

# TOOLKIT FOR NATIONAL BRAIN COUNCILS AND NATIONAL ACTION GROUPS

This toolkit aims at offering a collected set of tools to National Brain Councils/National Action Groups and is intended to serve as inspiration when engaging with national stakeholders.

European Brain Council

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## Scope

Since 2013, EBC has been undergoing a strategic review to ensure that EBC focus on what matters to its members and where the greatest impact can be made. This work has generated into a new mission and a new set of objectives, cf. Figure 1.

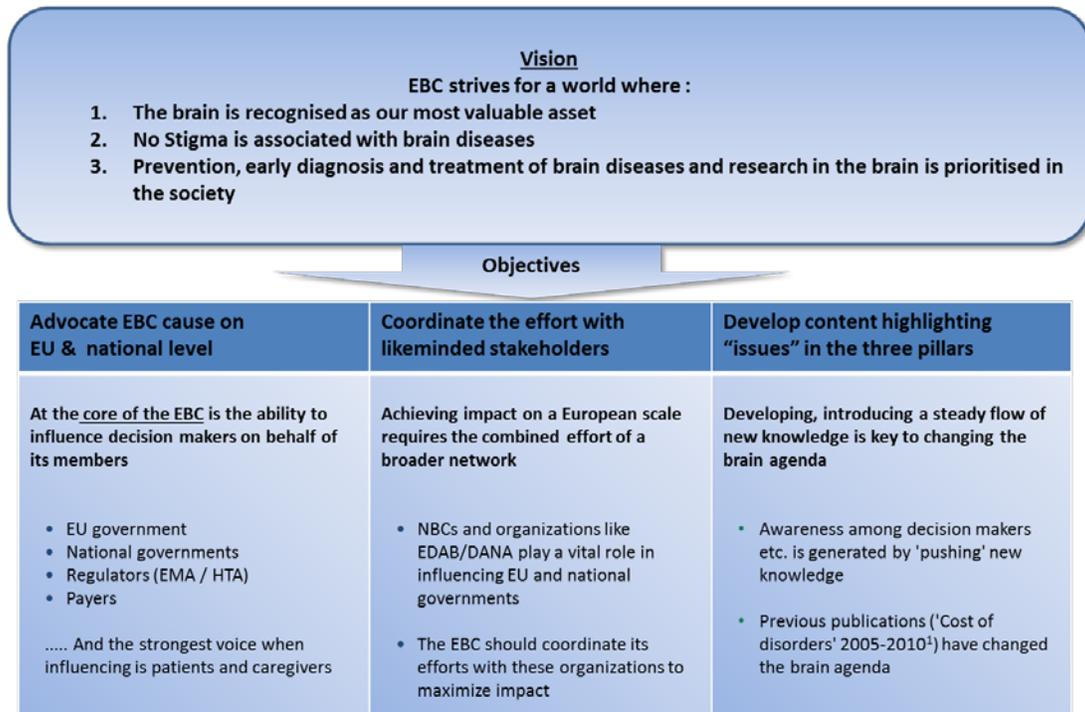


Figure 1 – EBC Vision & Objectives

Based on the above framework, EBC will further promote its work in becoming a trusted partner to the Brussels Based Community (Commission, Parliament, EU institutions, Council (Presidency)) for the Brain space. This enables being the focal point on cross-cutting, horizontal brain issues acting as a catalyst and enabler where the EBC can add value while not detracting from activities at the national and individual disease level.

EBC realizes that the best results are created in close alignment with NBC/NAGs in a bottom-up and top-down approach thereby ensuring optimal key stakeholder management on both a national level as well as at EU level. It is thus the hope of EBC that this toolkit will help everyone meet the same goal and create mutual benefit.

This toolkit has been developed to reflect the current environmental strategic set up that National Brain Councils (NBCs) and National Action Groups (NAGs) are independent bodies but aligned with the main goals of the EBC. With this toolkit, both EBC and NBCs/NAGs gain a common platform and the toolkit provides a set of tools that your NBC/NAG can use and is intended to serve as inspiration for you when engaging with your national stakeholders.

## 1. Introduction

The aim of this toolkit is to support your NBC/NAG when undertaking activities and starting new initiatives. This toolkit will provide you with knowledge, ideas, tools and step-by-step advice. Furthermore, this toolkit aims to encourage closer collaboration between EBC and individual NBCs/NAGs, in order to share knowledge and learnings. This toolkit should be seen as an aide to your work with your stakeholders and is expected to increase communication on two fronts:

1. Between your NBC/NAG and your national stakeholders
2. Between your NBC/NAG and EBC

Among other things, the toolkit will provide NBCs/NAGs with a guide on how to transform a NAG into an NBC, how to raise awareness, how to develop a communication plan, one pagers on how to approach the media and politicians, best practice examples from successful NAGs and NBCs, and guidance on how to host a Year of the Brain event (YotB event).

## 2. Two way communication strategy

EBC would like to promote more regular contact and knowledge sharing between EBC and the NBCs/NAGs.

In order to do this, EBC has set up a regional communication strategy to ensure that knowledge sharing is conducted in smaller settings and groups and allows everyone to have a voice. Below you will find a list of the different regions.

The rationale behind the regional groups is to bring together NAGs and NBCs at reoccurring events where the units can inspire and help each other. Most obviously, the large and successful NBCs can through their experience help NAGs or other NBCs transform and become better structured, more influential and action oriented themselves.

These regional meetings will take place online through skype or Webex and will be set up and managed by EBC. During these meetings EBC will provide an update on the status of their work and each NBC and NAG will provide an update on the status of their work and current challenges.

### Regional meetings

Regional Meetings – Geographical Set Up			
Region	Country	Status	Established
Northern European Region	Denmark	Not established yet	N/A
	Sweden	Not established yet	N/A
	Norway	NBC	2007

	Iceland	Not established yet	N/A
	Finland	NBC	2011
Baltic Region	Estonia	Not established yet	N/A
	Latvia	NAG	2011
	Lithuania	NAG	2008
Eastern European Region	Croatia	NBC	2012
	Czech Republic	NBC	2011
	Hungary	NAG	N/A
	Serbia	NBC	2015
	Slovenia	NBC	No data available
	Slovakia	NAG	N/A
	Romania	NAG	2011
	Bulgaria	NBC	2011
	Turkey	NAG	2013
	Poland	NBC	2014
	Macedonia	NAG	No data available
	Montenegro	Not established yet	N/A
	Bosnia and Herzegovina	Not established yet	N/A
	Southern European Region	Spain	NBC
France		NBC	Possibly to be established in 2015
Italy		NBC	No data available
Portugal		NAG	2009
Malta		NAG	2008
Cyprus		NAG	2008
Greece		NAG	2010
Israel		NAG ( not active)	2010
Central European Region	Luxembourg	In progress	N/A
	Netherlands	NBC	No data available
	Belgium	NBC	2005
	Ireland	NBC	2010
	UK	Not established yet	N/A
	Liechtenstein	Not established yet	N/A
	Austria	Not established yet	N/A
	Germany	Not established yet	N/A
	Switzerland	NBC	2013

Tabel 1 - Regional Meetings – Geographical Set Up

To further encourage interaction between the individual NBCs and NAGs, an overview can be seen in Annex 1 containing an overview including contact details of each of the Councils and Action Groups.

### 3. Toolkit

#### 3a. 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.

### 3.b. Key messages for politicians, media and wider audience in your country

#### Politicians

Politicians are probably the first target that comes to mind, when one wants to change the state of society. When approaching politicians, it is important to have a clear plan, in order to appear as a serious and professional organisation. Below are three steps to aide you in your contact with your national politicians:

Step 1 – Identify relevant politicians in your country – Annex 3.1 - template for stakeholder mapping (for inspiration, please see Annex 3.2 for EBC Stakeholder mapping).

Step 2 – Create communication messages – what are your key messages/key political asks that you want to put forward to your local politicians cf. example of messages in Annex 4.

Step 3 – How to approach the politicians

- a. Introduction letter template (cf. Annex 5)
- b. Set up meeting (Template meeting package i.e. powerpoint, briefs, bios)
- c. Thank you note (cf. Annex 5)

Advice is to have a template with your main messages

For inspiration on political messages, please see [EBC's manifesto](#) which reflects EBC's priorities on an EU level.

### Media

The media can play an important role in creating awareness and provide a vital platform for accessing decision makers. Local, national, and EU politicians often receive dozens of letters, phone calls etc. but they are also members of the public and as such media coverage can be useful to catch their attention, cf. Annex 4 - For this purpose, the media can be an effective tool. It is advisable to create an overview of the media in your country and split it into the relevant sectors e.g. broadcast/trade/consumer etc. and highlight the differences of each. This will enable the NBC/NAG to have a much more targeted approach when comes to dealing with the media.

The media can also be used to create awareness and drive attendance to a local conference or event, through organizing round tables, participating in radio shows, writing contributed articles, looking for the interview opportunities.

Cultivating a good network with journalists is an asset. On the one hand, you can ensure that your messages are heard, and communicated in an appropriate manner. On the other hand, it will increase the amount of opportunities for being included as a source in the future, which will also add to your credibility. For example, the Norwegian Brain Council is the most reliable source in Norway when it comes to anything concerning the brain. However, EBC would also like to advice caution in dealing with the media. It is very important to be extremely well prepared for a meeting with any representatives from the media. It is further advised that when dealing with the media nothing is off the record.

How to establish your NBC/NAG as the go to partner:

Step 1 – Identify relevant journalists and media – Annex 3.1 - template for stakeholder mapping

Step 2 – Identify your key messages (key priorities) cf. Annex 6

Step 3 –Approach a journalist/media cf. Annex 7

Step 4 –Maintain the relationship cf. Annex 7

In case of a national event, consider hosting a press conference, which could include a panel of speakers from the event. However, this approach is best used if you have some groundbreaking news which you would want to share with the press.

## Use of Ambassadors

EBC has a wide network of ambassadors across Europe cf. [http://www.europeanbraincouncil.org/year-of-the-brain/?page\\_id=17](http://www.europeanbraincouncil.org/year-of-the-brain/?page_id=17) . The list of these ambassadors includes politicians, highly profiled scientists, and celebrities. EBC urge you to identify potential ambassadors in your country and EBC will then reach out to these to become part of the EBC network of ambassadors. In Annex 8, you will find a check list on how to identify a potential ambassador and in Annex 9 the Role of an Ambassador.

The use of ambassadors will help you get the attention of the politicians and more importantly, the media. However, it is important that this is done in careful consideration of the audience that you wish to the get attention from.

An initial first contact with a potential Ambassador starts with a walkthrough of the NBCs mission, members and activity as well stating achievements. This will stimulate the interest of the potential ambassador and the envy to also become an Ambassador.

**Brain Ambassadors Day** - A way to create more awareness, is to host a Brain Ambassadors Day. This was done by the Belgian Brain Council during the Brain Awareness Week 2014 cf. 3.c. The program of the Belgian Brain Ambassador Day can be found in Annex 10.

## Social media

Social media is now a critical part of the media landscape and in many cases stories develop and break online before they are covered in traditional media channels. Social media is interactive and fast moving – with content updated in a matter of minutes. Therefore, it is critical to have a robust social media plan in place to ensure you are maximizing the potential it has and using it in the right way. For guidelines as to how to build up a social media strategy and a social media campaign, please see [section 3.e](#).

## How to create even more visibility

Another suggestion as to how to create more visibility for your NBC/NAG, is to create a leave-behind leaflet, which describes the importance of having a NBC/NAG and visualises through infographics why there is a need for such an organisation. This leave-behind leaflet could be handed out at all key national meetings. Please see Annex 11 for an example of such a leave-behind leaflet created by the Belgian Brain Council.

## 3.c. Best practices – based on EBC/NBC

### Example 1 (Resource demanding)

#### The Brain Plan, Poland

Lead; The National Polish Brain Council

Content; Development of a national program addressing, preventing and combating brain disorders (Brain Plan)

Background; The Polish Brain Council met on October 31, 2014 in Warsaw, Poland. This was the first meeting in a series of meetings with the goal of developing a “national program addressing preventing and combating brain disorders” (Brain Plan). The strategy is being developed based on recommendations from the EC (DG Research) following the Month of the Brain in May 2013 and the Dublin conference Healthy brain: healthy Europe - A new horizon for brain research and health care:

“Consequently, there is a need for countries to develop, or refine, national strategies on brain research and healthcare within an overarching European context. Successful examples of national strategies in other research areas, such as cancer, already exist in Europe.”

At the meeting, a detailed strategy was presented and discussed and an executive committee was formed, with EBC as a committee member. The Polish First Lady will be asked to become the Brain Plan’s Patroness.

In 2015, a number of preparatory actions are planned, including conferences, consultations and raising awareness campaign. Furthermore, it is planned to launch the Brain Plan in the first quarter of 2016.

EBC involvement; EBC functions as committee member and a trusted advisor

Status; When final plan for the Polish Brain Plan is ready, a template will be drafted by EBC (for current status of this, please contact Tadeusz Hawrot, European Brain Council) that will provide you with knowledge to possibly do a similar Brain Plan for your country.

### **Example 2 (Resource demanding)**

As an example of a resource demanding event, the Belgian Brain Council (BBC) has since its creation in 2005 hosted a conference every second year. This is the main BBC (easily measurable) activity in which the BBC board is concentrating. The program is a mixture of presentations on key topics and poster sessions, cf. program for the 2014 event: Belgian Brain Council: Congress 2014 - Oct. 4 in Annex 12. The date for the next meeting has already been set and it October 8, 2016. Annex 13, will provide you with a template for how to organise a similar event.

The conference of the Belgian Brain Council is chosen as a best case example as it reflects;

- All disciplines and patients represented
- ‘Market stalls’ of patient societies
- Variety of topics discussed – policy, ethics, the Commission

### **Example 3 (Less resource demanding)**

An example of a less resource demanding event is the National Brain Awareness Week. NBCs/NAGs have the possibility of organising events related to the annual Brain Awareness Week.

The Brain Awareness Week is today a wellknown worldwide event, which provides a lot of visibility. To register within the BAW calendar (see <http://www.dana.org/BAW/Calendar/>) gives higher visibility and introduce competition between countries.

The Belgian Brain Council has participated in the Brain Awareness Week

### 3.d. Guidelines on how to organize a YotB event

Year of the Brain (YotB) runs from 2014-2015 with the goal of highlighting the needs of the millions of Europeans, who are currently affected by a brain disorder. Coordinated by the EBC with the support of more than 200 patient, clinical and industry organizations, YotB will raise awareness of brain disorders and the importance of nurturing and protecting one's most vital asset, the brain.

The Year of the Brain has three objectives:

1. To educate society about how to nurture and protect the brain and prevent brain disease.
2. To improve care and treatment access for those affected by a brain disease.
3. To increase investments in brain-related R&D for the benefit of future generations.

A NBC/NAG can use YotB to promote itself and its activities. Below are two examples of how this can be done;

#### **Example 1 (Resource demanding)**

In November 2014, the Bulgarian Brain Council hosted the 1st Bulgarian EBC Symposium in Sofia. This event was branded with the EBC and YotB logo and had guest speakers from the EBC. The objectives of the meeting were to present the challenges and opportunities that Bulgarian neurology, neurosurgery, psychiatry, patients and business have to face in this period of economic crisis. All aspects were interpreted in the framework of the European perspectives. Please see Annex 14 for how such an event could be hosted in your country.

#### **Example 2 (Less resource demanding)**

This event was hosted in the UK and is an example of a less resource demanding event, which both require less planning and lower budget, cf. Annex 15.

### 3.e. Guidelines on social media strategy

The most important social media networks that you should know are:

- Facebook
  - Facebook has become something that almost everyone has, including businesses and organisations. It is not a place for debate in the same way as e.g. Twitter. Instead, it is a good place to share information and events that are important to common people.
- Twitter
  - Especially the media and politicians are using this media as a way to interact with their audience. Therefore, this is also a good place to catch these subjects' attention and interact with them. The use of hashtags (#) makes it easy to track certain debates and events.
- LinkedIn
  - Business oriented network, which mainly focuses on professional networking. However, LinkedIn can also be used to post more scientific articles and create discussions. Therefore, LinkedIn could be used to create interest and awareness among e.g. professionals working with the brain, but it should probably not be the first focus when entering the social media stage.

- Youtube
  - Can be used to share videos. It is possible to create a “channel” on which all the organization’s videos can be uploaded. If a person follows a channel (s)he will receive a notification about new uploads.

Facts and figures for who uses each of the above should be carefully developed i.e. who uses Facebook and Twitter for example. Facebook pages can for instance be two way/conversational – which would then need to be monitored and responded to in a timely way. This would then again have resource implications. The Facebook pages can also be locked – which means they are just useful for posting information rather than getting feedback.

In addition to the above it should also be carefully considered what demographics use each platform. This would ensure that the right elements are being used.

#### How to create a social media strategy

1. Create a social media strategy
  - a. Use the communication strategy section as base for a social media strategy and carefully consider which of the above social media networks fits your organisation and if you have the right competences in your organisation or will need external advice.
2. How to implement a social media strategy
  - a. As a first step - Create the content decided upon in your social media strategy on your social media page before going live and ensure that it is carefully aligned with the information on your website. When you add people on e.g. twitter, they will often look upon who you are – this is a great opportunity to get followers. The more content you have on your profile, the more likely it is that people will recognize and/or find you interesting and worth following
  - b. Add a recognisable profile picture (and backgroup picture) and a brief paragraph about your organisation including a link to your website as well as a reference to the remaining social medias at which you are present
  - c. Invite your network to follow/like your profile
  - d. Ask individuals in your network to recommend your organisation on the social media e.g. through #FF (follow Friday). NB be careful to not to be considered too demanding e.g. do not use #likeforlikes etc. Instead it is recommended that you write an email to some of you contacts making them aware that you now have a profile on XX social media and/or mention it via your other communication channels i.e. other social media, newsletter etc.
3. How to maintain
  - a. Keep up the interest through regular updates. However, know your media: if you make too many updates on Facebook, it will tend to be perceived negatively by your audience. On twitter, on the other hand, it is almost impossible to create too many updates

#### How to create a social media campaign on a specific topic (when the social media strategy is in place)

A social media campaign a potential topic or a specific event. Taking outset in a specific event that you would like to draw attention to, a suggestion could be to follow the below procedure

1. Choose a theme for campaign

2. Identify which social media that are relevant (though your might be present on several social media, it might not be relevant to use them all or use equal amount of energy on them all)
3. Identify your local stakeholders and consider how to engage with these and encourage them to participate in the social media campaign, e.g. by “liking”, “share”, “re-tweet” or “follow”. Awareness can also be created by contacting them directly on the social media e.g. “Does @EUPres agree with XX?”
4. List suggested topics for social media posts including a timeline for when you post these – alternatively, use a software provider that can assist you in “timing” your tweets, facebook updates etc.
5. Event Day
  - a. Make people aware of the event prior to the event, this might increase the amount of participants.
  - b. Have participants sign a pledge supporting your cause (potentially use social media channels (Facebook, twitter)) to collect signatures; encourage signatories to advertise their commitment in their personal social media status updates and invite others to sign it too
  - c. Post audio clips of interviews given during the event on social media platforms. OBS! Make sure that such are taped and uploaded in the right format. Make people aware of the fact that they are being recorded and check if there exist local laws about this
  - d. Make a press release immediately after event and publish this on social media

**Advice:** To make it easier for participants to create attention about an event; distribute a tweet (cheat sheet, in which you both suggest sentences (including relevant facts), an official hashtag and/or other relevant hashtags (such as #fightstigma) and, if it exist, an official profile. Example” More than 350 million people suffer from #depression, join @EU\_Brain and #depressionkills”

#### How does EBC use social media

The EBC uses the social media channel Twitter to create attention about EBC’s activities. This is especially useful to communicate to and with people and organizations that are not members of EBC and might not know EBC.

On twitter, EBC mainly share:

- Links for the newest newsletter to increase its influence
- Tweets from events that EBC is hosting, co-hosting or participating in, to increase awareness
- Retweets of member tweets and other relevant tweets that create awareness about a healthy brain and brain disorders.

To increase tweet views and attention, EBC

- Adds photos (or infographics) to tweets as often as possible

- Has a list with important #hashtags etc. that should be used at different events, often based on the “cheat sheets” that hosts send out themselves before an event.
- Has a goal of reaching 500 followers in 2015

A key action here for your NBC/NAG to consider would be to follow EBC and where possible to re-tweet EBC tweets etc. not only to further the reach but also to create additional content for your own pages. EBC thus invites you to join by “liking”, “share”, “re-tweet” or “follow”.

## 4. Communication strategy

Below you will see an outline of points which need to be considered when drafting your communication strategy:

- Statement of purpose + key messages
  - Your communication strategy should of course be aligned with the overall strategy of your organisation, i.e.
    - Consider what you want to achieve with a communication strategy e.g. being better equipped to communicate with and attract new members, funding, creating impact with politicians, media and society in general?
  - Ensure that the goals encompassed in your strategy are SMART (Specific, Measurable, Achievable, Results-focused and Time-bound) goals. When you have clearly defined and measurable goals – think about how you will meet them. What tools and activities do you need to have in place?  
In addition also consider how your communication tactics can fall out your strategy and how you can prioritize with limited resources.
  - Review the goals in relation to your stakeholders . Will they reach your audience?
  - Are you clear on who your audience and key stakeholders are? Does any additional stakeholder mapping need to take place?
  - Define a clear approach in advance to manage the different stakeholder groups and their representation .
  - E.g. will “industry”, patient groups and scientists expect to be equally represented when it comes to content?
- Learn from others – competitors and friends
  - Look around; what is working for others? Ask others what is working for them. Remember to be critical, what works for others might work due to a specific audiences or circumstances and this needs to be taken into consideration.
- Identify possible communication channels e.g.
  - Monthly newsletter
  - Social media
  - Homepage
  - Meetings – one-to-one or group
  - Speaking opportunities
  - Media opportunities

- Resources
  - Realistically look at the resources you have at your disposal and identify how you can best use what you have. If you only can spend two hours on a newsletter per week, you probably should not aim for a weekly newsletter but rather a monthly newsletter etc.
- Evaluate
  - Is the communication strategy/tool meeting your targets?
    - Why/why not?
    - Can this be changed? How?
  - Decide when the strategy or tool should be evaluated – e.g. three months after the launch

For further information, please see Annex 16.

## 5. Communication (briefing) package

EBC has created a site on their website, which contains relevant information that can be utilized by your NBC/NAG to create awareness. Please see the following:

Factsheets

Infographics

EBC position papers

Disease Fact Sheets

- [Alzheimer's disease](#)
- [Depression](#)
- [Dystonia](#)
- [Migraine](#)
- [Parkinson's disease](#)
- [Schizophrenia](#)
- [Stroke](#)

## Position Papers

- [EBC contribution to the Green Paper: From Challenges to Opportunities: Towards a Common Strategic Framework for EU Research and Innovation Funding](#)
- [EBC Position Paper on the protection & use of animals in research](#)
- [EBC Position Paper on its relationship with its member organisations and National Brain Councils](#)
- [EBC Position Paper on counterfeit and substandard medicines](#)

[Cost of Disorders of the Brain in Europe 2010](#)

[Consensus Document on European Document on European Brain Research 2011](#)

[The Size and Burden of Mental Disorder and Other Disorders of the Brain in Europe 2010](#)

[Resources Allocation for Brain Research in Europe](#)

## 6. Funding

Why fundraise - Fundraising is important to ensure that your NBC/NAG has the right level and types of funding and finance that your organisation needs, when you need it and to be able to deliver your mission effectively.

This section will mainly focus on NBCs since NAGs are not a legal entity. However, as for NAGs it should be considered if funding could be done indirectly, through other bodies such as scientific societies that could for instance cover travel costs to attend a meeting.

Fundraising takes time and resources. Therefore it is key to work out what fundraising activities your NBC needs to have and have a clear strategy and action plan as to how this is achieved.

### Step 1: Build a fundraising strategy

To build your fundraising strategy, it is recommended to go through the following steps:

- Knowing the fundraising goal
  - Assess your internal implementation capacity (existing level of funding)
  - Assess level of funding needed to support your mission
  - Ensure that your mission statement and fundraising strategy are aligned
  - Assess your organisation's credibility and reputation i.e. why should a potential funder "invest" in your NBC
  - Analyse the legal situation in your country
    - Check out applicable laws in your country
    - Check out the tax situation eg. are there applicable tax benefits which encourage donations (individuals, private sector businesses and corporations etc.)
    - Look to what other organisations are doing
- Who in your organisation will do the fundraising
  - Assess experience and internal skills of your existing organisation
    - Past experience in fundraising
    - Available human resources and skills
  - Are additional competences required in your organisation
    - Many of the skills and techniques of fundraising have been developed by, and adapted from the commercial profession of MARKETING. Thus, ensure that you have these competences in your organisation and be ready, willing, and able to "sell" your NBC and the programs for which you are raising money.
- Identify sources of funding and how can they be reached
  - Assess a potential funder's credibility and reputation
  - Who will you take money from? (Are there people or organisations that you would not want to be associated with?)
  - Keep in mind; It is not begging: When you are fundraising you are actually selling the mission of your NBC and it benefits the community

- To build a realistic fundraising strategy, it is important to identify all the types of resources that are available or that can be mobilised for your national brain council. It is recommended to do this as a brain storm session with your team
- When working with your team on identifying potential funding options, it is suggested to consider the funding options mentioned in the below Figure 2. These are only few options for your inspiration, it should be identified for your specific country, who could be considered as a potential funder and then pro-actively reach out to these.

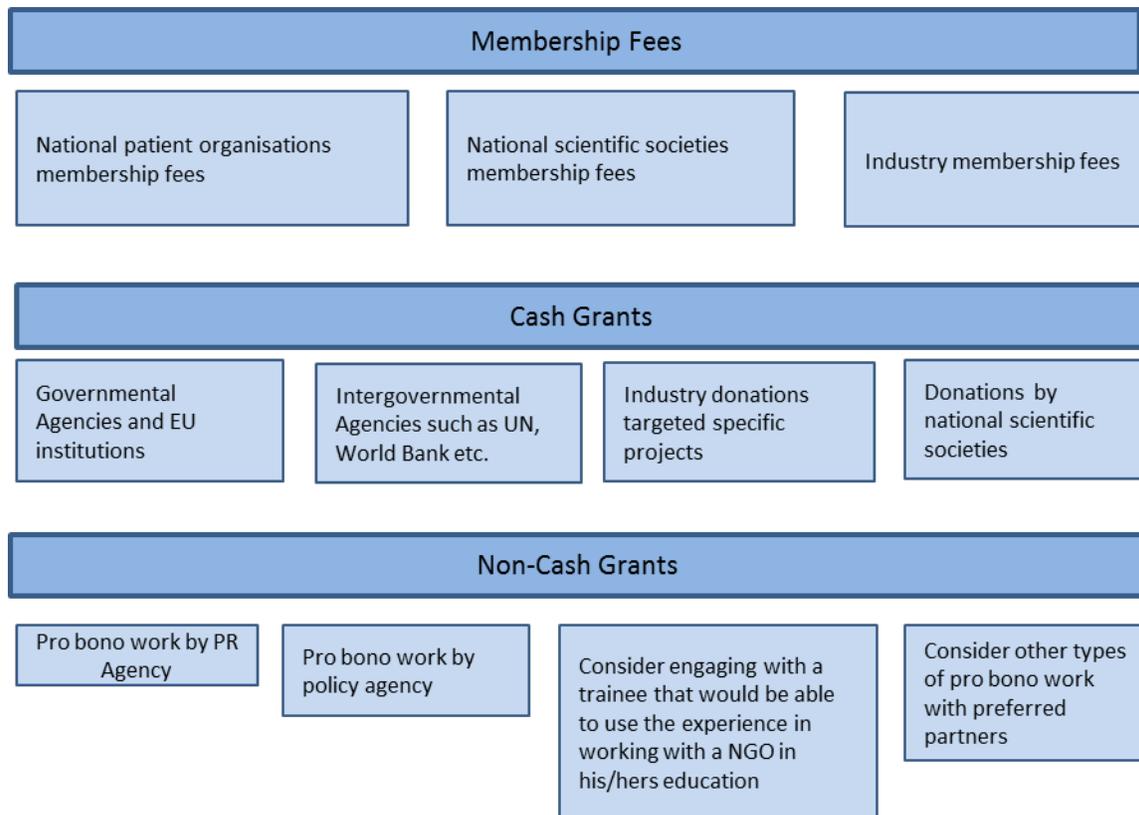


Figure 2

It is recommended that the level of fees is different for different types of organisations (e.g. smaller for patients).

As contribution in kind examples are pro bono work carried out by a PR agency, Policy Agency (such as [Fipra](#) doing pro bono work for EBC), a legal advisor, a company lending an employee to do pro bono work on a specific project.

#### Step 2: How to reach out to a potential funder

- Make a background check on your potential funder to see if there are common interests and synergies
  - Ensure also that your contact person has sufficient budget responsibility in the organisation to make decisions on funding amounts and involvement.

- Before reaching out to a potential funder, it is important to prepare documentation and leave-behind material that demonstrates the outcome and impact of your strategy and if the ask is funding for an event then the same applies i.e. being able to demonstrate the outcome and impact of this specific event.
  - Provide data that demonstrates that what your non-profit is doing is making a difference
  - Consider getting feedback from beneficiaries, either through surveys, interviews, or other approaches – this will both help you assess whether you are being effective and also provide you with testimonials that you can make use to make your case support even stronger
- When drafting agreements with potential funders be aware that most funders have their own templates that they are required to use

### Step 3: Maintain a good and long-term relationship to your funder

It is important to be strategic about the type and the frequency of the communication that your NBC initiate with funders.

Below you will find some steps to take to ensure that this is happening;

- Establish and maintain a funding database or funding overview that will allow you to make a note of key information about each funder. Below please see a list of possible content
  - Organisation name
  - Address
  - Contact person, contact details, title
  - Mission of the organisation
  - Main Area/Sectors of interest
  - Funding availability – Time and levels (maximum & minimum)
  - Special restrictions if applicable
  - Formate of legal contract/sponsorship agreement
  - Remarks
  - Past contacts & results
- Always ensure that the contact details that you have on file is up to date
- Examples of ways to obtain ties with your funder
  - Examine with each funder their need for being kept in the loop
  - Ensure that whatever type of communication that you send out to your funders is targeted and personalised. Avoid lumping all funders together in the same category and expecting everyone to be happy with the information sent to them
  - Ensure that you convey a clear message on your success, i.e. inform of your successes in measurable terms
  - Information sent to your funder can be of various sort such as annual reports, newsletters etc. in an attempt to maintain this with the donors that have granted them funds. However, be very clear on who your target group is

- Smaller funders, such as family foundations or small corporations, may not wish to receive even program updates, because of the lack of resources to handle them

## 7. Annexes

Annex 1 - Overview including contact details of NBCs and NAGs

Annex 2 - Guidelines on how to form a NBC/NAG

Annex 3.1 – NBC/NAG template for stakeholder mapping

Annex 3.2 - EBC stakeholder mapping

Annex 4 – Key messages to policy makers

Annex 5 – Template letter to politicians

Annex 6 – Key messages to wider audience

Annex 7 – How to approach a journalist and maintain the relationship

Annex 8 - How to identify a potential ambassador

Annex 9 – Role of an Ambassador

Annex 10 – Program for Brain Ambassador Day

Annex 11 – Example of a leave-behind leaflet

Annex 12 – EBC/NBC Resource Demanding Event – Belgian Brain Council; 2014 event

Annex 13 – EBC/NBC Resource Demanding Event – Belgian Brain Council template

Annex 14 - Guidelines on how to establish a YotB event – Resource demanding event

Annex 15 – Guidelines on how to establish a YotB event – Less resource demanding event

Annex 16 - Communication guidelines – general steps to be considered

## Annex 1 – Overview including contact details of NBCs and NAGs

Country	Type*	Organisation	Contact	E-Mail	Website
Austria	NBC	Not established yet			
Belgium	NBC	Belgian Brain Council	Dirk Van Roost, President / Roland Pochet	dirk.vanroost_AT_ugent.be / rpochet@ulb.ac.be	<a href="http://www.belgianbraincouncil.be/">http://www.belgianbraincouncil.be/</a>
Bosnia and Herzegovina	Not established yet				
Bulgaria	NBC	Bulgarian Brain Council	Nikolay Gabrovsky	gabrovsky@gmail.com	
Croatia	NBC	Croatian Brain Council	Dinko Mitrecic	dominic@mef.hr	<a href="http://www.hvim.hr">www.hvim.hr</a>
Cyprus	NAG		Marios Tannous	mgannous@gmail.com	
Czech Republic	NBC	Czech Brain Council	Pavel Mohr, President	mohr@pcpf3.cuni.cz	
Denmark	Not established yet				
Estonia	Not established yet				
Finland	NBC	Finnish Brain Council	Jyrki Korkela	jyrki.korkela@pp.inet.fi	<a href="http://www.neuro.fi/suomenaivot/">http://www.neuro.fi/suomenaivot/</a>
France	NBC (Possibly to be established in 2015)				
Germany	NAG		Wolfgang Oertel	oertelw@med.uni-marburg.de	
Greece	NAG		George Panagis	panagis@psy.soc.uoc.gr	
Hungary	NAG		János Tajti / László Vécsei	tajti.janos@med.u-szeged.hu / vecsei@nepsy.szote.u-szeged.hu	
Iceland	Not established yet				
Ireland	NBC	Irish Brain Council	Richard Roche, President	Richard.Roche@nuim.ie	<a href="http://irishbraincouncil.com/">http://irishbraincouncil.com/</a>
Italy	NBC	Italian Brain Council	Monica Di Luca	monica.diluca@unimi.it	
Israel	NAG (Not active)		Joseph Zohar / Yoram Cohen / Ilana Gozes	Jzohar@post.tau.ac.il / cohen.yorav@gmail.com / igozes@post.tau.ac.il	
Latvia	NAG		Angelika Gudreniece / Vija Kusa / Andrejs Milers	ebc.latvia@inbox.lv / vijaklus@latnet.lv / milersandrejs@gmail.com	
Lichtenstein	Not established yet				
Lithuania	NAG		Nijole Gostautaitė Midtun	nigomi@hotmail.com	
Luxembourg	In progress				
Macedonia	NAG				
Malta	NAG		Dolores Gauci	ceo@richmond.org.mt	
Montenegro	Not established yet				
Netherlands	NBC	Dutch Brain Council	Robert Scholten, President / Rob Heinsbroek	r.scholten1@chello.nl / r.heinsbroek@NWO.NL	<a href="http://www.dutchbraincouncil.nl">www.dutchbraincouncil.nl</a>
Norway	NBC	Hjernerådet	Hanne Flinstad Harbo	h.f.harbo@medisin.uio.no	<a href="http://www.hjerneradet.no/">http://www.hjerneradet.no/</a>
Poland	NBC	Polish Brain Council	Grzegorz Opala	grzegorz.opala1@gmail.com	
Portugal	NAG		António Freire	afreireg@hotmail.com	
Romania	NAG		Leon Zagrean	leon.zagrean@gmail.com	
Serbia	NBC	Serbian Brain Council	Vladimir S. Kostic	vladimir.s.kostic@gmail.com	
Slovakia	NAG		Livia Vavrusova	vavrusova@ruzinov.fnspsba.sk; Vavrusova.consulting@gmail.com	
Slovenia	NBC		Jure Bon	jure.bon@gmail.com	<a href="http://www.sinapsa.org/slo">www.sinapsa.org/slo</a>
Spain	NBC	Spanish Brain Council	Julio Bobes / Julio Albusua, President	bobes@ctv.es / J.Albusua@fjd.es	<a href="http://www.spanishbraincouncil.org/">http://www.spanishbraincouncil.org/</a>
Sweden	Not established yet				
Switzerland	NBC	Swiss Brain Council	Jürg Kesselring / Lisa Schmitt	kesselring.kival@spin.ch OR juerg.kesselring@klinken-valens.ch / lisa.schmitt@link.ch	<a href="http://www.swissbraincouncil.ch/">http://www.swissbraincouncil.ch/</a>
Turkey	NAG		Hakan Gurvit / Şerefnur Öztürk	gurvit@istanbul.edu.tr / serefnur@yahoo.com	<a href="http://turkiyebeyinyili.org/">http://turkiyebeyinyili.org/</a>
UK	Not established yet			gurvit@istanbul.edu.tr / serefnur@yahoo.com	<a href="http://turkiyebeyinyili.org/">http://turkiyebeyinyili.org/</a>
* National Brain Council (NBC) / National Action Groups (NAG)					

## Annex 2 – Guidelines on how to form a NBC/NAG

### Starting up an 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 an NBC's purpose 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. Furthermore, it would be preferable, 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.

### Steps to set up a National Action Group → National Brain Council

#### Phase 1: Preparatory actions

Timing: 2-3 months to organize the kick off meeting.

1. Set up a database, which should include:

- b) Who should be members of the NAG?

An NAG should have representatives of:

- the main academic and medical fields (neuroscience, psychiatry, neurology and neurosurgery),
- neurological & psychiatric patient groups,
- industry (pharmaceutical and non-pharmaceutical).

There should be a proper balance between clinical and basic neuroscientists, and between academic and industrial representatives. The relevance of industry participation varies very much from one country to another, depending, for example, on whether there is an industrial research base, and whether medicines and treatments are fully reimbursed by the state. The EBC will be able to advice on how to manage industrial sponsors and supporters in order to preserve a suitable board structure. While the EBC Board is restricted to those organisations that have a European span and represent large constituencies, an NBC can be as broad and inclusive as it wishes.

- c) Research:

- Identifying presidents of major national organisations representing brain researchers. Keeping in mind that these are usually very busy people, trying to get their general support for the idea and if needed, asking for delegates who could represent them.
  - Identifying major national patient organizations
  - Connectivity to European organizations: Checking all the EBC member organizations for representatives from the respective countries.
  - Consulting EBC Board Members in order to get further feedback on the proposed participants and to identify a person who will be suitable to take the lead.
2. Making the first contact:
- a) Approach the possible leader:
    - Evaluate his/her degree of interest and involvement
    - consult him/her on the names of possible participants and inviting his/her input on the final shape of the list
    - check whether he/she is able to contact everyone in order to introduce them to the EBC proposal and investigate their interest in the project
    - make sure that the leader is willing to receive EBC representatives at the kick off meeting and proposing best dates for it.
  - b) Send an official letter, if possible, cosigned by the leader, to all identified people to introduce the EBC, to describe the idea of setting up NAG/NBCs and to invite them to participate in the kick off meeting.
  - c) Follow up where no reply was received, first by email and if not successful, conducting a phone follow-up.
  - d) Identify whether it is possible to select one representative from each brain discipline to make a short presentation during the meeting on the situation of his/her field in the respective country. If it is difficult, organizing an open discussion where everybody can speak.

#### Phase 2: A kick off meeting:

Timing: One day,

1. Objectives:
 

Gathering a small number of people (8-15) in order to:

  - a) Present the EBC and its activities
  - b) Introduce the idea of setting up NAGs/NBCs
  - c) Hearing what participants have to say and what are the particular needs for their discipline or area of interest in their country.
  - d) Looking into possible ways of creating a NAG and setting up a draft action plan
2. Agenda
3. Follow up
  - a) Sending a follow up letter to all the participants.

#### Phase 3: Actions leading to setting up a NBC:

Timing: One to two years between a kick off meeting of NAG and forming NBC.

1. Following up with a country leader regarding the progress in establishing NBC. Offering any possible help, including :
  - a) English version of constitution that could be then adapted to national needs.
  - b) Contacts of potential member organisations and representatives e.g. the EBC's industrial partners could use their national subsidiaries to help in the task of identifying industry participants
  - c) Providing a standard slide set about the EBC and other NBCs.
  - d) Support/visits from EBC Board members in the early stages of discussions to help catalyse the establishment of the NBC.

### **1. How should an NBC be governed?**

To secure an equal distribution of power, the President and Vice-President should come from different stakeholder groups. Moreover, a proper balance should be kept regarding NBCs' presidents – there is a tendency that most of the presidents come from neurological societies and psychiatry field is neglected. A General Secretary should be appointed for administrative matters. The Board should consist of the Presidents of the various member societies or their deputies plus elected representatives from industry. In some countries patient organizations and professional organizations have an equal number of board members.

#### [Actions that can be taken by NBC at the national level:](#)

An NBC should have goals reflecting national needs and should develop its own processes for the achievement of its aims. The most important task for NBC is to influence national research programs, where the greatest part of funds is available. This can be achieved through:

- a) Organising conferences to gain broad stakeholder support, and the involvement of parliamentarians and other policy makers. Using the conferences as leverage to campaign for a national assessment of current activities and gain governmental support for an action plan to meet gaps and needs.
- b) Further mobilising national forces such as government agencies and decision makers, members of parliament and other stakeholders to support brain research e.g. through presentations to government Ministers and National Research Councils about European, as well as national policy, priorities and needs.
- c) Leveraging 3<sup>rd</sup> party events to convey the message by influencing the agenda, distributing info materials, making a use of media presence.
- d) Increasing public awareness of the need for more brain research (read more about how under XXX)
- e) Focusing on informing and alerting national patient groups, scientists, physicians and health care providers about the impact of brain disorders and the importance of brain research e.g. through organising national initiatives and multidisciplinary conferences on brain research.
- f) Improving/working towards the prevention, early diagnosis and optimal treatment of neurological and psychiatric diseases.

In addition to this, NBCs can help EBC in its work to promote brain research in Europe and to improve the quality of life of those affected by brain diseases. This can e.g. be done by

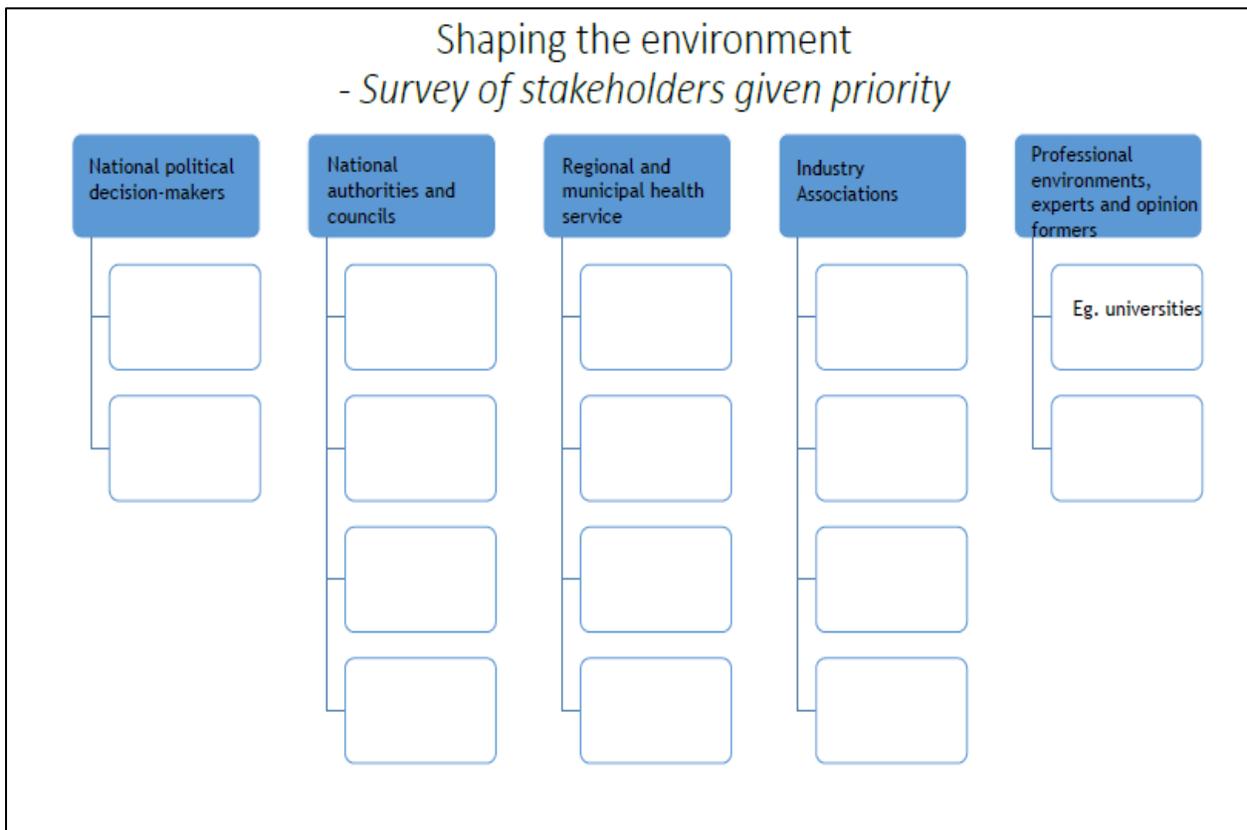
- g) Supporting the EBC's European initiatives e.g. through influencing MEPs and facilitating access to them for the EBC
- h) Acting as the vehicle for dissemination of national versions of the EBC's main European projects
- i) Organizing together with the EBC, policy forums in countries where the EU presidency takes place.

Annex 3.1 – NBC/NAG template for stakeholder mapping

# NBC/NAG stakeholder mapping template

Shaping the environment - Priorities 2015 • Goal relating to the priority				
Stakeholders given priority Who? (unit/organisation) The most important stakeholders	Stakeholder challenge What does xx NBC/NAG want to achieve in relation to the specific stakeholder?	Xx NBC/NAG activities What activities are carried out to meet the challenges?	Assessment Are the challenges realised or in process?	Why/why not a realisation Primary reason/barrier for a realisation to succeed or not

Building trust- Priorities 2015 • Goal relating to the priority				
Stakeholders given priority Who? (unit/organisation) The most important stakeholders	Stakeholder challenge What does xx NBC/NAG want to achieve in relation to the specific stakeholder?	Xx NAG/NBC activities What activities are carried out to meet the challenges?	Assessment Are the challenges realised or in process?	Why/why not a realisation Primary reason/barrier for a realisation to succeed or not



## Annex 3.2 - EBC stakeholder mapping

# EBC stakeholder mapping template

Shaping the environment - Priorities 2015				
• Goal relating to the priority				
Stakeholders given priority Who? (unit/organisation) The most important stakeholders	Stakeholder challenge What does EBC want to achieve in relation to the specific stakeholder?	EBC's activities What activities are carried out to meet the challenges?	Assessment Is the challenges realised or in process?	Why/why not a realisation Primary reason/barrier for a realisation to succeed or not
European Commission (DGs: Research, SANCO, CONNECT)	The EC is the executive body of the European Union and is responsible for driving EU policies and coming up with legislation. More specifically: DG Research: prioritize brain research, allocate more funds to it, improve coordination, incentivize member states to develop national brain plans and other relevant policies. DG SANCO: work on better prevention, diagnose and access to treatment, address stigma associated with brain disorders. DG CONNECT: working on applying new technologies like internet, apps, ehealth to improve brain health. Note: DG CONNECT is funding the Human Brain Project.	Maintaining good relationships with the Commissioners and key staff (e.g. Directors General, health directors, officials dealing directly with brain disorders). To this end EBC regularly meets with the EC officials as well as invites them to its Board meetings, dinners etc. EBC also provides the EC with evidence on how burdensome brain disorders are ( <a href="#">Cost study</a> ) and what are the priority areas to address ( <a href="#">Consensus Document</a> ).	No doubt it's always in the process. However, EBC is now widely known in the European Commission key Directorates General. The EC has been using extensively findings from EBC studies. The amount of funding allocated from brain research from European funds increased many-fold since EBC started operating. The EC designated May 2013 the European Month of the Brain as a direct result of EBC advocacy efforts and EBC was closely working with the EC on delivering the Month.	The European Commission is a highly bureaucratic body with time consuming procedures and complicated hierarchy. It is also fragmented, with many policies that are spanning over several DGs and yet being dealt with without enough coordination. This requires an intelligent approach taking into account all these characteristics.

**Shaping the environment - Priorities 2015 continued**  
 • Goal relating to the priority

Stakeholders given priority Who? (unit/organisation) The most important stakeholders	Stakeholder challenge What does EBC want to achieve in relation to the specific stakeholder?	EBC's activities What activities are carried out to meet the challenges?	Assessment Is the challenges realised or in process?	Why/why not a realisation Primary reason/barrier for a realisation to succeed or not
European Parliament	<p>The EP exercises the legislative function, it has control over EU budget and the EC is accountable to it.</p> <p>The EBC is particularly targeting members of the relevant EP Committees - Committee on the Environment, Public Health and Food Safety and Industry, Research and Energy as well as MEPs that are involved in policies that are of relevance to EBC as well as other health/research/brain related MEPs. The EBC can initiate legislative acts through engagement with the EP, raise awareness about the brain among policy makers as well as exert additional influence over the EC.</p>	<p>EBC meetings organized in the EP, involving MEPs and other stakeholders (e.g. lunch of the Cost study where most of the NBCs representatives were present). EBC Members run interest groups on the brain in the EP and EBC is contributing to the meetings and shaping the agenda. EBC is meeting with individual MEPs that have particular interest in the brain or are responsible for relevant dossiers. EBC is also attending the many relevant meetings organized in the EP by various stakeholders. EBC prepared EU elections manifesto that has been distributed to MEPs.</p>	<p>Engaging with MEPs is an incremental process and is helping to shape the favorable environment for EBC so that when the opportunity or a need emerges, we can react swiftly and efficiently, e.g. by having established contacts with key MEPs.</p>	<p>The EP is extremely busy place with dozens of meetings happening every day. MEPs are extremely busy and are involved with multiple dossiers which makes it imminently difficult to engage with them. For this reason tailored and ideally national approach is needed.</p>

## Shaping the environment - Priorities 2015

### • Goal relating to the priority

Stakeholders given priority Who? (unit/organisation) The most important stakeholders	Stakeholder challenge What does EBC want to achieve in relation to the specific stakeholder?	EBC's activities What activities are carried out to meet the challenges?	Assessment Is the challenges realised or in process?	Why/why not a realisation Primary reason/barrier for a realisation to succeed or not
EU Member States	When it comes to public health, the scope for EU legislative action is limited. Most health issues, in particular the organization, management and funding of health services, fall within the exclusive competence of the Member States, the national governments. Hence, the role of the EC is mostly to support and complement national policies. Additionally, some 95% of funding for research comes from national budgets. Therefore it is of an imminent importance to engage in a dialog with MS. To this end, the work of NBCs is of particular importance. However, EBC is also making efforts at the EU level to interact with them through means such as meetings with MS permanent representations, and most importantly engaging with countries that are holding EU Presidencies.	Meetings with health/research attaches from MS permanent representations, contacting relevant government bodies to engage in discussions over EU presidencies. E.g. EBC was part of the process of formulating priorities for Polish presidency and executing them which culminated in the presidential conference co-organized by EBC, DG SANCO and Polish Ministry of Health.		Getting into agenda of countries holding EU Presidencies is an extremely difficult process due to a high competition. The process should start 2-3 years before the presidency and the role of the NBCs can be crucial in achieving success due to local connections that have.

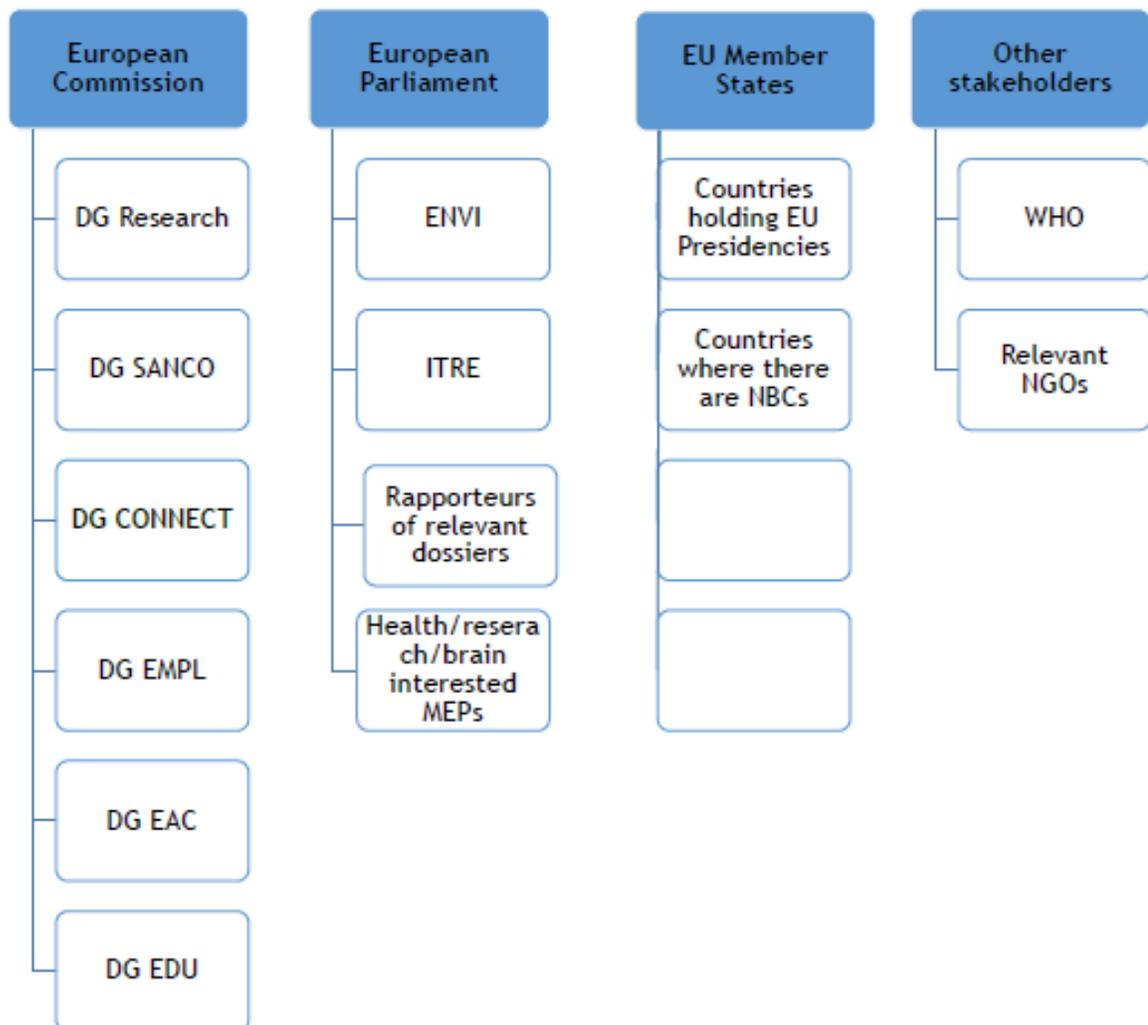
## Shaping the environment - Priorities 2015 continued

### • Goal relating to the priority

Stakeholders given priority Who? (unit/organisation) The most important stakeholders	Stakeholder challenge What does EBC want to achieve in relation to the specific stakeholder?	EBC's activities What activities are carried out to meet the challenges?	Assessment Is the challenges realised or in process?	Why/why not a realisation Primary reason/barrier for a realisation to succeed or not
Other NGOs in the fields of relevance to the EBC such as EPHA, EPA, EuroCarers etc.	The EBC should promote its goals and projects in the wider European context and build alliances with other organizations in order to be well connected and informed as well as to form alliances should the need comes, e.g. on the occasion of threats to cut research/health budget in the Horizon 2020.	Attending meetings of other NGOs, personal meetings, exchange of best practice, common approaches to policy makers.		

# Shaping the environment

- Survey of stakeholders given priority



## Annex 4 - Key messages to policy makers

### **(National – insert you country) Brain Council (NBC):**

Xx NBC is a unique structure that encompasses a vast network of patients, doctors, scientists and industry that is united around a common vision - *by bringing together science & society, to advance understanding of the healthy and diseased brain in order to improve the lives of those living with brain disorders* (anxiety, brain tumours, chronic pain, dementia, epilepsy, migraine, mood disorders (depression and bipolar disorders), multiple sclerosis, Parkinson's disease, stroke, traumatic brain injury and many others)

Xx NBC is based on 3 pillars:

- Advocate EBC cause on EU & national level
- Coordinate the effort with likeminded stakeholders
- Develop content highlighting “issues” in the three pillars

Xx NBC is member of the European Brain Council and member of the Network of National Brain Councils.

### **[Key messages to health ministers]**

Brain disorders, including developmental, pain, psychiatric and neurodegenerative diseases, represent an enormous disease burden in terms of human suffering and economic cost. Brain disorders:

- account for 35% of the burden of all diseases in Europe (WHO)
- cost Europe €798bn a year (far more than cancer, CD and diabetes combined)
- affect at least one in three persons during their lifetime – 165 million people in Europe and many more family members or friends who are affected
- are set to rise due to demographic challenges
- Many brain disorders are chronic and incurable conditions whose disabling effects may continue for years or even decades.

To address this challenge and to work towards eliminating a huge discrepancy between the huge impact of brain diseases, and the modest financial and time resources allocated to better understanding the brain, there is a need:

- for more research to address the causes and developmental pathways of brain disorders
- to encourage and incentivize industry and investors to engage in brain research
- to actively involve patients and caregivers in the planning of research approaches, execution of services and maintenance of standards of healthcare practice
- to work towards earlier and better diagnosis, prevention, and treatment

AND

To adopt national plans addressing brain diseases:

The European Commission designated May 2013 the [European Month of the Brain](#). Following the campaigns key event - the conference; “ *Healthy brain: healthy Europe - A new horizon for brain research and health care the Commission made the following recommendation* “ - there is a need for countries to develop, or refine, national strategies on brain research and healthcare within an

overarching European context. Successful examples of national strategies in other research areas, such as cancer, already exist in Europe.”

What is clearly required is a coordinated policy covering disorders of the brain in general, mental and neurological alike, because together they constitute by far the biggest health problem in the EU.

Therefore, national policies in each European country should adopt national plans addressing brain diseases according to the specific situation in every country. This will help promote health of the citizens and limit the immense and expanding cost of brain disorders. Moreover, more coordination should be taking place between member states and the EU.

### **[Key messages to research and finance ministers]Key policy /public affairs messages**

The EU and the Member States face many economic challenges. While economic priorities understandably come first in the current environment - “it is only with a healthy brain that we will solve so many of the challenges that face modern societies. Brain Health equals National Wealth.” (Prof. Martin Rossor).

The healthcare sector accounts for 8% of the total European workforce and 10% of the EU’s GDP<sup>1</sup>. It is the basis for a strong life sciences industry of pharmaceuticals, biotechnology and medical devices. Yet, European research and development investments in health have stagnated since 2010, for the first time after decades of annual increases. The findings are worrying in the light of Europe’s increasing disease burden and ageing population, as well as the millions of people whose health cannot be improved without new health care approaches.

Increase of Europe’s R&D investment in health and in particular in better understanding brain and its disorders will have a number of positive effects including improved health that leads to better productivity among the working population. Health R&D investments also have the potential to provide high economic yields, both in terms of return on investment and in producing and deploying a highly educated workforce with technical skills.

Importantly, return on investment in brain research far exceeds the return from any other branch of research.

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<sup>1</sup> Investing in Health: Commission Staff Working Document - Social Investment Package, February 2013

## Annex 5 Template – Letter to politicians

### Template – Introductory letter or email

Dear Mr./Mrs./Dr. XXX

(Take the time to find the full name of the person to whom you are writing. In case, this information is not available, start the letter with “Dear Sirs or insert title”)

- Introduce yourself and the organization
- If you have met the person before, you will of course need less introduction, however, keep in mind that politicians meet many people every day and might not remember you. Therefore, start with a short introduction of yourself and the organization as well as a reminder of where you met
- State your reason for approaching this particular politician, e.g. is it to get the person sign a petition, participate in an event, to set up a meeting, etc.

Conclusion

Kind regards

(insert title, your name and name of your organization)

### Template – Thank you note

After having had a meeting with a politician, it is important to keep in contact. First step is to send a thank you letter after your meeting.

Dear Mr./Mrs./Dr.

On behalf of \_\_\_\_ NBC/NAG, we would like to thank you for your participation in **(name of event)** on **(date)**.

Other points to cover in the letter, cf. below;

Short summary (reminder) of the meeting/event

- If it was a round table or similar; shortly describe the conclusions
- Any other important information/what has happened since the meeting
- A quick reminder of the actions/asks from the original letter  
(Further actions)

Kind regards

(insert title, your name and name of your organization)

## Annex 6 – Key Messages to a Wider Audience

### **(National – insert you country) Brain Council (NBC):**

NBC is a unique structure that encompasses a vast network of patients, doctors, scientists and industry that is united around a common vision - *by bringing together science & society, to advance understanding of the healthy and diseased brain in order to improve the lives of those living with brain disorders* (anxiety, brain tumours, chronic pain, dementia, epilepsy, migraine, mood disorders (depression and bipolar disorders), multiple sclerosis, Parkinson's disease, stroke, traumatic brain injury and many others)

NBC is based on 3 pillars (EBC's three pillars used as example):

- Advocate EBC cause on EU & national level
- Coordinate the effort with likeminded stakeholders
- Develop content highlighting "issues" in the three pillars

NBC is member of the European Brain Council and member of the Network of National Brain Councils.

### **The human brain**

The human brain is the seat of our personality, thoughts, feelings and other human characteristics.

When we fall in love, it is with our brain, not our heart. Emotions reside in the brain, stress is when the brain cannot cope anymore, anxiety, lust, aggression and all other human expressions are brain functions.

Brain science has implications for all aspects of us as human beings in determining the society we live in. Brain science focused on learning and memory is absolutely crucial to better education. Preservation of healthy brain function is decisive for the independent living and good quality of life of our older citizens.

The brain is, by far, the most efficient computer ever developed. This small organ has a fantastic capacity for data handling and the study of brain circuitry can teach engineers how to develop better computers in the future.

Given this complexity, it is no wonder that the brain often fails. Both so-called psychiatric (mental) disorders and neurologic disorders are due to disturbances in brain function. Together we call them brain disorders. They:

- affect at least one in three persons during their lifetime – 165 million people in Europe and many more family members or friends who are affected
- cost Europe €798bn a year (more than cancer, CD and diabetes combined)

There is a significant need to increase the awareness of what we now know about the brain and how we can develop, protect and nurture the brain and treat the various disorders which can affect it. It will contribute to leading healthier, happier and more productive lives.

## Annex 7 – How to approach a journalist and maintain the relationship

### Media/journalists

- Identify the target group for a specific event/issue; some events might be relevant to national media, while others will only be relevant to local or specific (e.g. scientific journal) media
- Content of the invitations:
  - o Be specific in you invitation: “Dear ‘Local News’...”
  - o Make at least three different invitations if your are making more general invitations
  - o Do not send the same invite to several media at the same time
  - o Include details in the invitation that will show the media why this is relevant to this specific paper/news channel etc. E.g. case from the local area, numbers from the region etc.
  - o If possible, relate the story to something that the media already has covered
- Get attention
  - o Call to the media –they will probably tell you that you will have to send an email to a certain person – Make sure to prepare by creating ‘pitch points’ so you can ‘sell’ your story quickly and effectively. Calling the media in advance to learn whom to speak to will;
    1. ensure that you get in contact with the right person from the start
    2. create more attention from the start, if the email starts with “as agreed with XX, I hereby send you...”
  - o Write to the journalist personally
  - o Do not send an invitation to both the journalist and the editorial office, if you are in doubt who you should send the invitation to, it is better only to send it to the editorial office
  - o Send a physical invitation, if the invitation stands out it will also create more attention. It is recommendable to send via email and if this can be an HTML email – so the invitation can be viewed in the body of the email rather than a separate attachment – this is usually preferred
  - o Journalists receive many stories every day, just because they do not use your story the first time you contact them, does not mean that you should not contact them again next time you have a story for them
  - o Send out press releases to create attention. However, do not send press releases at the same time on the same weekday, each week. Also, do not send several press releases at the same time

## Annex 8 – How to identify a potential ambassador

### How to find suitable Ambassadors

- When attending events and conferences, if possible approach speakers and participants. Speak to them about being an Ambassador and follow up with the letter below. Ask your network to make recommendations for suitable Ambassadors.

#### **Letter 1 - Request to potential Ambassador**

##### *Opening words from Mary*

The European Brain Council (EBC) seeks to promote brain research in Europe and to improve the quality of life of those affected by brain diseases. The EBC has embarked on a major campaign, the 'Year of the Brain', throughout Europe to raise awareness and societal responsibility for looking after our most vital asset, the brain. We want to seize this opportunity to influence and improve the lives, the health and the future for many millions of people to illustrate that everything we achieve is through the power of the brain and that the brain is at the core of our body's response to all other illnesses. We have held a series of events and have more planned going forward, with each programme addressing ethics, health economics and societal impact.

As part of this initiative, we are recruiting high profile individuals from all walks of life to lend their support and I would like to invite you to become one of our esteemed ambassadors. All we seek is a few lines about what it means to society to protect, preserve, develop and nurture our most vital asset, our brain. Please be assured that we do not require any further input from you; it is your written support that will be so valuable to us.

All endorsements are added to our website which you can view at:

<http://www.europeanbraincouncil.org/year-of-the-brain/>

We would be most honoured if you feel able to accept our invitation as your name will add gravitas to this important initiative.

#### **Letter 2 – If we receive agreement to act as an Ambassador**

Thank you so much for coming back to me so quickly. I am absolutely delighted and honoured you are willing to become one of our esteemed Ambassadors.

We really appreciate your support in lending your name to such an important initiative. It would be an enormous privilege for us if you could prepare a few words about the importance of societal responsibility for looking after our most vital asset, the brain. All quotes will be uploaded on to our Year of the Brain website.

Again, my very sincere thanks for your participation in our campaign; it is highly valued and I look forward to hearing from you.

#### **Letter 3 – Thank you for giving a quote**

My very grateful thanks to you for sparing the time to give us a few words of support. It is enormously appreciated.

Again, my sincere thanks to you for lending your name to our important campaign.



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### Year of the Brain



### A European Brain Council (EBC) Initiative

### Role of Ambassadors

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Following your agreement to become an Ambassador for the Year of the Brain, we would firstly like to say how delighted we are for your support. It is an ambitious and exciting project and we are very appreciative of your generous and vital support.

We are very conscious of how busy you and other ambassadors are and want to make sure that any support you provide is not burdensome to you and fits with your schedule.

We would like to work through specific opportunities with you as and when they arrive. However, the activities are likely to include one or more of the following:

#### **General endorsement**

This would involve providing support to the Year of the Brain through the use of pre-drafted quotes and testimonials as well as the use of your name and/or photograph as an official Ambassador.

#### **Features and editorial**

We anticipate the Year of the Brain will generate considerable media interest and we would very much like to work with you to develop specific features and editorial regarding your involvement with the campaign. This would be done by one of our journalists interviewing you and then agreeing the final copy before being placed in the media.

With very significant media, we may ask if you would have a chat with a journalist. We would never do this before gaining your agreement and at a time which would suit you. We would also agree, prior to the interview, the nature of the interview and the topics to be covered.

**Generating additional Ambassadors**

We would also be very appreciative if you could refer us to other high profile people whom you believe would be appropriate and may be interested in becoming part of this campaign. The introduction could be the use of your name and we approach them or if you could approach them initially and then we make direct contact.

Mary Baker MBE  
President, Year of the Brain  
European Brain Council

## Annex 10 – Program for Brain Ambassador Day



**BELGIAN BRAIN AMBASSADORS DAY**  
**10th Anniversary Meeting of the BBC**  
**Tuesday March 17th 2015 – Egmont Palace, Brussels**

**WELKE TOEKOMST HEEFT HET HERSENONDERZOEK IN BELGIË?  
QUEL AVENIR POUR LA RECHERCHE SUR LE CERVEAU EN BELGIQUE ?**

**15:00-15:15 Séance d'Ouverture / Openingszitting**  
- *Introduction / Inleiding: Johan Raï, Moderator*  
- *Mot de bienvenue / Welkomstwoord: Dr. Daniel Bacquelaine, Ministre des Pensions*  
- *"10 jaar Belgian Brain Council": Dirk Van Roost, Voorzitter Belgian Brain Council*

**15:15-15:30 Hersenonderzoek in België:  
vragen en verwachtingen van de patiënt en zijn omgeving.**  
*Paul Arteel, Executive Director, GAMIAN Europe*

**15:30-15:35 Témoignage/Getuigenis de/van Salvatore ADAMO**

**15:35-16:00 La recherche sur le cerveau en Belgique:  
constats et pistes de réflexion**  
*Jean Schoenen, Membre-fondateur et trésorier du BBC*

**16:00-16:15 Public-private partnership in brain research**  
*Michel Goldman, Executive Director, Innovative Medicines Initiative*

**16:15-16:30 Pauze / Pause**

**16:30-17:00 De Belgian Brain Ambassadors aan het woord**  
*Jacques Brotchi, Geert Dom, Steven Laureys, Gustave Moonen, Christine Van Broeckhoven*

**17:00-17:45 Débat: Grand temps pour une stratégie commune?  
Panelgesprek: Hoog tijd voor een gemeenschappelijke strategie?**  
*Charles van der Straten Waillet, Véronique Halloin & Elisabeth Monard (tbc),  
Didier Malherbe, Jo De Cock/Ri De Ridder (tbc), Gianni Franco, Jean Schoenen*

**17:14-18:00 Conclusions: Maggie De Block / Elke Sleurs (tbc)**

**18:00-19:00 Cocktail**

**YEAR OF THE BRAIN  
2015  
EUROPE**

Registration: free but MANDATORY at [www.belgianbraincouncil.be](http://www.belgianbraincouncil.be)  
Deadline for registration: March 11, 2015  
Editeur responsable: Roland Pochet, Secrétaire Général du BBC

# Annex 11 – Example of a leave-behind leaflet



## The Belgian Brain Council. What for?

<sup>1</sup>Roland Pochet\*, <sup>2</sup>Jean Schoenen, <sup>3</sup>Dirk Van Roost, <sup>4</sup>Rufin Vogels, <sup>5</sup>Charles van der Straten, <sup>6</sup>Gianni Franco, <sup>7</sup>Lia Le Roy, <sup>8</sup>Bart Stulens, <sup>9</sup>Chris Baeken, <sup>10</sup>William Pitchot

<sup>1</sup>U.L.B., <sup>2,10</sup>Ulg, <sup>3,9</sup>UGent, <sup>4</sup>KULeuven, <sup>5</sup>Multiple Sclerosis Liga, <sup>6</sup>EpiC, <sup>7</sup>Hersentumoren, <sup>8</sup>Medtronic, <sup>9</sup>VUB

BBC aims: To improve the quality of life of persons living with neurological and mental disorders to raise awareness of this subject to stimulate research to foster exchange between the different disciplines and associations, to lobby government for enhancing research and treatment

Why is BBC needed?: To speak with one voice to be strong enough to influence policy makers and budget holders at the national level, to act at national research programs. BBC is the best bottom instruments to contribute to the alignment of National research policies to EU policies

### BBC members

### Total yearly cost of brain disorders in Belgium (2010)

All brain disorders: 18,396 million € (1,672 €/inhabitant/year)

42% increase over 6 years

### Yearly costs of diseases in Europe (2010)

800 Billiards € (Neuropsychiatric diseases)

170 Billiards € (Cardiovascular diseases)

### Disability due to brain disorders (WHO-QALY)

Brain disorders: 44%

Other diseases: 35%

Research budgets: 10-15% of medical research!

### Public funds for brain research per inhabitant (€ per capita)

<1€ /inhabitant

FWD-PHRS figures: 0.9€ /capita

### Pharma withdraws from Brain Disorder program

Table 1. CNS Program Portfolios in Large Pharma: 2009 versus 2014

	2009	2014
Total Programs	267	129 ↓ 52%
Abbott/AbbVie	17	10
AstraZeneca	21	7
Bristol-Myers Squibb	12	2
GlaxoSmithKline	40	14
Johnson & Johnson	18	17
Lilly	16	9
Merck/Schering-Plough	32	7
Novartis	14	15
Pfizer/Wyeth	48	15
Roche/Genentech	22	21
Sanofi/Genzyme	29	12

### Brain Research is highly profitable!

NIH-sponsored clinical trials (phase III) over 10 years (neurological disorders – stroke)

Cost: \$ 3.6 billion

Quality-adjusted life years (QALYs): ± 470,000

1 QALY = \$ 40,000

Value gained = \$ 18.8 billion

Net benefit to society = \$ 15.2 billion

Annual return = ± 50%

### CONCLUSIONS: BBC is a pluridisciplinary platform gathering researchers, clinicians, patients and pharma industry which has a key role to play at the national level

### The MICX: Our next BBCongress MONS, Oct. 8, 2016

## Annex 12 – Guidelines on how to organise an EBC/NBC event(resource demanding) – Belgian Brain Council; 2014 event

### Programme

09.00 – 10.00	<b>Main Auditorium</b> <b>PLENARY SESSION 1</b> (chairpersons: R. Vogels, J. Schoenen)  <b>ELECTRICAL NEUROMODULATION</b>	
09.00 – 09.30	<b>Mechanisms of action of invasive neurostimulation</b> Georgios A. Keliris, Tübingen	
09.30 – 10.00	<b>Mechanisms of action of non-invasive neurostimulation</b> Walter Paulus, Göttingen	
10.00 – 11.00	<b>Forum</b> <b>POSTER Session 1</b>  Exhibitions, Coffee	<b>Breakout room Van Eyck</b> <b>Satellite Symposium 1</b> Neurotransmitter imaging: a tool for detecting and monitoring brain modulation (General Electric)
11.00 – 12.40	<b>Breakout room VanderGoes</b> <b>TOPICAL SESSION 1</b>  (chairpersons: P. Santens, S. Henri)	<b>Breakout room Van Eyck</b> <b>TOPICAL SESSION 2</b>  (chairpersons: K. Audenaert, R. Müller)
11.00 – 11.20	<b>Movement disorders</b> Alain Maertens de Noordhout, Liège	<b>Obsessive compulsive disorder</b> Bart Nuttin, Leuven
11.20 – 11.40	<b>Epilepsy</b> Dirk Van Roost - Paul Boon, Ghent	<b>Depression</b> Chris Baeken, Ghent-Brussels
11.40 -12.00	<b>Pain</b> Benoît Pirotte, Brussels	<b>Consciousness disorders</b> Steven Laureys, Liège
12.00 – 12.20	<b>Tinnitus</b> <b>CANCELLED</b> Dirk De Ridder, Antwerp	<b>Stroke</b> Yves Vandermeeren, Mont-Godinne
12.20 – 12.40	<b>Headache</b> Delphine Magis, Liège	<b>Addiction</b> Jürgen Voges, Magdeburg
12.40 – 14.00	<b>Forum</b> <b>POSTER Session 2</b>  Exhibitions, Lunch	<b>Breakout room Van Eyck</b> <b>Satellite Symposium 2</b> Deep brain stimulation at an earlier stage of Parkinson's disease (Medtronic SA/NV)
14.00 – 15.00	<b>Main Auditorium</b> <b>PLENARY SESSION 2</b> (chairpersons: W. Fias, J. De Keyser)  <b>BEHAVIOURAL NEUROMODULATION</b>	

- 14.00            **Critical appraisal of cognitive enhancement**  
Nicole Wenderoth, Zürich
- 14.30- 17.00    **Forum**  
Exhibitions, Coffee
- Breakout room VanderGoes**  
15.00 – 16.00  
**Satellite Symposium 3**  
OnabotulinumtoxinA as a biologic neuromodulator – motor effect ok, but a sensory effect? (Allergan)
- Breakout room Van Eyck**  
15.00 – 16.30 **Medico-Social Workshop Ethics, economics and quality of life in neuromodulation anno 2014-Year of the Brain.**  
Chairpersons: Mary Baker (Past-President European Brain Council) and Gianni Franco (EplC-Together for the Brain)
- 16.30 – 18.00    **Main Auditorium**  
TOPICAL SESSION 3:  
(Chairpersons: A. Ivanoiu, G. Moonen)
- 16.30 – 16.50    **Hypnosis**  
Marie-Elisabeth Faymonville, Liège
- 16.50 – 17.10    **Cognitive revalidation**  
Steve Majerus, Liège
- 17.10 – 17.30    **Neurofeedback**  
Bettina Sorger, Maastricht
- 17.30 – 17.50    **Cognitive training in depression**  
Rudi De Raedt, Ghent
- 17.50 – 18.20    PLENARY SESSION 3  
**Perspectives in neuromodulation**
- Optogenetics**  
Wim Vanduffel, Leuven-Boston
- 18.20-18.30    **Poster Prizes**
- 18:30 – 19.30    **Farewell cocktail & Musical Neuromodulation.**

For last minute changes, please consult the website:  
<http://www.belgianbraincouncil.be/congress2014/index.html>

15.00 – 16.30

**Medico-----Social Workshop: Ethics, economics and quality of life in neuromodulation anno 2014-----Year of the Brain.**

CHAIRS: Mary Baker (Past-----President European Brain Council) and Gianni Fran (EplC-----Together for the Brain)

**Breakout room Van Eyck**

(Co-----chairpersons: L. Leroy ----- Werkgroep Hersentumoren, M. Mormal ----- Alzheimer Belgique, Ch. van der Straten Waillet ----- National Belgian MS League, A. Dechamps ----- Parkinson Association)

**HOW CAN NEUROMODULATION IMPROVE QUALITY OF LIFE?**

**Bruno KASCHTEN**, Neurosurgeon (ULg), President Belgian Society for Stereotact and Functional Neurosurgery

**SOCIO-----ETHICAL, ECONOMICAL AND POLITICAL POINTS OF VIEW.**

**Serge GOLDMAN**, Neurologist (ULB).  
**Ignaas DEVISCH**, Philosopher (UG)  
**Dominique JACQUEMIN**, Ethics (UCL)  
**Jo VANDEURZEN**, Flemish Minister for Welfare, Public Health and Family  
**Monica DE CONINCK**, Federal Minister of Employment

**THE REALITY OF LIFE IN BELGIUM**

**R. DERIDDER**, General Director, INAMI-----RIZIV

**DEBATE** with the assembly, only via questions from the floor (collected before the meeting on paper sheets)

**Satellite** General Electric Healthcare  
**Symposium 1**

**Breakout room Van Eyck**

**10:00– 11.00** **Neurotransmitter imaging: a tool for detecting and monitoring brain modulat**

Welcome and introduction by Dr. Marie-Agnès Oliva, Medical Director, GE Healthcare

1) 10 years of Datscan® ioflupane (<sup>123</sup>I) in Belgium

Interactive session between a neurologist and a nuclear medicine physician on specific clinical cases.

Chair: Pr. Adrian Ivanoiu, UCL

By Pr. Koen Van Laere (KUL) and Dr. Michel Goncè (CHR Liège)

2) Early Diagnosis of Alzheimer's disease, contribution of amyloid plaques imaging.

Presentations of last development and data on amyloid PET imaging.

Co-chaired by By Pr. Koen Van Laere (KUL) and Dr. Michel Goncè (CHR Liège)

By Pr. Adrian Ivanoiu (UCL)

**Satellite** Medtronic SA/NV  
**Symposium 2**  
**Breakout room Van Eyck**

12:40 – 14.00 ***Deep brain stimulation at an earlier stage of Parkinson's disease***

CHAIR: Michel Goncè (CHR Liège)

- 1) *DBS: 25 years later, more than 110.000 patients QoL improved (Patrick Santens, UZ Gent)*

Overview of mechanism of action and key clinical studies  
Video cases of DBS from various indications

- 2) *Early DBS in PD: who can potentially benefit and how? Prof Schüpbach (Bern, Switzerland)*

Earlystim study overview  
Patient selection – EARLYSTIMULUS  
The future of Deep Brain Stimulation

Case-----based presentations and interactive discussion with audience.

**Satellite** Allergan SA/NV  
**Symposium 3**  
**Breakout room VanderGoes**

15:00 – 16.00 ***“OnabotulinumtoxinA in the neurologist's patients – not only motor effects, but also sensory effects ?”***

CO-----CHAIRS : Prof K. Paemeleire (UG) & Prof J. Schoenen (Ulg)

*Introduction: Chronic Migraine recommendations of the Belgian Headache Society*  
*Jean Schoenen (Ulg)*

*1) Science of onabotA's neuromodulating mechanism of action: an accepted motor effect but a surprising sensory effect ?*

*Oliver Dolly (Dublin, IRL)*

*2) OnabotA neuromodulation in clinical management of chronic migraine symptoms.*

*Michel Vandenheede (CHC Liège)*

*3) OnabotA neuromodulation in clinical management of chronic post-----stroke symptoms.*

*Kristine Oostra (UZ Gent)*

## Annex 13 – EBC/NBC Resource Demanding Event – Belgian Brain Council template

### **NBC biennial conference template**

#### TIME LEFT BEFORE THE CONFERENCE

##### 20 months :

- Date : one day meeting on a Saturday (because of clinicians)
- Location : meeting place with a large forum hall allowing to gather :
  - The scientific posters (define the size of the posters according to the size of the support)
  - The (permanent) coffee distribution with high table
  - The Patient association booths
  - The Pharma/Devices companies (size variable according to the sponsoring)
- The choice of a thematic topic (i.e. The gene-environment tango in treatment resistance, sleep disorders and MS has been chosen for the 2016 BBCongress)

##### 17 months:

- Composition with task description of the organizing committee made of chair, fundraiser, treasurer, abstract selection committee (3 persons), patient organisation liaison, industry liaison, poster conference designer, catering, jobsite (trainee) and audio technician
- Session choice
- Session chairs nomination
- WEB page : a) Pre-announce of the meeting, b) adaptation for the on line registration

##### 15 months

- Speakers invitations
- Agreement on the conference poster design
- Printing of the conference posters

##### 12 months

- WEB page :
  - Announce of the conference
  - Programme with speakers
  - Abstracts on line
  - Registration on line with registration fee (payment via credit card, paypal, bank transfer)
- Spreading of the poster, the conference programme, abstract submission and registration amongst all the stakeholders

##### 8 months

- Revised budget
- Distribution of plan for patient booths, for poster location and pharma/industry booths

6 months

- Registration survey
- Re-difusion amongst the stakeholders
- Online Abstract submission with rules and deadline
- First request for abstracts to speakers

10 WEEKS

- Budget
- Deadline for abstract submission
- Translation of the abstract for lay people in the national language

8 weeks

- Last recall for speakers abstract
- Translation follow-up

4 weeks

- Emailing recall to all stakeholders
- Abstract book formatting

2 weeks

- Emailing recall all stakeholders
- Abstract book printing

1 week

- Closing of the online registration
- Printing of badges

## Annex 14 – Guidelines on how to organise a YotB event(resource demanding event)

Below is an example of an event done by the Bulgarian National Brain Council. This event was branded with the EBC and YotB logo and had guest speakers from the EBC.

### Event outline proposal

1st Bulgarian EBC Symposium in Sofia

#### How to position the event:

The objectives of the meeting were to present the challenges and opportunities that Bulgarian neurology, neurosurgery, psychiatry, patients and business have to face in this period of economic crisis. All aspects will be interpreted in the framework of the European perspectives.

#### Why:

Our aim was to bring together all the stakeholders with the experienced and knowledgeable support of the EBC for passing around the message of the initiative “2014 - Year of the Brain” in Bulgaria:

- to raise the public awareness and educate the society about how to protect our brain and about the economic burden of brain diseases;
- to improve treatment and care for those affected by brain disease by sending a clear message about the urgent need of prioritizing of brain disease in the national health systems;
- last but not least, we hope to advocate for increased funding for basic research into the brain.

-The speakers bring their expertise and international reputation to support the Bulgarian National Brain Council in the name of this important cause.

#### Program:

A snapshot of the program will provide you with inspiration as to the type of stakeholders to invite to a similar event:

From	To	
08:00	09:30	<b>Registration</b>
09:30	09:40	<b>Syposium opening and welcome</b>
09:40	10:00	Prof. Mary Baker <i>Societal and Health Challenges in Europe</i>
10:00	10:20	Dr. Diana Indjova <i>Protection, legislation and services for people with mental disabilities</i>
10:20	10:40	Prof. Marin Marinov <i>Neurosurgery in Bulgaria - opportunities and challenges</i>
10:40	11:00	Prof. Vihra Milanova <i>Psichiatry in Bulgaria - past, present and future. Opportunities and challenges</i>
11:00	11:20	Corr. Member Prof. Ivan Milanov <i>Neurology in Bulgaria - recent advancements, challenges and opportunities</i>
11:20	11:40	Prof. Roland Pochet

		<i>The Belgian brain council: the National Brain Council leader</i>
11:40	12:20	<b>Coffee break</b>
12:20	12:40	<u>Mrs. Kathy Oliver</u> <i>Out of the shadows: raising awareness of the challenges of brain tumours – the IBTA experience</i>
12:40	13:00	<u>Prof. Albena Jordanova, Assoc. prof. Radka Kaneva</u> <i>Fundamental science in Bulgaria - opportunities and challenges</i>
13:00	13:20	<u>Prof. Ducati</u> <i>Costs analysis of the treatment for drug resistant epilepsy - new technological advancements and opportunities</i>
13:20	13:40	<u>Dr. Krasimir Minkin</u> <i>Organization of the deep brain stimulation of the subthalamic nucleus for patients with Parkinson disease</i>
13:40	14:40	<u>Prof. Vladimir Benes</u> <i>Where Do We Come From? What Are We? Where Are We Going? related to neurosurgery</i>
14:40	15:00	<b>Discussion</b>
15:00	16:30	<b>Cocktail</b>

How can your NBC/NAG host a similar event:

One day event bringing together national and European perspective on the field of the brain and its disorders

- ✓ Aim:
  - To present the challenges and opportunities that neurology, psychiatry, neuroscience, neurosurgery, patients and industry are facing – national and European perspective
  - To raise public awareness and educate society about how to protect our brain and about the economic burden of brain diseases.
  - To improve treatment and care for those affected by brain disease by sending a clear message to policy makers about the need to prioritize brain disease in the national health systems
  - To encourage government to address brain disorders in a coherent manner by developing national brain plan
- ✓ Two languages – national + translation to English
- ✓ Free event
- ✓ Funding (Seeking in kind contribution along with pro bono support from PR companies etc. is strongly advised.
- ✓
- ✓ Mandatory registration
- ✓ Draft of scientific programme developed before inviting speakers and audience are invited

- ✓ A letter of intent/invitation sent to the potential speakers
- ✓ Website
- ✓ Defining target audiences (policy makers, scientists, clinicians, patients, media)
- ✓ Sending invitations
- ✓ Reaching out to media (if possible with a pro bono help from a PR agency)
- ✓ EBC can provide support with:
  - Facilitating the contact with potential international speakers
  - Facilitating the contact with industry
  - Providing EBC speaker

## Annex 15 – Guidelines on how to organise a YotB event (less resource demanding event)

### Less resource demanding event: Year of the Brain ‘lecture’ – Event outline proposal

#### How to position the event:

##### Why:

The European Brain Councils Year of the Brain (YotB) initiative has three key aims:

1. To educate society about how to nurture and protect the brain and prevent brain disease
2. To improve care and treatment access for those affected by brain disease
3. To increase investment in brain-related R&D for the benefit of future generations

The most complex structure in the universe lies inside each and every one of us. It is the human brain; still not fully understood by science, despite considerable progress in recent decades.

As well as providing the basis of our very humanity – our thoughts and feelings – the brain is subject to many disabling diseases. In fact, problems associated with the brain are the leading cause of death and disability worldwide.

General comments: The event can be held at rather low costs, as e.g. many universities are willing to lend out their facilities for free or at a very low cost. In addition to this, many speakers are also willing to participate in such an event for very low costs. At this event, four different speakers were invited to talk about the brain from each of their perspectives; Mary Baker, President of Year of the Brain, a professor of neuroscience, a person who had been held in isolation for almost five years and a now Paralympic skier, who had to change her plans for the future, when she broke her leg as a snowboarder.

#### Proposed program

##### What:

Focus is on the achievements in brain research, and to become aware of the secrets of this most complex of organs. The audience will learn about the science behind the brain; about the brain’s ability to cope in a crisis and about how the brain can help motivate us and enable us to push ourselves to the limits of our physical ability.

##### Proposed Speakers:

- A speaker that can position the ‘**science**’ of the brain
- Followed by 2 speakers that are able to **demonstrate the amazing achievements** of the brain  
e.g.
  - o A survivor’s story: A patient that has overcome a traumatic brain injury or a traumatic experience and their road to recovery
  - o A disabled athlete - that has overcome adversity to compete in competition again (e.g. paralympic athlete)

- Closing Speech - Year of the Brain – NBC representative, Key messages

**Who we have used:**

**Sir Colin Blakemore – Director of the Institute of Philosophy’s Centre for the Study of the Senses, a member institute of the University of London’s School of Advanced Study, Emeritus Professor of Neuroscience at the University of Oxford**

“Understanding how the brain works is the greatest remaining challenge for science. And brain disorders are the greatest challenge for society in the 21st century. The Year of the Brain is aimed at raising awareness of the vital importance of brain research.”

**Terry Waite CBE - Special envoy of the Church of England in the 1980s, to negotiate the release of hostages held by Hezbollah militants in Lebanon. Held hostage himself from 1987-1991.**

“Many years ago I spent almost five years in strict solitary confinement. During that time I had no contact whatsoever with the outside world and for years was denied books and papers. It was then that I realised how important it was to keep my mind active and alert in order to maintain both physical and mental health. I would add my support to the ‘Year of the Brain’ as from personal experience I recognise how vital it is that we understand the workings of this complex organ more fully.”

**Anna Turney – Paralympic Skier**

In 2006 Anna broke her back snowboard racing, pushing herself at what she loved best. Determined not to be defeated, Anna decided to become a Paralympic Ski Racer.

**Dr Mary Baker, MBE – President, Year of the Brain**

We need to demonstrate to society, the importance of ‘protecting, preserving, developing and nurturing our most vital asset – the brain’

**Timings:**

**Allow 5 minutes** - for welcome speech (cover health and safety, fire exits and ask for mobiles to be switched off!)

**Allow 20 minutes** - for each of the key speakers

**Allow 10 minutes** – for Question and Answer session

**Allow 5 minutes** – for closing speech

Offer the opportunity for the audience to come and meet the speakers and have photos taken.

**Other things to consider:**

- Venue/capacity
- Timings (we have run these as an evening event, which works well : 6.00 – 8.30)
- Follow the event with a reception for VIPs?

- Partnerships – we have run these events in partnership with Universities, which works very well as you have the venue, audience and even potentially accommodation for speakers all available to you
- Promotion – if using a university, via their website and also the Year of the Brain website
- You might like to consider appointing a chair for the event to help the overall flow. (A well known name will add gravitas).
- Budget considerations– venue costs, accommodation as necessary, speaker fees, chair fees
- Issue expenses guidelines to all your speakers ahead of the event
- Issue a speaker release form to be signed and returned prior to the event – which authorises you to record and photograph speakers and covers you for use on social media sites e.g. Twitter.

## Annex 16 - Communication guidelines – general steps to be considered

Below you find some general steps that needs to be considered carefully when you create your communication strategy:

- Define target audience (see stakeholder map)  
e.g.  
General target audience:  
Members
  - CEOs, presidents, management – show them what we are doing/that we are pleasing their interests
  - Communication departments etc., who can use the information to contact us for further cooperation

### Meetings and events

Identify key stakeholders and targets. For each target, develop a short overview of goal of contacting this person. After the event/meeting follow up: what the target meet?

- Meetings
- Events that we participate in
- Events arranged by us
  - budget

### Communication materials

- Tools (examples from EBC)
  - EER
    - A weekly, overview of the most important events, only for members (i.e. this is a service we provide and that the members appreciate according to their feedback)
      - Goal of this specific publication? – provide a service
      - Target audience - members
  - EBCnews
    - A physical magazine that can be given to people at conferences etc., catch people's attention
      - Goal of this specific publication?
      - Target audience
  - Newsletter
    - Online, bi-weekly newsletter, distributed to +1000 emails,
      - Goal of this specific publication? Awareness about our organization and our goals
      - Target audience
  - Social media
    - Twitter: Online forum to interact and share current event
      - Goal?
      - Target audience
      - Should other social media accounts be added, e.g. Facebook?
  - Fact sheets/Leaflet

- Short information material, that can be given out at conferences and meetings
  - Goal
  - Target audience
- Homepage
  - Step 1 – obtain a domain name
  - Step 2 – define goal and target audience of the homepage
  - Step 3 – Create an overview of the content of the homepage
  - Step 4 – Ensure a process is in place so that the homepage is regularly updated
- Measurability
  - Readers
  - New subscribers
  - Reactions
  - Funding