

Guidelines on how to form a NBC/NAG

These guidelines will guide those who wish to set up a NAG, or guide the NAG that wishes to transform into an NBC.

Introduction

A NAG is a multidisciplinary, temporary, and informal body consisting of representatives from national organisations covering sectors related to the brain. A NAG is easy to create (cf. Annex 2 for guidelines) as it does not need to have a formal structure (statutes established according to current local legislation, general assembly, board election, bank account, etc).

As an informal body a NAG has limited authority and where possible it may be beneficial for the NAG to transform into an NBC (cf. Annex 2 for guidelines), which will then have the necessary legitimacy to speak to local and international institutions (national research and health ministries, national governments, European Parliament, European Commission etc). As the NAG transforms to an NBC, the members become official representatives of their relevant national organisations.

In the establishment of a NAG/NBC, EBC can assist in establishing connections between national stakeholders (e.g. relations between neurologists and psychiatrists)

Both NBCs and NAGs are independent, multidisciplinary units that unite scientific organisations of neuroscientists, psychiatrists and research workers, patients' associations, and the pharmaceutical and medical device industry. Although NBCs and NAGs are independent, they are aligned with the main goals which includes improving the quality of life of people living with a neurological or mental disorder, raising awareness of these disorders, stimulating brain related research, fostering exchange between the different disciplines and associations, and lobbying government for enhanced research and treatments.

Local NBCs and NAGs are important, as they not only represent a stronger, unified voice for better mental health but also provide the deep understanding of the local area and its complexities.

Some of the advantages of being part of a NAG/NBC are:

- Easier access to policymakers and other decision makers.
- NBCs/NAGs have more impact/influence with national decision makers

Although brain disorders are a huge cost to all European countries, little money is spent on this issue. To create an impact and to create change, there is a need for having a solid two-way dialogue in place. It is essential to understand the local country dynamics and local pressures which can only be done at a local country level but also provide an above country European perspective to highlight commonality and increase priority.

Why are the NBCs/NAGs important to EBC:

- NBCs/NAGs have more impact/influence with decision makers' at a local level than an European organization, such as EBC
- Having a strong voice at the member state level will make EBC's voice stronger in the European institutions, and vice versa. Therefore, it is in both EBC, the NAGs and NBCs interest to help each other grow bigger and stronger.
- The ultimate aim is to develop a pan-European report on brain disorders (plan currently in development). In 2010 EBC was successful in developing the report Cost of disorders of the brain in Europe 2010.

Relationship between EBC and NBCs

As previously mentioned, a NAG/NBC is an independent unit separate from the EBC, but both parties can still gain from collaboration. When an NBC is established and only when, there should be formal contact with the EBC in order to ensure mutual alignment and to encourage joint initiatives. As a minimum requirement this includes:

- a) An annual meeting of the Presidents of the NBCs. EBC will host such an annual meeting and the first meeting will take place in June 2015
- b) Joint work on approaches to MEPs to further both European and national goals.
- c) EBC to receive the Statutes of all NBCs and make these visible through the EBC web page, i.e. <http://www.europeanbraincouncil.org/>

Other initiatives that are currently in the planning phase are;

- d) Invitations will be extended to the Presidents of newly established NBCs to attend a Board meeting of the EBC, and to attend occasional meetings thereafter as appropriate.
- e) Invitations to the President or a Board Member of the EBC to attend occasional meetings of NBCs and present a report on EBC activities.
- f) Attendance by NBC members at the EBC's General Assembly with the possibility to present achievements and projects.
- g) Exchange of minutes of board meetings and newsletters between the NBCs and between the NBCs and the EBC.
- h) A section of the EBC website devoted to news from the NBCs and vice versa.
- i) Joint work on dissemination of European projects and documents at national level.