical research. This problem was solved in two ways. Firstly, the ordinary members of the EBC Board, who can vote on EBC issues, are restricted to those organisations that represent the largest constituencies of their respective disciplines. To take an example, the Federation of European Neuroscience Societies (FENS) represents basic science within the EBC, but FENS itself has a very wide membership, comprising not only national neuroscience societies but also Europe-wide organisations that focus on particular aspects of brain research. Consequently, it is possible for basic science interests to be represented by one organisation that has a single vote on the EBC Board. However, to ensure that the EBC is as inclusive as possible, it has admitted several European-wide organisations representing particular specialities as associate members, who do not have voting rights. An example is the European Academy of Child and Adolescent Psychiatry.

The same principle has been applied to patient organisations whose active involvement is central to the mission of the EBC. The EBC Board has delegates from two European-wide organisations, EFNA and GAMIAN-Europe, representing patients with neurological diseases and psychiatric diseases (mental illness) respectively. The EBC supports the interests of all people affected by brain diseases through these two bodies, and therefore does not have member organisations who campaign on behalf of patients with individual diseases.

Representation from the private sector was more difficult. The European pharmaceutical industry, for example, does not have a representative body that deals only with brain diseases and brain research, and therefore it was not possible for EFPIA (the European Federation of Pharmaceutical Industries and Associations) to provide a delegate. Given that pharmaceutical and medical device companies are major financial supporters, it was important for the EBC to find a way to give them a voice on the Board without distorting the balance of interests. The creation of the industry partners' group solved this problem. This group meets twice a year with EBC officers and staff in order for industry to provide their comments and advice on EBC activities. The group also elects delegates representing pharma and medical devices respectively to the EBC Board, and these delegates have full voting rights.

Having established the rules of membership, it is also important that the EBC is recognised by these members as an organisation that furthers their interests rather than competes with them. Conversely, the EBC itself needs to ensure that its activities support all our members impartially. This has consequences for the kind of activities in which the EBC involves itself. The EBC's European Brain Policy Forum illustrates this very well. The first meeting in 2008 on Parkinson's Disease and the European Society was designed to be quite different from the more usual science-based meetings that might be sponsored by EFNS or one of its members. The aim of bringing together scientists, patients, policy makers and media was to improve communication and understanding between the various participants, to highlight the major issues around the treatment of this disease but also to bring home to policy makers the importance of brain research and brain

diseases for the health and wealth of European citizens. This common theme will be reiterated at future meetings.

The relationship between the EBC and its member organisations also influences the kind of research in which the EBC participates. The EBC does not conduct brain research itself. This is done by individual scientists who belong to our member organisations. In order to be impartial towards those member organisations, the EBC does not support any of the usual grant applications made under the European Commission's collaborative research programmes. There are, however, projects which the EBC can join as a partner. These are projects that are designed to produce data that the EBC considers important for furthering its goals. Examples include studies on the epidemiology, burden and cost of brain disorders, studies on healthcare systems, access and delivery of treatment, dissemination of research findings and education in brain sciences in Europe. In the EC's Seventh Research Framework Programme (FP7, 2007-2013) there are several examples of projects addressing such issues, many of which are not specific to the brain. The EBC is happy to cooperate in such critically important projects because, in doing so, it ensures that an otherwise general topic can be oriented towards brain science. What role can the EBC play in a successful consortium? First, it would lend credibility and prestige to any application. Second, with its extensive network of stakeholders across Europe it can bring potentially valuable members to the consortium. Third, via the same network, the EBC can take charge of disseminating the project's results—an increasingly important part of any EC-funded project. On rare occasions, the EBC may submit its own application as the project co-ordinator. It is more likely, however, that it will act as a partner in consortia which address general issues that the EBC considers fall within its aims and scope.

The third issue concerns the relationship between the EBC and National Brain Councils (NBCs). Over the last few years, a number of these have been established, and the EBC has recognised that such organisations are enormously influential in alerting member state governments to the importance of brain research and brain diseases, and exerting pressure at both national and European level to increase funding. As a result, the EBC has been helping to set up other National Action Groups and Brain Councils in many EU countries. What is the relationship between these groups and the EBC? It is important to point out that the EBC is not and never shall be a federation of NBCs. The EBC is a shared facility for European organisations and shall remain so. However, there is already intensive, informal collaboration between NBCs and the EBC and this will continue. The EBC should serve as a clearing house for ideas and successful initiatives from different parts of Europe, disseminating information about these to other countries. To that end, it already makes its research documents available to NBCs. Conversely, NBCs can help the EBC by influencing national members of the European Parliament and other organisations with an important function in Brussels. A meeting to bring all NBCs together was held on the occasion of the EBC's 1st European Brain Policy Forum.

The EBC believes that clear delineation of roles and responsibilities built on a foundation of mutual understanding and collaboration will enable the EBC, its member organisations and the national groups to become a potent force for improving the lives of those affected by brain disease in Europe.