

Meeting with [REDACTED] of the European Brain Council and [REDACTED]

Brussels, 10 December 2019, 12:00-13:00, CAB Room

Scene setter

You will meet with [REDACTED] the **European Brain Council**, and [REDACTED] of the European Brain Council. [REDACTED] E2 (Combating Diseases) of DG RTD, will also be present at this 1-hour meeting.

Brain conditions include neurodegenerative diseases like Alzheimer's disease, neurological / mental disorders like depression and addiction, and traumatic brain injury. Taken together, they are the **leading cause of disability in Europe** with an estimated **179 million Europeans affected** by such conditions and an estimated cost of €800 billion per year to treat/alleviate them. This high burden is not limited to patients, but also shared by their families, carers and the healthcare systems. Noteworthy, there is also **gender dimension** to some brain conditions where, for example, women have a higher risk to develop Alzheimer's disease.

The European Brain Council is a non-profit organisation **representing key actors in the brain area**, namely scientific societies, patient organisations, healthcare professional societies and industry partners. Its main mission is to promote brain research and it has the ultimate goal of improving the lives of Europeans living with brain conditions.

The **European Brain Council would like to** (1) **raise awareness** that brain diseases and disorders are the leading cause of disability in Europe and worldwide with a huge socio-economic burden that will likely continue to grow driven by an ageing population; (2) emphasize the importance, value and urgency of basic and clinical **research on brain health**, as there is a limited understanding of underlying mechanisms and a high failure rate in the development of therapeutics that has led to industry having largely withdrawn from the brain area (particularly the neurodegenerative disease area); and (3) explore possible **support by the Commission** for brain research in the current and particularly upcoming Framework Programme.

The European Brain Council has been a constructive and active interlocutor for the Commission. It is currently leading the EU-funded European Brain Research Area (**EBRA**) **project** whose partners are the main European brain research players, namely the EU Joint Programme on Neurodegenerative Disease Research (JPND), the Network of European funding for Neuroscience research (NEURON), and the Human Brain Project (HBP). The main aim of the project is to **promote the coordination of European brain research** and to **develop strategies at global level**.

As with the current research Framework Programme (Horizon 2020), funding strategies in the upcoming health cluster of Horizon Europe will be developed for non-communicable diseases as a whole, and not at the more granular disease level. Therefore, the **budget is usually not allocated specifically to diseases**. However, as cancer has been singled out for the health-related mission, this has prompted concern in the brain research community. As such, the European Brain Council will be looking for **reassurance that brain research will remain a strategic priority area in Horizon Europe and in future policies of the EU**. With regard to this, note that brain research funding in Horizon 2020 (€3.2 billion with a year to go; rate of €600 million/year) has

increased compared to the previous Framework Programme (FP7, €3.1 billion; rate of €400 million/year).

The brain research community have also concerns with the **partnerships** under Horizon Europe. The process to rationalise the partnership landscape together with **insufficient support by Member States**, makes it likely that there will be no brain-related partnership in the first strategic programme. However, it could be foreseen in the second phase of Horizon Europe, while in the meantime Horizon 2020 can still provide brain research support for a number of years.

Objectives

- Inform that the health cluster of Horizon Europe has six main areas of intervention, (“Health throughout the life course”, “Environmental and social health determinants”, “Non-communicable diseases”, “Infectious diseases”, “Tools, technologies and digital solutions for health and care” and “Health care systems”), which are well-aligned with the priorities of the European Brain Council.
- Highlight the EU’s aim to continue to support health research in Europe, including brain research, and to foster better coordination and develop strategic international cooperation; Reinforce the role of the European Brain Council in these endeavours.
- Stress the importance to build an ambitious brain research partnership providing new impetus for comprehensive Member State-led initiatives.
- In particular, encourage the European Brain Council to engage further with patients and citizens, and to translate research results into guidelines.
- Stress the importance of securing an ambitious research and innovation budget for Horizon Europe, which would strengthen EU support to brain research.

Lines to take

- Recognise the importance of brain diseases as the leading cause of disability in Europe and worldwide, as well as the great burden it imposes on patients, families, carers and healthcare systems.
- Acknowledge that the road from research results to their translation into clinical practice is particularly long in the brain area owing to its complexity, and that learned societies like the European Brain Council have an important role in reducing this time.
- Underline that despite the non-disease focussed approach to EU funding, brain research has been increasing from FP7 to Horizon 2020, and currently stands at a rate of €600 million/year.
- Recall that the EU also counts on the EU-funded European Brain Research Area (EBRA) project, which is being led by the European Brain Council, to structure research in Europe and to develop strategic international initiatives.
- Acknowledge that EU priorities in non-communicable disease research are well aligned with the scientific priorities and enabling activities proposed in the Strategic Research Agendas of the key European brain research players. These include the development of personalised medicine approaches, clinical research focussed on prevention, early diagnosis and treatment or disease-modifying strategies, and assistive digital technologies.
- Get support from the European Brain Council to develop an ambitious brain research partnership.
- Update on the cancer mission with its strong focus on prevention, which will address risk factors common to all non-communicable diseases.

Background notes

1. The European Brain Council (EBC)

The European Brain Council is a coordinating council formed by European organisations in neurology, neurosurgery, psychiatry, basic brain research, as well as patient organisations and industry. It therefore represents a vast network of patients, doctors and scientists, and these stakeholders along with its industrial partners make it well-suited to work in close partnership with the European Commission and Parliament, national governments and other policy-making bodies.

EBC continues to make efforts to quantify the societal cost of brain conditions in Europe and to identify research priorities, which are usually well aligned with EC views. It frequently refers to the estimate that **1 in 3 Europeans are set to live with a brain disorder** within their lifespan and that treating **brain conditions accounts for 35% of Europe's total disease burden** with a **yearly cost of €800 billion**.

EBC advocates for more 1) basic, clinical and translational research on, for example, prevention or the use of biomarkers in identifying patients with brain disorders as early as possible; and 2) policy implementation research at healthcare level where, for example, health system evaluations can identify impactful interventions, which can then be replicated in other settings.

Two key EBC papers: In line with its mission on “advocating for brain research in Europe”, the EBC published in 2016 the third edition of its “*Consensus Paper on Brain Research in Europe*”¹. A year later (2017) the EBC published a Policy White Paper on the “*Value of Treatment for Brain Disorders in Europe*”² aimed at addressing the challenges that arise from the **treatment gap**, which is the lack of treatment for patients with a brain condition. The treatment gap is considered the result of a lack of investment in research and care.

EBC's involvement in Horizon 2020: EBC leads the ongoing Horizon 2020-funded European Brain Research Area (EBRA) project: “*Coordinating European Brain Research and Developing Global Initiatives*” with the aims to structure brain research in Europe and to develop strategic global initiatives. The EBC is also a partner in some projects, including the MULTI-ACT project³, which focusses on patient engagement.

EBC's position on the new framework programme, Horizon Europe: EBC has had several meetings with the Commission services: In January 2018, EBC met with [REDACTED] of the **Cabinet of the previous Commissioner Moedas** and were invited to develop a brain mission concept; In February-April 2018: EBC met with the previous (Robert-Jan Smits) and newly elected **Director General, Jean-Eric Paquet**, to exchange views on the new framework programme and the concept of missions.

Noteworthy, in February 2018, Prof. Mariana Mazzucato published a key report⁴ providing guidance on how research and innovation can address global challenges,

¹ Consensus Paper: <http://www.braincouncil.eu/wp-content/uploads/2016/03/Consensus-Doc-pol-summary-Launch-2016-03-18-final.pdf>

² Value of Treatment Paper: http://www.braincouncil.eu/wp-content/uploads/2017/06/EBC_white_policy_paper_DEF26072017_Low.pdf

³ MULTI-ACT: A collective research impact framework and multi-variate models to foster the true engagement of actors and stakeholders in health research and innovation

⁴ Prof. Mariana Mazzucato, Mission-Oriented Research & Innovation in the European Union - A problem-solving approach to fuel innovation-led growth

which included a brain-related mission as an example (“Decreasing the burden of dementia”) that raised a lot of expectations in the brain research community.

2) EBC & the Innovative Medicines Initiative (IMI)

IMI2 is the world’s largest public-private partnership in health with a total budget of €3.3 billion (half from the EU and half from the pharmaceutical industry (via European Federation of Pharmaceutical Industries, EFPIA)). IMI supports collaborative research projects and builds networks of industrial and academic experts in order to boost pharmaceutical innovation in Europe. IMI has made significant investments in brain research, in particular in the field of neurodegenerative and psychiatric diseases. The EBC is a partner in the IMI-funded project called AETIONOMY⁵. Through IMI, the industry is slowly returning to brain research.

3) EU Brain Research efforts

EU funding for brain-related research has been increasing, from €3.1 billion in FP7 (~€400m/y) to €3.2 billion (~€600m/y) so far in Horizon 2020; and as an overall percentage of FPs, from 6.8% in FP7 to 8.2% in Horizon 2020.

An increasing proportion of FP funding is going to basic research via ERC and MSCA (from 40.2% in FP7 to 58.1% in Horizon 2020), while collaborative research via the health programme seems to be decreasing.

Efforts to foster cooperation and coordination also continue through the Joint Programme on Neurodegenerative Disease Research (JPND), the International Initiative for Traumatic Brain Injury Research (InTBIR), and the Global Alliance for Chronic Diseases (GACD).

⁵ AETIONOMY – Organising Mechanistic Knowledge about Neurodegenerative Diseases for the Improvement of Drug Development and Therapy

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