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ORIGINAL ARTICLE

# The French Brain Council Advocacy for 10 priorities regarding the National Brain and Mental Health plan in Europe



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## KEYWORDS

Brain;  
Mental health;  
Psychiatry;  
Policy;  
Research;  
Funding

**Summary** The French Brain Council, which has a balanced representation of Neurology, Psychiatry and Neurosciences, participated in the launch of a survey on the current status of care for patients suffering from brain diseases with the aim to identify 10 consensual priorities to be emphasized in the building the National Brain Plan in all European member states. This National Brain and Mental Health plan was approved by the National Brain Councils of 17 European member states. The present report details the 11 responses that obtained a consensus, the top five (over 90% of agreement) being the needs to: (1) improve multidisciplinary integrated home care and structures of coordinated health care, (2) increase homogeneity within regions for current state of prevention, (3) develop evidence based and socially responsible policy by collecting data from ongoing clinical trials and basic research to optimally address unmet needs, (4) promote education on innovative technologies, and (5) facilitate translational research.

In May 2019, a list of 10 priorities for National Brain and Mental Health plans was approved by the National Brain Councils of 17 European member states [1] (see [Appendix 1](#)).

The French Brain Council was deeply involved in the process that permitted such a consensual achievement. The FBC is a transversal and multidisciplinary structure, members of which are the *French Society of Neurology*, the *Society*

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of Neurosciences, a college of Psychiatry and Addictology associations (including the *French Congress of Psychiatry*, which official journal is the *French Journal of Psychiatry*), the *Brain and Spine Institute [ICM]*, the *FondaMental* and *Neurodis* Foundations and a college of patients associations. Through the FBC, Neurology, Psychiatry and Neurosciences are speaking with a single voice for the first time in our country, aiming at increasing the awareness of the public, as well as that of political and economical decision makers. The emergency to rank research on Brain as one of the Europe's 'moon shots' for the post 2020 EU Research and Investment program, was immediately seen as one of the most needed achievement (see the LAB-FAB-APP report of the High Level group of the European Commission [2]). Moreover, without the engagement of patients 'walking along' with caregivers and researchers, the FBC claim would remain a *vox clamans in deserto*. The FBC therefore fully endorsed the three key challenges of the 2019–2024 European mandate proposed by the European interest group on 'BRAIN, MIND and PAIN' [3], speaking on behalf of EU associations of patients suffering from brain disorders. These important points are:

- to eradicate stigma, isolation and discrimination;
- to ensure equitable access to treatment services and support and;
- to promote patient empowerment for increased involvement and engagement.

## The economical context of the FBC creation

In August 2011, a study of the costs of brain disorders in Europe for the year 2010 was published by a panel of European Experts [4], which had a tremendous impact upon the community of caregivers, researchers and patients. This economical survey estimated the total cost of brain disorders at €798 billion in 2010, including 37% of direct healthcare costs, 23% of direct non-medical costs and 40% of indirect costs associated with patients' production losses for a European population of 514 million people. Psychiatric diseases represent 56% of this economic burden [4]. Compared to these enormous health costs the weakness of funds allotted to research on brain disorders looks derisory, particularly for psychiatric diseases. For instance in France for an annual cost of psychiatric diseases that was of €59.4 billion in 2010, the annual budget allotted to research on mental health including salaries of all full time employees was of €24,3 million in 2007, representing a ratio of 0.04% [5]. Faced to this economical deadlock, the European Brain Council has sounded the alarm and mobilized European authorities during the past ten years. However a mandatory condition for reaching a full efficiency of this action is that it must be relayed and supported by European member states, hence the creation of "National" Brain Councils [NBCs] and the development of National Brain Plans. In this context the French Brain Council [FBC: <http://conseilfrancaisducerveau.org>] was created on February 22<sup>nd</sup> 2016 to promote basic and clinical research on brain and mental diseases, to improve the care of brain and mental diseases at national and European levels and to facilitate dialogue between Science, Medicine and Society.

## A European survey on status of care for patients suffering from brain diseases

In coordination with the Belgian, Spanish and Serbian national brain councils the FBC proposed to launch a survey, on the current status of care for patients suffering from brain diseases with the aim to identify 10 consensual priorities to be emphasized in the building the National Brain Plan in all European member states. This proposal was adopted during a meeting of NBCs held in Lisbon in April 2018. During this meeting the FBC also proposed the title of 'Brain and Mental Health Plan' rather than merely that of 'Brain Plan' as title for the initiative that should be in fine supported by European member states.

The first step was to establish a questionnaire that was submitted to all NBCs. This questionnaire consisted of 10 main questions in which sub-questions were included in order to have 29 questions made of only 3 possible answers (YES/NO/No answer) eventually associated to free comments and recommendations from responders. Seventeen countries responded to this questionnaire (see Fig. 1, detailed in [1]).

Consensual responses (> 75% of positive responses) concerned the following statements:

- need to develop evidence based and socially responsible policy by collecting data from ongoing clinical trials and basic research to optimally address unmet needs [Yes: 100%];
- need to increase education on innovative technologies [Yes: 100%];
- deficiency in multidisciplinary integrated home care [Yes: 100%] and need to improve structures of coordinated health care [Yes: 90%, No: 10%];
- current state of prevention is not homogeneous within regions [Yes: 90%, No: 10%];
- need to develop translational research [Yes: 90%, No: 10%];
- weaknesses in rehabilitation programs and non-pharmacological therapeutics and need to improve rehabilitation programs [Yes: 90%, No: 5%, No answer: 5%];
- there is a delay in diagnosis for neurocognitive and sleep disorders [Yes 85%, No: 15%];
- need to increase budget and research in psychiatry (Yes: 80%, No answer: 20%);
- coordination for brain diseases care is still left behind when compared with other diseases [Yes: 80%, No answer: 20%];
- existence of national policy to reduce hospitalization by improving healthcare pathways and ambulatory management [Yes: 77%, No: 14%, No answer: 9%];
- existence of national centers for better diagnosis of rare neuro-diseases [Yes: 77%, No: 18%, No answer: 5%].

About the efforts made to increase collaboration amongst medical (General practitioners, neurologists and psychiatrists) and paramedical staff (GPs, nurses, other trained assistants) for the care of patients [Q7] 60% of votes were 'Yes' [versus 30% of 'No' and 10% of 'No response']. Interestingly 75% of responders were unable to evaluate the efficiency of this cooperation so that we obviously need better monitoring and evaluation. To the question whether the



**Figure 1.** Countries that participated in the survey [Belgium, Bulgaria, Croatia, France, Germany, Greece, Ireland, Latvia, Luxembourg, Malta, Netherlands, Norway, Poland, Portugal, Serbia, Spain, Turkey].

current state prevention was of good quality of care except for psychiatry [Q1B] 50% of responses were 'No', 25%: 'Yes' and 25% of No answer; interpretation of this vote might be that the dominant opinion was that prevention is tremendously deficient but not worse for psychiatric diseases than for other brain disorders.

## The specific input of the FBC to the survey

The FBC supported the following statements on the present status of care for Brain and mental diseases in France:

- detection and prevention of neuropsychiatric diseases need major improvement;
- there is a too long delay for diagnosis of psychiatric diseases;
- the impact of sleep disorders on global health and on risk of neurodegenerative diseases should be emphasized. Diagnostic rates should be improved at early stages of neurocognitive disorders;
- funding of multidisciplinary integrated homecare and rehabilitation programs is globally deficient. Post-diagnosis supports to optimize quality of life and to provide secondary prevention dynamics are needed. Access to advanced directives and to clinical trials should be ameliorated;
- stroke, Alzheimer disease, Multiple sclerosis and Parkinson disease have been prioritized in France but Epilepsy, Headache and Sleep disorders should be included in the list of priorities for which allocated resources are presently deficient. Psychiatric diseases were not sufficiently considered as a health priority. The term psychiatric diseases was assessed as too generic to qualify many specific and important diseases such as depression, schizophrenia, obsessive-compulsive disorders, autism. . . They indeed affect 38% of the population, representing the first cause of DALYS (20%);
- national centers or networks have been created to improve the status of care for stroke, Alzheimer disease and rare diseases. A national cohort of patients with multiple sclerosis has been launched in 2012. Such initiatives should be undertaken and founded for other frequent diseases such as schizophrenia, bipolar disorder, obsessive compulsive disorders, autism, sleep disorders, epilepsy;
- efforts should be made to increase collaboration amongst medical (General practitioners, neurologists and psychiatrists) and paramedical staff (GPs, nurses, other trained assistants) for the care of patients;
- access to non-pharmacological treatments should be facilitated after evidence-based evaluation of their efficacy;
- regarding the challenges of research on Brain and mental diseases: development of translational brain research, amelioration of education on innovative technologies and increase of budget for research in psychiatry should be rated as first priorities;

- the FBC proposes that the term 'Brain and Mental Health Plan' be preferred to that of 'Brain Plan' to build up the forthcoming plan at National and European levels.

## Elaboration and endorsement of 10 consensual priorities

Based on responses to the questionnaire and comments of responders the FBC established a first list of 10 priorities elaborated with the help of its task force [see [Appendix 2](#) for the list of FBC task force members]. This first draft was established and then submitted to responders for comments and approval. The final text presented here [see [Appendix 1](#)] is the outcome of an agreement made by consensus. These priorities were published in April 2019 [1], and presented at a NBCs meeting in Dubrovnik in May 2019.

## The engagement of the FBC in favour of 'Brain and Mental Health'

The robustness of these 10 priorities obtained by consensus from National Brain Councils from 17 countries gives them a high legitimacy that cannot escape to the attention of Members of the European Parliament (MEP) and European governments. These recommendations should be a high priority in their agenda and in the coming health programme of each European government.

In the elaboration of these priorities, the FBC strongly stressed the necessity to emphasize the particular need for support of psychiatry in terms of research and organization of care. This view is validated through comparison with some recommendations expressed within the 2018 OECD-EU report: *Health at a Glance: Europe* [6]. Among other statements and recommendations this report makes a strong case for promoting mental health and preventing mental illness. This justifies the specific mention of psychiatric diseases in the two first priorities as well as the position of the FBC that a French 'Brain' plan should be a 'Brain and Mental Health' plan. This position may not be fully endorsed by all National Brain Councils for several reasons:

- composition of NBCs is heterogeneous among countries and some NBCs may not include Societies of Psychiatry among their members. Interestingly none of the 16 associations of patients which endorsed the objectives of the European Interest group on BRAIN, MIND and PAIN [4] represented patients suffering from psychiatric diseases;
- a conceptual argument is that psychiatric diseases are brain disorders so that there is no reason to mention specifically 'Mental health' in a 'Brain' plan. This view, apart from neglecting the enormous costs of mental health problems and the urgency to ameliorate the quality of care for patients suffering from psychiatric diseases, overlooks the fact that the term 'Mental Health' covers a field which is larger than that of medical research and care and is open to humanities, social sciences and economy. Unlike some experts most patients with mental diseases have no difficulty to grasp the meaning of 'Mental Health';
- a last argument, essentially political, is that communicating on 'Brain' rather than on 'Brain and Mental

Health' would have more impact to convince the European Commission to mention 'Brain' as a specific item, with a dedicated budget, in the Health cluster of the Horizon 2021–2024 program. There is no doubt that 'Brain' would be better than nothing in the final wording of this program but little doubt either that those of national and European decision makers who are in favour of fostering research on 'Brain' would not be indifferent to the social challenge of promoting also 'Mental Health'.

## Appendix 1. List of 10 priorities for national brain and mental health plans [1]

1. To increase the budget devoted to basic and clinical Brain research in particular in psychiatric diseases.
2. To improve detection prevention and treatment of brain disorders, in particular psychiatric diseases, to facilitate access to dedicated acute care of stroke, and to increase the homogeneity of prevention and early treatment between regions.
3. To shorten the diagnostic delay for brain disorders; in particular through the development of biomarkers crucial for clinical testing of new treatments at early stages of neurodegenerative diseases.
4. To develop multidisciplinary home care and rehabilitation programs and provide funding for the authorities responsible for the delivery of these programs.
5. To facilitate collaboration amongst General Practitioners, Neurologists, Psychiatrists, Psychologists, Geriatricians, Nurses and paramedical staff for improving patient care.
6. To involve Patient Organizations in the coordination of care for brain disorders.
7. To develop and disseminate evidence-based recommendations and socially responsible policy based on ongoing clinical trials and basic research.
8. To foster translational research programs with clear outcomes for patients and evaluated through their final impact on patients' quality of life and for the general population on healthy brain aging.
9. To facilitate patients' access to innovative technologies and new disease modifying drugs by shortening the approval delay for reimbursement by national health insurance systems.
10. To increase education on innovative technologies including digital medicine, bioengineering and genome screening.

## Appendix 2. Members of the FBC task force



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## Disclosure of interest

The authors declare that they have no competing interest.

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