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The European Brain Council (EBC) is a network of key players in the "Brain Area", with a membership encompassing scientific and professional societies, patient organisations and industry partners.

EBC aims to:

FOSTER COOPERATION

between its member organizations and other stakeholders.

PROMOTE DIALOGUE

between scientists, industry and society.

EMPHASISE THE IMPORTANCE

of continued interaction with European Institutions to build strong European health policy

RAISE AWARENESS

and encourage education on the brain.

To improve the lives of those living with brain disorders, we advance the understanding of the healthy and diseased brain by bringing science and society together.

EBC works towards this **mission** through:

Advocating for brain research



Demonstrating the societal impact of brain disorders



ADVANCING
BRAIN
KNOWLEDGE
AND DRIVING
ADVOCACY



Building consensus within the brain community



Raising
awareness and
promoting
education on
the brain

EBC Policy Roadmap

1

Advocate for brain health as a public health priority

- —Promote holistic EU Vision and Mission on brain health
- —Address full spectrum of brainrelated diseases
- —Ensure COVID-19-related impact on patients is fully addressed
- —Raise awareness on the cost of non-action
- —Advocate for the expansion of non-communicable diseases to include brain health

Improve access to treatment and care and focus on better health outcomes

- —Advocate equal patient access to care across Europe
- —Upgrade strategic and regulatory policy framework (Pharmaceutical Strategy)
- —Collaborate with European Medicines Agency
- —Advance research on real-world evidence (RWE)
- —Support joint clinical assessments Raise awareness on efficiency of precision medicine

2

Foster Brain Research Policy and Programmes

- —Promote collaboration and coordination in brain research
- —Strengthen Horizon Europe, and other public-private partnerships from basic to translational research
- —Implement monitoring and evaluation framework; build on EBRA
- —Promote stronger European Reference Networks (ERNs)
- —Ensure safe and quality data use and exchange (European Health Data Space)

Call for an integrated approach

- —An integrated, holistic approach to brain research and health would maximise impact and improve health outcomes
- National Brain Plans are an essential basis for a comprehensive EU strategy

4



Become a full Industry Partner of EBC for access to all activities and a seat on the Industry Board to bring forward ideas and be part of strategic planning. (See next page)

2

Project-based Sponsorship

Be part of EBC projects and/or activities on an individual project-by-project basis (i.e. support of VOT case study or funding of white paper).

3

Industry Partnership & Project Support

Be part of the Industry Board for a voice in all EBC activities and provide support to any additional projects of interest to your company.

Industry Partner Benefits



Access and be part of a broad network of key players in the brain space, including representatives from all main fields.



Opportunities to initiate and/or join key research projects, political advocacy activities and awareness-raising initiatives.



Representation of your company on the EBC Industry Board, which represents the voice of the industry and private sector within EBC



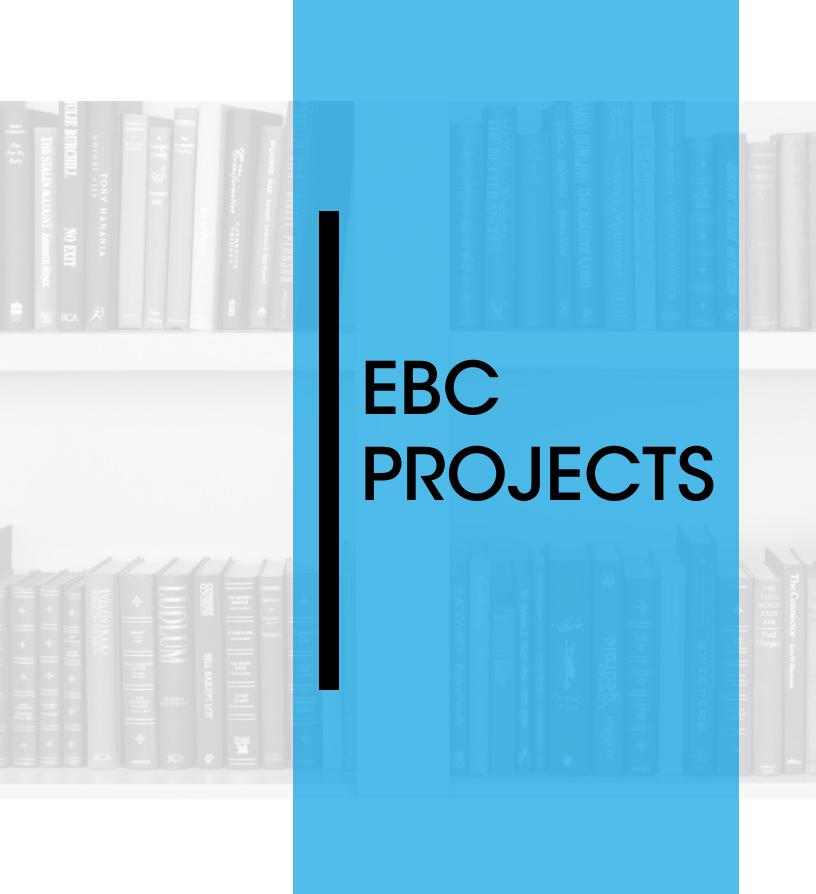
Support evidence-based policy recommendations in the context of the current EU research and health policy.



Contribute to multi-stakeholder consultations and take part in multi-stakeholder projects and activities.



Stay up-to-date with the latest in the brain ecosystem and be part of community reactions and activities in real time.



EBC Project Involvement

Starting from our main mission of promoting brain research, we unite the European brain community and translate the findings of our work. We emphasize the building of strong European health policies, raise awareness and highlight the repercussions of neurological and mental health conditions. We manage EBC- and partner-initiated projects (eg. Value of Treatment) and are actively involved in EU-funded projects (eg. EBRA).

All projects result from concerted discussions with EBC members and partner organisations. For each project, the project group typically consists of an international consortium, including various stakeholders such as academics, clinicians, SMEs, patient organizations and frequently Industry. The topics of these projects are linked to the brain area (neurological and mental alike) and are in line with the mission and vision of EBC.

Through the years, EBC has built expertise in:

General awareness raising and advocacy
 Multi-stakeholder consultations & strategic agenda design
 Health economics & outcomes research
 Brain innovation activities
 Training for researchers in the brain space

Therefore, EBC offers the services included over the next pages to any partner in the context of EU- funded projects (e.g. Horizon Europe, EIT, etc.) and private-funded projects (e.g. industry, foundations, etc.).

General awareness raising and advocacy

Through its wide network in the brain area, **EBC** raises awareness and performs communication, dissemination and advocacy activities on a regular basis.

In this context - to name a few - EBC is typically involved in:

- Organisation of meetings, events, participation at major congresses and other related dissemination/communication activities targeted to specific audiences and/or general awareness, including to policymakers and the public.
- Content production, such as **online and social media materials** including text, graphics, **podcasts**, **video interviews**, etc. and printed and/or digital **written material** such as project brochures, policy briefs, one-pagers, etc.
- Dissemination of above-mentioned materials towards key players in the brain area, using additional EBC communication channels such as the website, newsletters, events and distribution of printed material at major congresses and directly to target stakeholders (i.e. policymakers).
- Adapting key messages accordingly towards different audiences.



EBC holds many events and communication-oriented activities throughout the year, one major annual event being its <u>Brain Awareness Week</u> session in the European Parliament. EBC works with host MEPs to organise an awareness event on the importance of brain research. Look back at previous events <u>here</u>.

Multi-stakeholder consultation and strategic agenda design

EBC is in the perfect position to facilitate consultation and consensusoriented activities, always including various stakeholders. Effective and efficient collaboration and cooperation among the various projects/initiatives and stakeholders are often identified as a key success factor to achieve brain research full impact (and is a requirement in many EU-funded calls.) In this context, EBC created a methodology for consultation/consensus and liaison activities which can be adapted and finetuned based on the specific project.

The following activities can be organised by EBC:

- Stakeholder mapping and identifying the right stakeholders from EBC's network for potential collaboration; EBC's network consists of academia, clinicians, patients and patient representatives, industry, policymakers at EU and global level, regulatory authorities, funders, infrastructure and other key stakeholders in the brain space.
- The set up of various meetings aimed at collaboration and knowledge exchange: networking/liaison meetings to identify mutual barriers/challenges and drivers; co-creation workshops to brainstorm on specific topics; consensus/consultation meetings to define strategic agendas; writing groups to provide outcomes, such as evidence-based policy recommendations/guidelines.



The EBC-coordinated EU project <u>The European Brain</u> <u>Research Area (EBRA)</u> began in 2018. EBRA was created as a catalysing platform for brain research stakeholders to streamline and better coordinate brain research across Europe while fostering global initiatives. More details on page 17.

Health economics and outcomes research

Over the years, EBC has built expertise in cost studies and care pathway analyses including socio-economic assessments. This work began in 2005, when a cost study on brain disorders (mental and neurological alike) in Europe was undertaken, followed by an update in 2010.

These studies spurred the EBC-led Value of Treatment (VOT), a **health economics and outcomes research project** with a framework conceptualised on the basis of the aforementioned cost and burden studies. The VOT case studies cover all types of mental and neurological disorders. Each study includes the following tasks:

- Care pathway analysis including the identification of treatment gaps and causing factors along the care pathway. This is followed by a proposed solution to address the key gaps.
- Assessment of the health gains and socio-economic impacts
 resulting from the implementation of the proposed solution (best
 practice healthcare interventions), in comparison with current care
 or inadequate treatment.
- Drafting of **evidence based** (results of study) **policy recommendations** on how to improve the care pathway through a patient centered and sustainable model of care.



<u>Value of Treatment</u> currently has three existing streams of work focused on a number of diseases. A second round and transversal topics are currently underway for 2019-2022, focusing on the Value of Early Diagnosis and Coordinated Care for Rare Diseases, the Value of Early Intervention and Continuity of Care for Mental Disorders and a case study on chronic pain. More details on VOT are included on page 18.

Brain innovation activities

EBC has built a platform to **showcase** the importance of brain innovation and how it is changing Europe and the world and to **bring together** the various stakeholders from the brain innovation ecosystem to create synergies.

Our aim is to **potentiate** an enabling environment to foster investment and facilitate innovation in brain disorders.

See below for more concrete details on the type of activities:

- Showcasing the latest in brain innovation and using the platform to expand the community via an annual Brain Innovation Days event, a series of <u>innovation-highlighting podcasts</u>, a continuously updated website with articles, videos, job opportunities and more, as well as active social media presence.
- Connecting and creating synergies between relevant stakeholders in the brain innovation space.
- Building and sharing knowledge to facilitate brain innovation through organized expert meetings and **networking** opportunities.



The <u>Brain Innovation Days</u> were launched in 2020, kicking off one full year of brain innovation through a series of digital sessions and culminating with a first physical event in October 2021. This two-day event brought hundreds from the community together, showcasing the latest in brain innovation as well as a policy-focused European Brain Summit. More information is available on page 20.

Training for researchers in the brain area

Training needs of relevant stakeholders in the brain area - such as researchers or clinicians - are identified through a survey, taking into consideration their existing access to training within their institution's educational programmes.

Training programmes can include general research skills (e.g. paper or grant writing, open science methods) and soft skills (e.g. communication towards policymakers, patients and the general public); and are organized in different formats such as master classes, online courses, mentoring and hands-on work where researchers can practice their skills (eg. secondments to other labs, poster sessions).

Examples of expected learning outcomes for our 'Bridging Science, policy and society' trainings are:

- Tools and techniques for effective science communication and advocacy;
- Challenges of advocacy activities and resources needed to effectively perform advocacy activities in brain research;
- Patient engagement in research and advocacy activities.



EBC took part in a project within the Marie Skłodowska-Curie action on Innovative Training Networks, <u>ASCTN-Training</u>. As part of this Horizon 2020 project, EBC organised a <u>workshop</u> on the role of science in the European policy-making process in April 2021. The workshop, addressed to a group of early-stage researchers, aimed to empower them with ways to become a voice for neuroscience research throughout their careers.

Recent and ongoing projects of EBC

















PROMOTING GOOD PRACTICE
FOR THE OFF-LABEL
USE OF MEDICINES:
A harmonised European approach to prioritise patient safety





Want more details on each EBC project? Scan the QR code or click <u>here</u>.





www.ebra.eu

The European Brain Research Area project — EBRA — was created as a catalysing platform for brain research stakeholders (researchers, clinicians, patients, governments, funders and public institutions) to streamline and better coordinate brain research across Europe while fostering global initiatives.

EBRA is based on a conceptual approach that focuses on two levels:

Strategic Level



Mapping of the **European brain research landscape** - an overview of the scale and scope of brain research activities funded in the EU.



Developing the Shared European Brain Research Agenda (SEBRA), aimed to identify research opportunities and R&I gaps to be addressed and to provide recommendations on future areas for brain research in Europe.

Operational Level



EBRA's call for **clusters** aims to promote cooperation between brain research projects, to enable European and international collaboration and to develop research communities in all areas of brain research. There are 6 clusters working in various fields of brain research - more info **here**.



EBRA aims to **promote open science** by organizing workshops, meetings, and events.











EBRA
3rd Parties























www.braincouncil.eu/projects/vot

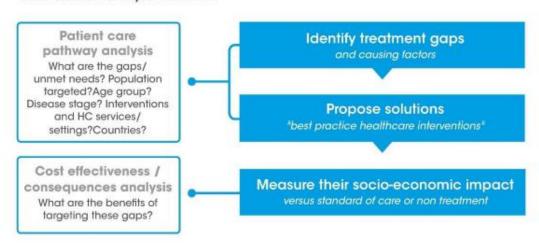
The Value of Treatment project aims to:

- I. Identify treatment gaps (or barriers to care) and causing factors along the patient care pathway and propose solutions to address them;
- II. Assess health gains and socio-economic impacts resulting from best practice healthcare interventions, in comparison with current care or no treatment;
- III. Converge data evidence to policy recommendations on how to improve the care pathways.

Case studies are conducted in collaboration with experts from the EBC network and with the support of academic partners, applying empirical evidence from different European countries.

The research method is similar for all case studies. It is important to harmonize datasets for the case studies— a standardised and homogenous approach, which facilitates interpretation and comparison, for the Final Paper.

Case studies analysis aims to:



RETHINKINGMS IN EUROPE





www.braincouncil.eu/projects/rethinkingms/

Building on the findings from the 'Value of Treatment (VOT)' studies, the 'Rethinking' studies, as a health systems and policy research project, aim to create greater visibility for the unmet [medical, psychosocial, health care] needs experienced by people with brain disorders at country level.

Standardised methods on the measurement and valuation of services in the health and social care sector that are applicable across countries were used (SWOT analysis as a tool for prioritization and strategy development)

Multiple Sclerosis (MS) was the first case study (2018-2020) developed by EBC using the 'RETHINKING' concept. Focus was on three key areas: timely diagnosis and personalised treatment; interdisciplinary and coordinated care; and adaptable support in daily life, including rehabilitation and social protection.

Additionally, an extension of <u>Rethinking MS in times of COVID-19</u> was carried out, highlighting how the lives of people living with MS and their families have been affected by COVID-19 and to provide concrete and tangible testimonies from relevant stakeholders – clinicians, MS patients, patient advocates, pharma representatives – impacted by the disruption in care, which proved both an obstacle and an accelerator for the implementation of good practices.

A virtual exhibition, <u>'Living with MS during COVID-19: A case for rethinking MS care in the EU'</u>, is currently open, showcasing portraits of the people supporting EBC's RETHINKING MS call.

Rethinking Migraine in Times of COVID-19 is currently underway, with the potential for more Rethinking case studies in the near future.













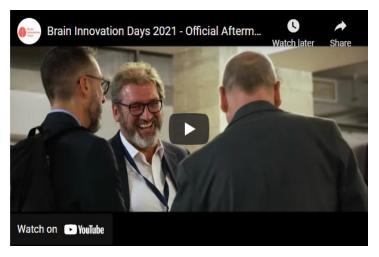
www.braininnovationdays.eu

The **European Brain Council** launched the first **Brain Innovation Days** virtually on 13 October 2020, kicking-off one full year of a packed brain innovation agenda leading up to the Brussels on-site event on 12-13 October 2021 and a series of annual events.

Brain treatments remain insufficient and research is disproportionately underfunded compared to other disease areas. At the same time, we have inspiring innovators in the brain space paving their way to building solutions for patients with brain disorders. In order to connect all parties involved, enhanced multi-stakeholder engagement in the brain ecosystem is needed to foster dialogue, exchange knowledge, accelerate investment in research and innovation, facilitate business development and showcase on-going work.

This is what the Brain Innovation Days are about: a platform bringing together science and society and an annual event where leaders in the brain ecosystem, researchers, industry, start-ups, innovators, policymakers, investors, health care professionals and patients are invited to discover the potential for innovation and build strong matchmaking opportunities.

Since the launch, 3 digital events and 1 physical event have taken place, including the first **European Brain Summit**, with annual events set to take place going forward. EBC works with sponsors and other partners to power the Brain Innovation Days. Further details on how to get involved can be found **here**.



Watch the event video & more on our social media channels.



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