

4th Academy Meeting of National Brain Councils

17th-18th April 2018

Champalimaud Foundation, Avenida Brasília, Lisbon

Minutes of the Meeting

17th April

Present: Andjus, Pavle (Serbian Brain Council) - Boyer, Patrice (European Brain Council) – Czarnecka, Izabela (Polish Brain Council) - Destrebecq, Frédéric (European Brain Council) – Freire, António (Portuguese Brain Council) - Hawrot, Tadeusz (European Brain Council) Kvalbein, Aud Johanne (Norwegian Brain Council) - Mauguière, François (French Brain Council) - Pochet, Roland (Belgian Brain Council) – Radovanović, Saša (Serbian Brain Council) - Scholte, Marijn (European Brain Council) – Sotiropoulos, Ioannis (Greek representative) – Storstein, Anette (Norwegian Brain Council) - Trejo, Jose Luis (Spanish Brain Council)

Setting the scene and progress update, including European Brain Research Area project application and EU Framework Programmes - *Frédéric Destrebecq*

Highlights from the presentation:

- A summary of the outcomes of the event “Expanding Brain Research in Europe: Education, Behaviour and Brain Development”, organized by the European Brain Council (EBC) in Strasbourg against the backdrop of Brain Awareness Week (BAW) 2018, was presented. It was underlined that the three hosting MEPs, Anne Sander, Daciana Sârbu and Lieve Wierinck came out in favour of continuing support for neuroscience and research as well as further empowering brain researchers to communicate the results of their work to the general public.
- Some of the main conclusions of the EBC consensus statement on “the need to expand brain research in Europe” were presented, such as the need to tackle brain health in an integrated manner, increase support of basic and clinical research and accelerate translation of basic research into tangible solutions.
- A short overview of EBC’s activities carried out within the Good Off-Label Use Practices (GOLUP) framework was presented, which include the national workshop organized in Rome on 13th December 2017 and a recent interview held with main GOLUP-author Prof. Marc Doms. Additionally, it was highlighted that the Spanish Brain Council, in cooperation with EBC, will hold a workshop in Madrid on 25th April that aims to raise awareness of the 5 GOLUP criteria and facilitate dialogue on challenges related to the practice of off-label use in Spain.
- An outline of EBC’s advocacy towards the next EU Research and Innovation programme was provided. It was highlighted that EBC aims to work towards a proposal for a mission related to the brain and that the need to understand and enhance the brain by 2030 was included as a potential mission “Lab - Fab - App” report drafted under the leadership of Pascal Lamy.

Discussion:

- F. Destrebecq underlined that by applying to the Horizon 2020 call “Coordinating European brain research and developing global initiatives”, EBC aims to build a platform through which large brain-related initiatives can collaborate which will reduce fragmentation and unnecessary duplication. He explained that the platform will establish clusters in areas of unmet need and that National Brain Councils will have a key role to play in disseminating initiatives related to the project.
- Following the example of the Lisbon Academy meeting, which happened for the first time outside Brussels, F. Destrebecq highlighted that the hosting city of the Academy Meeting of NBCs of 2019 still needs to be chosen and that EBC is open for expressions of interest from NBCs that could support the organization of the next Academy Meeting.

National Brain Plans - case study based on the Norwegian Brain Plan launched in December 2017 and update from Poland - *Anette Storstein, Aud Kvalbein, and Iza Czarnecka-Walicka*

Highlights from the presentation:

- It was underlined that, as a result of lobbying efforts of patient organizations, the Norwegian Parliament made a formal request to launch a national brain strategy in autumn 2015.
- A short presentation on the need for a Norwegian Brain Strategy was made. As such, it was highlighted that issues associated with brain disorders are undervalued, underestimated and underfinanced. However, it was noted that there is an increasing public interest in Norway in diseases that affect the brain.
- It was explained that Norwegian cancer strategies were taken into account when working towards launching a Norwegian Brain Plan. Slogans addressing the burden of cancer became very popular and successful in Norway. In view of this, the idea surfaced to develop similar slogans for addressing brain health.
- It was highlighted that the Norwegian Brain Council aimed to establish a brain plan with a focus on 4 issues in particular, namely high-quality research, good clinical practice, education of competent professionals and patient participation.
- The Norwegian Prime Minister announced the forthcoming brain strategy in May 2017. During the months that followed, the Norwegian Brain Council worked closely with health bureaucrats in order to support its development. It was highlighted that keeping health officials close was key for sustaining the work on the strategy.
- The Brain Health Strategy, presented in December 2017, revolved around four objectives:
 - Good life-long brain health prevention and quality of life
 - Health care service tailored for the needs of the user and caretakers
 - Good health care from onset, diagnosis and treatment to habilitation and rehabilitation, given that most brain diseases affect patients for life
 - Adequate knowledge and quality through research and innovation, which serves as the platform on which the other objectives are built

- It was explained that one of the current main challenges is to implement the strategy. In view of this, it was highlighted that it was considered important to keep pressuring the Norwegian government and hold ministers accountable for what happens in the coming 6 years.
- It was highlighted that in working towards a Polish Brain Strategy, an approach similar to managing a project was contemplated and that it was important to keep in mind that few public funds were available.

Discussion:

- P. Boyer highlighted that psychiatrists are likely to be reluctant to endorse a strategy that only focusses on the brain, and that most psychiatrists will say that psychiatry is connected to mind and brain. They will argue that brain is mind and mind is brain. Furthermore, he underlined that, in order to successfully develop national brain plans, psychiatrists need to be convinced that there is much to gain by joining these brain-related programmes.
- T. Hawrot underlined that EBC was pleased to witness the development and presentation of the first brain plan and that the Norwegian model brings many important elements together.
- A. Storstein explained that the importance of specialist care is undervalued in the current strategy and highlighted that, if she would work on the strategy again, she would make sure that specialist care is emphasized better.

Questionnaire on the state of national brain health care - Roland Pochet

Discussion:

- F. Mauguière underlined that he was in favour of circulating the survey and that it would be advantageous if a consensus could be reached on 5 aspects or issues that could be addressed in all countries.
- R. Pochet highlighted that all delegates should be aware that communication between EU and national level does not exist.
- P. Boyer explained that there is a connection between decision-makers at the level of Heads of State, and that they can be conveyed via their advisors.
- A. Storstein underlined that surveys are important and that the NBCs should continue on this track. Additionally, she mentioned that it would be beneficial if NBCs continue to talk to their national politicians and meet on a regular basis in order to share knowledge.
- F. Destrebecq confirmed to move forward with the survey.

Value of Treatment – general update, dissemination and future plans - Patrice Boyer

Highlights from the presentation:

- It was explained that there is no limit to the number of case studies that can be selected, as long as they meet the 3 project criteria.
- The overall objective of the Value of Treatment (VoT) case studies, i.e. providing policy recommendations on how to provide optimal care in the disease areas under study by addressing the current treatment gaps, was presented as well as the 3 specific objectives:

- Identify the current treatment gaps and patient needs along the care pathway and analyse the underlying causes & Identify/propose solutions addressing the them
 - Evaluate the costs and burden associated with the treatment gaps and the socio-economic impact of closing/reducing them by applying the solutions identified/proposed
 - Propose policy recommendations on how to improve the care pathway
- It was highlighted that the VoT study identified clear gaps for diagnosis and treatment, which varied between disease areas.
- It was explained that the main VoT publications, among which the VoT White Paper and the Poster Booklet, were distributed at various congresses in 2017, such as the 27th Alzheimer Europe Conference, the European Alliance for Personalized Medicine (EAPM) and the 11th European Headache Federation Congress.

Discussion:

- F. Mauguière highlighted that he considered it important to disseminate up-to-date information about the outcomes and recent developments related to VoT. What is more, he highlighted that cooperating with the specialized groups is key in sustaining the participation of NBCs in the VoT study.
- F. Destrebecq announced that EBC now has the opportunity to acquire additional resources to support VoT dissemination at national level. Additionally, he highlighted that this currently concerns specific disease areas, though funding opportunities in other therapeutic areas may present themselves in the future.
- F. Mauguière highlighted that many experts involved in VoT are primarily working for their own societies.

Discussion - proposed topics include: elections of NBC delegates to the EBC Board, progress updates from NBCs and possibility of organizing regional NBCs meetings (e.g. Nordic region)

Discussion:

- F. Destrebecq explained the election procedure: two delegates and two deputies were to be elected from the representatives of the NBCs
- F. Mauguière announced that he was willing to continue as delegate if the attendees wanted him to continue. Though he highlighted that the election provided an opportunity to select a delegate from a different country.
- P. Andjus and F. Mauguière announced their interest to continue as delegate.
- R. Pochet and J.L. Trejo announced their interest to continue as deputy.
- No other representatives announced their interest to run for delegate/deputy, therefore all candidates were elected by acclamation.
- J.L. Trejo suggested to organize the next Academy Meeting of NBCs in Spain. When responding, F. Destrebecq highlighted the need to prioritize Brain Councils on the basis of the EU presidencies.

18 April

NBCs and EFNA held a joint meeting which will be reported on in a separate document.