

NBC AND NAG GUIDELINES

Definition

National Brain Councils (NBC) and National Action Groups (NAG) are unique and multidisciplinary platforms which unite scientific organizations of neuroscientists, psychiatrists and research workers, patients' associations and pharmaceutical/device companies. Their main aim is to improve the quality of life of persons living with neurological and mental disorders, raise awareness of this subject, stimulate research, foster exchange between the different disciplines and associations, and lobby government for enhancing research and treatments.

Some 25 countries have formed, or are in the process of forming, an NBC or NAG. See a detailed map in Annex 1. They are independent but aligned with the main goals of the EBC.

During the meeting of NBCs and NAGs in Brussels in 2009 an informal Network of NBCs and NAGs was set up with two delegates representing the Network and attending EBC Board meetings (in capacity of observers).

NAG vs. NBC

NAG is a multidisciplinary temporary and informal body consisting of representatives from national organizations covering sectors related to the brain.

NAG are easy to create as they do not need to have formal structures (statutes established according to current local legislation, general assembly, board election, bank account, etc).

NAGs should swiftly transform into NBCs which will have the necessary legitimacy to speak to local and international institutions (national research and health ministries, national governments, European Parliament, European Commission etc).

Why there is a need for NBC and NAG

- a) The big scope and joint efforts in order to speak with one voice are needed to have a voice strong enough to influence policy makers and budget holders at the national level.
- b) The EBC studies demonstrated how expensive brain disorders are in every European country, how little public money is spent on brain research and finally what could be obtained if funding is increased. In this respect, an important task for NBCs is to act at national research programs, in which the greatest part of overall funds is available.
- c) National research policies should be aligned with the EU policies. The “low motivation” of the EC to fund brain research is the translation of the low level of priority in the Member States themselves. NBCs are the best bottom instruments to approach such challenge.
- d) NBC is ideally placed to increase public awareness of the brain, its diseases and the importance of brain research.

- e) NBCs together with EBC can serve to increase EC funding of brain research at the European level.

NBCs and NAGs should have goals reflecting national needs and should develop their own processes for the achievement of its aims.

Setting up a NBC

- a) Each country's legislation recognizes different types of organizations like foundations, non-profit organizations, non-governmental organizations etc. It needs to be checked which formula will suit NBCs purposes best.
- b) A constitution has to be written including the definition of member organizations, the procedure of board nominations by the members, their scope and responsibilities. The officers should be elected for a term of 3-4 years, renewable once. Board meetings and an annual general assembly must be scheduled.

Members should feature representatives of major national associations in the field of brain – scientists, doctors, patients as well as industry. Individual membership is not to be considered. Each member association will have voting rights.

It would be best if President and Vice-President(s) are appointed from different stakeholder groups. The Secretary General should be appointed for administrative matters. The Board should consist of Presidents of various member societies or their deputies plus elected representatives from industry. In some countries patient organizations and professional organizations have an equal number of delegates sitting on the board.

- c) A bank account should be set up in the name of the organization.
- d) Funding should be secured through membership fees and project related unrestricted grants.
- e) A webpage needs to be set up as a main tool of communication with the public and policy makers. This webpage should be regularly updated.

Upon request EBC can facilitate sharing the template constitution of other NBC or similar organizations.

Examples of activities:

- a) Organizing events related to the annual Brain Awareness Week.
- b) Organizing a major meeting every two years to discuss relevant topics.
- c) Assessing national overall costs of brain disorders as well as disease specific costs (Data comparison).
- d) Legislative and policy involvement through meetings with national policy makers and national funding bodies.
- e) Cooperation with EBC. One person should be delegated as a contact person with EBC.
- f) Organizing meetings, workshops and lectures in schools and universities.
- g) Increase public awareness by means of media involvement.

Annex 1

