

EBC

PRIORITY

Election

Manifesto

for the 2019

European

Elections

 179000K

 87000K

**For an improved quality of life
for Europeans living with brain conditions**

#BrainManifesto



European Brain Council Brussels Office

Rue d'Egmont, 11
BE-1000 Brussels
Tel: + 32 (0) 2 513 27 57
manifesto@braincouncil.eu

 @EU_Brain
#BrainManifesto
#EP2019
#ILoveMyBrain

www.braincouncil.eu

SUMMARY

THE CALL	4
RESEARCH	6
/ The Value of Research	
CARE	7
/ The Value of Innovation	
/ Going Digital	
/ The Value of Treatment	
SOCIETY	8
/ The Burden of Disease	
/ Preventing the Burden	
/ Support for Carers	
/ Fighting Stigma & Discrimination	
/ National Brain Plans	
REFERENCES	11

We call on Members of the European Parliament to:

- Guide the EU to the role of global leader in brain research
- Sustain EU funding to expand and boost brain research
- Improve the quality of care for patients across the EU
- Recognize brain health as a priority for European society
- Encourage awareness, early preventative measures and early intervention to address the growing burden of brain conditions

The human brain is complex. As the control centre of our body, this organ directly affects every function, ranging from rational thinking, emotions, heartbeat, breathing, food and fluid intake, sleep and sexual functions.

A healthy brain is the ultimate prerequisite for quality of life and sustainable well-being: yet, in Europe alone, 179 million citizens of all ages live with brain disorders, neurological and mental alike, with these numbers increasing steadily. For a continent and Union that strives to build and maintain healthy and prosperous lives for all citizens, disorders of the brain lack the awareness and recognition they are due.

Europeans are growing older and with this large demographic ageing comes the steady increased risk and incidence of neurological and psychiatric conditions, for which we are continuously striving to find cures or effective treatments. Furthermore, the increasing incidence of childhood and adolescent brain disorders, equally without cures, represents a constant threat to our society.

The burden of these conditions is staggering, not just for those affected and society as a whole, but also for our economies. Health economists have estimated that brain disorders alone amount to ca. 45% of the annual health budget in Europe, totalling around €800 billion every year (2010) ^{1,2}.

What are brain conditions?

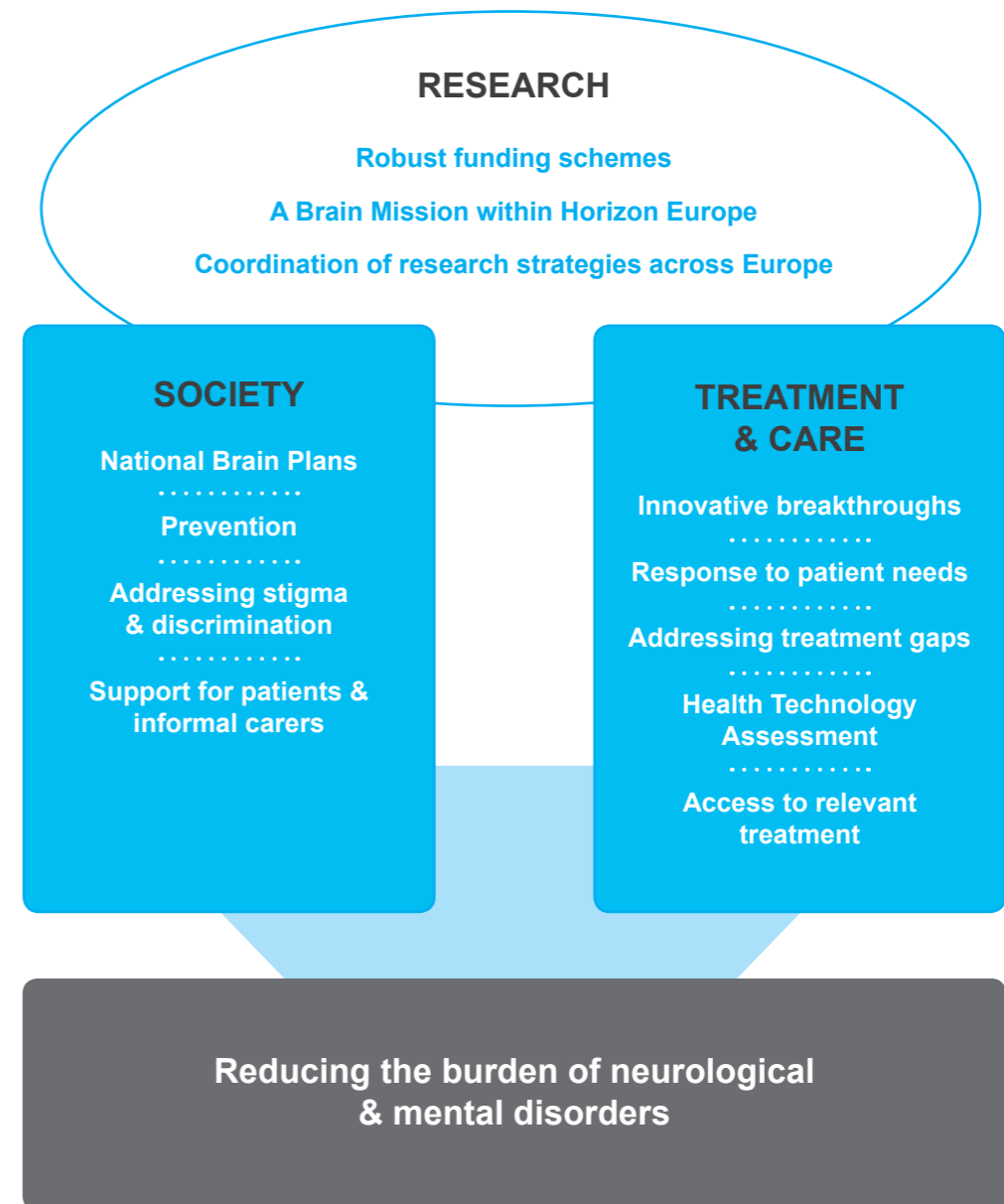
The term “brain conditions” is here used as an umbrella for diseases that encompass both neurological and psychiatric conditions. These include, for instance, diseases such as: anxiety, bipolar disorder, dementia, depression, epilepsy, headache, multiple sclerosis, Parkinson’s disease, psychosis and stroke. All together, these conditions equal the number one burden in Europe.

Disability Adjusted Life Years, or “DALYs”

A commonly used term in health statistics, “DALYs” are the sum of the years of potential life lost due to premature mortality and the years of productive life lost due to disability⁴.

More recent figures even place the costs of mental health alone at over €600 billion every year (2015)³. In addition, mental and neurological disorders are responsible for the biggest number of years lost due to disability at WHO Europe level (62 million DALYs) (2017)⁵.

It is clear that we need this situation to change. We need to improve the lives of our fellow Europeans living with these life-disrupting disorders. We need robust research, improved care and a society that prioritizes the health and wellbeing of **all** its citizens.



RESEARCH

The EU as a global leader in brain research

In 2018, the European Parliament called for increased research funding to fulfil the ambition to render the EU the largest research hub in the world. We call for the “moon-shot”: we call on MEPs to work to ensure that the EU becomes the global hub for brain research, too.

Understanding the brain is a mission on its own. Continued commitment to basic neuroscience research has advanced our understanding of the nervous system, with Europe successfully leading the efforts to increase our understanding of the brain, as well as the practical and clinical application of this knowledge.

Engagement of the scientific and clinical community is required at all levels in order for the European population to benefit from discoveries and for advances in basic neuroscience to be translated into new diagnostic tools and treatments for brain disorders. Fragmentation leads to unnecessary duplication, time-wasting repetition and a lack of concrete findings.

Despite the progress in medical science during recent decades and recent breakthroughs which have provided a powerful dual opportunity to relieve the societal burden of neurological and mental disorders and innovate at the frontiers of technology, the inherent complexity of the nervous system has hampered our translational capacity, suggesting that a higher level of understanding is required to efficiently cure brain disorders. It is therefore of paramount importance that sufficient financial resources are allocated to brain research across the EU.

Sustained funding by the EU is necessary to expand and boost brain research in Europe. However, in order to ensure that Horizon Europe becomes a robust instrument for supporting brain research, budgets need to match the challenge. At least 3% of the EU’s GDP would need to be invested in research and development to meet the goals set in the Europe 2020 Strategy.

The Value of Research

Discoveries and advances in **basic neuroscience** are the prerequisites for describing the normal functioning of the nervous system and improving our understanding of the etiology and pathophysiology of brain disorders, neurological and mental alike. It is crucial that the EU set bold targets aimed at accelerating brain research and reducing the societal impact of neurological disorders and mental ill-health. Now is the time to act, as Horizon Europe will address some of the most pressing societal challenges by means of specific missions.

CARE

Improving the quality of care for patients

The Value of Innovation

Despite the prevalence of brain disorders in Europe, there is currently no disease modifying treatment available to cure a wide range of mental and neurological conditions. Developing treatments that can significantly improve the lives of those living with brain disorders is extremely challenging. Timelines for developing medicines and devices required to treat Central Nervous System (CNS) conditions alone can take up to 18 years⁶ (compared to the average 12 years⁷ for other drug pipelines) and new drugs face low approval rates⁸. CNS drug development rates are continuously hindered by the complexity of the conditions, increased drug development costs and the high risk of failure throughout the pipeline⁹.

EU decision-makers should take further steps to transform Europe into a global leader with respect to treatment development, create an innovation-friendly environment and sustain scientific breakthroughs in the field of brain disorders.

Going Digital

Unprecedented innovation in technology and medical processes is rapidly revolutionizing day-to-day living. Over the last decades, various digital technologies have emerged that hold the promise of dramatically reshaping the way we deliver healthcare. Applications, in particular, that can be accessed through smartphones, computers and tablets have the potential, amongst others, to: monitor cognitive abilities and prevent impairment, improve adherence to treatment, encourage a healthy lifestyle or detect certain conditions early. Artificial Intelligence (AI), machine learning, blockchain as well as other technological developments are yet to unleash their full potential.

Member States should receive EU support for the development, assessment and establishment of efficient models for reimbursement of digital health technologies. Moreover, further **measures should be taken to improve digital health literacy** amongst healthcare professionals, patients and carers **and to foster the advancement and implementation of digital solutions.**

Women and the brain

As patients, women are at higher risk of several brain diseases, such as Alzheimer’s Disease¹⁰ or Depression and Anxiety Disorders¹¹.

Furthermore, women are more likely to take on the role of informal carers¹², leading to reduced working hours or stopping work altogether to care for a loved one, affecting their livelihood and the livelihood of their families.

The Value of Treatment

Current health systems, however, have not been able to adapt quickly enough to provide patients with optimum outcomes. This is particularly true for brain disorders and is particularly challenging for policymakers.

Treatment gaps —the proportion of people who require screening and treatment but do not receive these or receive inadequate care— pose the biggest barriers to improved diagnosis, treatment and care across Europe.

Member States should implement strategies of early diagnosis and intervention to ensure adequate care, which is proving to be cost efficient and cost effective in the long run.

SOCIETY - Brain health as a priority for European society

The Burden of Disease

Neurological and mental conditions have been identified as the leading causes of disability-adjusted life years (DALYs) and deaths worldwide. Statistics made available by the Lancet indicated that neurological conditions were the cause of 10,2% of DALYs and 16,8% of global deaths in 2015. Moreover, mental ill-health was found to be responsible for 13% of DALYs¹⁴ and 14,3% of global deaths¹⁵.

The OECD estimated the total costs of mental ill-health in the EU 28 at more than 4% of GDP, i.e. over €600 billion, every year³.

Preventing the Burden

The growing number of citizens being diagnosed with brain conditions makes clear that the burden these diseases place on society will not change its course.

As the European population ages, the chance of staggering numbers of people living with brain becomes immense.

Major Depression as 'DALY Leader' by 2030

The leading cause of DALYs by 2030 is projected to be unipolar depressive disorders¹⁶.

Growing public health concern seen in Alzheimer's

With a rapidly ageing population, Alzheimer's disease (AD) is a growing public health concern worldwide. In Europe, an estimated 10.5 million people have dementia and this number is expected to increase to 18.7 million in 2050¹⁷. AD is a neurodegenerative disease that progresses in stages and is the underlying cause in 70% of people with dementia.

Prevention and early intervention are seen as the solutions to help society cope. Primary prevention begins with raising awareness, developing resources and providing proper support. **Access to early intervention could mean personalized and effective diagnosis and treatment as well as the delayed development or exacerbation of the disease.**

Support for Carers

The environment around a patient, or person living with a neurological or psychiatric condition, is key. A majority of brain conditions are highly debilitating and severely disabling, with many needing constant assistance and support, particularly at later stages in their condition.

Informal care is now the largest form of patient care across Europe— approximately 80% of care across the EU is provided by spouses, relatives and friends, often unpaid. Without the work of these carers, formal care systems would be unsustainable; and many serious health and social care needs would be neglected¹⁸. **These carers need to be supported and enabled to provide this crucial care.**

Fighting Stigma & Discrimination

Stigma faced by people living with brain conditions plays a very important —yet insufficiently recognized— role in the burden of these conditions.

A lack of knowledge or understanding of what the disease is or what the person is living through often leads to severe discrimination, such as unsteady employment or non-supportive work environments, isolation, lack of social or medical support, fear of disclosing or seeking help and ultimately, further comorbidities such as depression or anxiety¹⁹.

Actions to raise awareness and high-profile support at the EU level can be revolutionary in the path towards addressing stigma, showing support and ultimately, making a change in the way people think and act.



"Brain disorders are now what cancer was a few decades ago. You suffered silently, for fear of the stigma of others, who feared the disease and thus, feared the person living with it. We must fight for the same rights for people living with brain conditions. No one should go to work fearing that it may be their last day there; no one should be abandoned by their colleagues or friends, who may not understand why they could not go out that night; and no one should be left out by society solely because they are living with a condition that we don't yet know how to treat and cure."

Prof. Monica Di Luca, EBC President

National Brain Plans

With 179 million Europeans living with a wide variety of neurological and psychiatric conditions— and many more set to develop them as the majority of the population ages— **brain health must be a priority for Europe.**

Robust strategies at national level and strong EU-wide coordination efforts are needed to effectively address the burden of diseases involving brain dysfunctions.

EU Member States should work closely with patient representatives, scientific societies and clinicians within National Brain Councils towards **designing and establishing National Brain Plans.** These plans are aimed to provide a holistic strategy to accelerate brain research and reduce the impact of brain disorders.

Good Practice

In December 2017, the Norwegian Health Ministry announced the launch of a Norwegian Brain Strategy, which constitutes a key tool for supporting brain research and improving the quality of treatment. This plan is of paramount importance for addressing the impact of brain disorders and should be replicated in other European countries.

This example of Norway should be disseminated Europe-wide and the EU should coordinate and support national efforts aimed at launching National Brain Plans.

EBC Election Manifesto for the 2019 European Elections



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