



Policy, priorities and practice: ‘Being in the room where it happens.’ The European Brain Research Area and the Europe, Middle-East and Africa Chapter, International Federation of Clinical Neurophysiology



While medicine is naturally drawn towards the treatment of acute diseases, there is an increasing recognition that chronic conditions and alleviation of symptoms are becoming commoner. Neurological disorders are the leading cause of disability and the second leading cause of death worldwide (GBD 2016 Neurology Collaborators, 2019). As such they impose a tremendous social and economic burden, which will worsen as populations age, particularly from Alzheimer’s Disease and other dementias. These pressures are already affecting high income countries but will also place a huge burden on low and middle income countries in forthcoming decades (GBD 2019 Dementia Forecasting Collaborators, 2022). Research into the nervous system might therefore be placed at the top of the public health agenda, and yet neuroscience is behind cardiovascular and cancer in policymaker’s funding. For instance, recently spending in Horizon Europe on Alzheimer’s was estimated to be less than 2% of the total (The Lancet Neurology, 2021). More recently, the recognition of a wide range of neurological manifestations of COVID-19, particularly as long-term mental health disease (Badenoch et al., 2022; Premraj et al., 2022), will add further neurological burden to national health and social services at a time when the pandemic and other forces are placing huge additional pressures on budgets.

The European Brain Council (EBC) is a network of key players in the area of brain research and treatment, with members from scientific societies, patient organisations, professional societies and industry partners. A non-profit organisation based in Brussels, the EBC’s main mission is to promote brain research. EBC stands as the platform to foster cooperation between its member organisations and other stakeholders, consistently promoting dialogue between policy makers, scientists, industry and society.

The Europe, Middle-East and Africa Chapter of International Federation of Clinical Neurophysiology (EMEAC-IFCN) has been an associate member of EBC since 2015. One of the important principles of clinical neurophysiology is the introduction of hard data into clinical diagnosis and management, which becomes even more important in research projects. Our aims at the EBC platform are to represent Clinical Neurophysiology as a key part of clinical and human neuroscience research in all its forms, to foster an understanding of the underlying mechanisms of nervous system disorders, to popularize our methodologies (and how cost effective they are), and to pinpoint our role in the development of potential predictive, diagnostic and treatment biomarkers of neurological and mental diseases. Nowadays, in crowded research fields, the

contribution of clinical neurophysiology requires continuous support.

The EBC has also been involved in deliberations about high-level research funding. In November 2018, EBC, and many other big actors in the field, (the Human Brain Project [HBP], the EU Joint Programme on Neurodegenerative Disease Research [JPND], and ERA-NET NEURON, launched the EU project “The European Brain Research Area (EBRA). This was designed to respond to the Horizon 2020 call, SC1-HCO-10-2018, entitled “Coordinating European brain research and developing global initiatives.” This, in turn, called for ‘the reduction of fragmentation and duplication of research efforts, fostering [of] synergies through enhanced coordination of brain research efforts at EU and at global level, improved access to and optimising of the use of research infrastructures and data sources by the neuroscience research communities, for better use of investments made in brain research, gaining of critical mass and economies of scale by initiating and fostering new global research initiatives, and lastly the enabling of translation of breakthroughs into clinical applications.’ These lofty and detailed aims might be summed up as trying to coordinate research, and for these organisations to help channel EU and other funding organisations to the worthiest causes. From a political perspective, those in power in Brussels will be assailed by many pleas for research funding; this initiative was to focus funding onto those priorities amongst the main areas in the neurological science. With that in mind, the EBRA project regularly has a “Call for Clusters” to promote cooperation and exchange among specific brain research projects, and to boost international collaboration in these areas. Up to date, six clusters have been selected: BRAINFOOD, EPICLUSTER, PSMD (Prevention of Severe Mental Disorders), PREMOS (Predictive Model Systems), TRISOMY21 (Down Syndrome) and ECIB (European Cluster for Imaging Biomarkers). These are all laudable but sit within a field with a large number of similarly laudable potential projects. Choosing between the many worthy projects must be very difficult.

The EBRA project has also set up a landscape analysis of brain research and a Shared European Brain Research Agenda (SEBRA). The aim of this mapping exercise was to provide an overview of the current state of brain research in Europe. SEBRA focuses on research opportunities and gaps, priorities for action in the short and long term, and research areas that would benefit most from cross – initiative cooperation. It also aims to integrate pre-existing documents, such as the Strategic Research Agenda of the different initiatives participating in EBRA, and the EBC Consensus Statement. These gaps and priorities were discussed at an expert workshop and then during an online consultation which gathered the perspectives of multiple brain research stakeholders such as HBP, JPND and ERA-NET NEURON. Our representatives from clinical neurophysiology participated in both of these. SEBRA will publish recommendations on future areas for innovative and translational

research soon, so encouraging cooperation, and reducing overlap and fragmentation in brain research.

Such politics and policy may seem very distant from our clinics and labs. But high-level decision making about where and how much to fund research into what condition are immensely important both for patient care in the coming decades and for the development of research in neuroscience, and so within clinical neurophysiology also. EBC is a platform that brings together basic and clinical researchers, healthcare professionals, industry, and patient organisations, with the aims of preventing duplication of efforts and research waste, and promoting networks, all with the hope of decreasing bureaucracy and improving the real world, social impact of research. EBC has developed some of its goals with the EBRA project. The EMEA Chapter recognizes that whilst clinical neurophysiology is a relatively small player in such a huge field, our representatives have been active and vociferous throughout the process of EBRA proposal, and continually promote the role of clinical neurophysiology in brain research. If you look at our EMEAC budget, you will see that we pay a couple of thousand euros per year to sit at the EBC table. We do not know how effective we will prove, but we are convinced that we should add our voice to those of others when European research priorities are being developed. This is why we need to be in the Brussels room where it happens.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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H. Tankisi*

Europe, Middle-East and Africa Chapter, International Federation of Clinical Neurophysiology, Executive Committee
Department of Clinical Neurophysiology, Aarhus University Hospital, Aarhus, Denmark and Institute of Clinical Medicine, Aarhus University, Denmark

* Corresponding author at: Aarhus University Hospital, Palle Juul-Jensens Boulevard 165, DK-8200 Aarhus N, Denmark.
E-mail address: hatitank@rm.dk

A. Kamondi

Europe, Middle-East and Africa Chapter, International Federation of Clinical Neurophysiology, Executive Committee
Department of Neurology, Semmelweis University, Budapest, Hungary and Department of Neurology, National Institute of Mental Health, Neurology and Neurosurgery, Budapest, Hungary

A. Gechev

Europe, Middle-East and Africa Chapter, International Federation of Clinical Neurophysiology, Executive Committee
West Hertfordshire Hospitals, and Royal Free Hospital, London NW3 2QC, UK

A.M. da Silva

Europe, Middle-East and Africa Chapter, International Federation of Clinical Neurophysiology, Executive Committee
Epilepsy Unit, Porto Epicare Centre for Refractory Epilepsy, Centro Hospitalar Universitário do Porto, Portugal, Neurophysiology, Neurosciences Department, Centro Hospitalar Universitário do Porto, Portugal

A. Antal

Europe, Middle-East and Africa Chapter, International Federation of Clinical Neurophysiology, Executive Committee
Department of Neurology, University Medical Center Goettingen, Robert Koch-Strasse 40, 37075 Goettingen, Germany

F. Destrebecq

Executive Director, European Brain Council, Belgium

K. Aarts

Project Manager, European Brain Council, Belgium

M. Di Luca

ⁱ Project Coordinator European Brain Research Area and Immediate Past President, European Brain Council, Belgium

J. Cole

Europe, Middle-East and Africa Chapter, International Federation of Clinical Neurophysiology, Executive Committee
Clinical Neurophysiology, University Hospitals Dorset, (Poole), and University of Bournemouth, Poole, UK

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