



Member of the
European Parliament
**INTEREST GROUP ON
BRAIN, MIND AND PAIN**



KEY MESSAGES

FOR POLICYMAKERS

INTRODUCTION

At least 1 in 3 people will experience a brain disorder in their lifetime, and 1 in 5 of us over the age of 18 live with chronic pain. The total cost of brain disorders in Europe is estimated to be €800 billion each year.¹ In 2016, chronic pain disorders cost an additional €441 billion. As life expectancy increases across Europe, the prevalence and cost of these conditions are expected to grow. Please see below some key statistics to further illustrate this point:



Neurological diseases were the largest cause of disability adjusted life years (DALYs) in 2015, making up 10.2% of global DALYs²



Neurological diseases are the second largest cause of global death, leading to 16.8% of global deaths²



Between 1990-2015, the number of deaths from neurological disorders increased by 36.7%²

That is why the European Federation of Neurological Associations (EFNA), and its partners at Pain Alliance Europe (PAE), launched the MEP (Member of the European Parliament) Interest Group on Brain, Mind and Pain (BMP) disorders and the broader BMP initiative. It aims to identify and implement EU and national policy solutions to tackle this growing burden.

This key messages document has been developed for policymakers and is based on the Book of Evidence (BoE) of the BMP initiative. By providing key messages and calls to action and requesting that MEPs engage with the BMP initiative in the 2019-2024 mandate, this document is designed to help you raise awareness and promote change for the benefit of people living with BMP conditions, as well as their families, carers and society as a whole.

¹ Olesen, Jes et al., The economic cost of brain disorders in Europe, European journal of neurology: the official journal of the European Federation of Neurological Societies, 2012, <https://www.ncbi.nlm.nih.gov/pubmed/22175760>

² The Lancet Neurology, Global, regional, and national burden of neurological disorders during 1990-2015: a systematic analysis for the Global Burden of Disease Study 2015, 2017, [https://www.thelancet.com/journals/laneur/article/PIIS1474-4422\(17\)30299-5/fulltext#seccestitle80](https://www.thelancet.com/journals/laneur/article/PIIS1474-4422(17)30299-5/fulltext#seccestitle80)

THE BRAIN, MIND AND PAIN INITIATIVE

The aim of the BMP initiative is to raise awareness of neurological, but also chronic pain and mental health conditions in Europe, underpinned by a strong patient-centric approach intended to prioritise these disorders, encourage research, increase access to innovative treatment, improve quality of life and decrease stigma.

To fulfil this objective, coordinated EU and national policy action must be taken in order to ensure that policy solutions for people with BMP disorders are implemented in line with patients' preferences and that their meaningful involvement is enshrined and supported in all policy and research initiatives.

In addition to activity on EU and national level, it is also important for the BMP initiative to be placed within the wider context of healthcare priorities at the global level. Historically, brain, mind and pain disorders have struggled to be included in initiatives on non-communicable diseases (NCDs). Now, with the global priority turning more and more towards NCDs, we need to ensure that neurology is part of the conversation – looking beyond the EU Institutions and to the WHO and the OECD, for example. To support this, the activity of the BMP group should align with work on the WHO's Sustainable Development Goals (SDG), especially SDG3.4 which aims to reduce premature mortality linked to NCDs by a third by 2030 through better prevention and treatment as well as through promoting mental health and wellbeing.³



FOCUS AREAS FOR THE 2019-2024 MANDATE

In the 2019-2024 mandate, the BMP initiative has collectively agreed to focus on the following thematic areas for action:



STIGMA, ISOLATION AND DISCRIMINATION

We must tackle the lack of public awareness of BMP disorders which feeds their stigma and the associated isolation and discrimination which affects the daily lives of BMP patients, carers and their families

ACCESS TO TREATMENT, SERVICES AND SUPPORT

We must address the large health inequalities which persist in the EU and the fact that many patients do not receive timely diagnosis and access to effective treatment

PATIENT EMPOWERMENT, INVOLVEMENT AND ENGAGEMENT

We must promote patient empowerment, through increased involvement and engagement in policy and research, to deliver better quality of care as well as potential long-term savings for healthcare systems

The following section outlines the key messages per thematic area as well as the policy recommendations that the BMP initiative will support and pursue in the 2019-2024 mandate

³ World Health Organization, SDG 3: Ensure healthy lives and promote wellbeing for all at all ages, WHO, 2019, <https://www.who.int/sdg/targets/en/>

KEY MESSAGES STIGMA, ISOLATION AND DISCRIMINATION



- » Most people living with BMP conditions experience some level of **stigma** owing to **a lack of knowledge and misconceptions amongst the public, employers and healthcare professionals**. This enhances the burden of BMP disorders on patients, their families and their carers
- » Stigma and discrimination mean that **the true scale of BMP disorders is underestimated**, thus, the **prevalence and economic impact is not fully known** by policymakers, healthcare systems, payers and research funders, resulting in **insufficient national and EU budgets**, policies and initiatives dedicated to these conditions
- » The **stigma and discrimination** attached to long-term BMP disorders can seriously impact educational and employment opportunities in studying and working age citizens
- » People with epilepsy are **more than twice as likely to be unemployed as the general population**, but this varies considerably between countries: **in Poland, 49% of people with epilepsy are employed, compared with 77% in Germany⁴**
- » **Improving social attitudes** towards BMP conditions will not only reduce stigma and associated isolation and discrimination, but will also be highly **cost-effective**

THE BMP INITIATIVE CALLS FOR:

- » **Public awareness initiatives on EU and national level to ensure that the public, employers, educators and healthcare professionals are aware of symptoms as well as the benefits of education, early diagnosis and treatment**
- » **The consistent implementation of the Employment Equality Framework Directive and the European Pillar of Social Rights by Member States**
- » **EU and national support to:**
 - Adapt social, professional and educational space and assign trained volunteers to help people affected by BMP disorders
 - Reduce stigma, isolation and discrimination by intergrating people with BMP disorders in the workplace and strengthening their workforce in the process, *eg: Supermarket chains in Denmark have introduced jobs to people with particular disorders that lend themselves to orderly and efficient working practices, such as autism*
 - Policy to protect people with neurological disorders from undue discrimination in the workplace, *eg: In Portugal, people with Huntington's disease are unwilling to disclose their condition to their employers owing to the potential implications of doing so*

OUR COMMITMENT

The BMP initiative commits to running regular awareness initiatives on the prevalence and impact of neurological disorders to improve public knowledge and social attitudes as well as raise awareness amongst employers, educators and healthcare professionals

KEY MESSAGES EQUITABLE ACCESS TO TREATMENT, SERVICES AND SUPPORT



» **Major health inequalities** persist in the EU and **many patients do not receive timely diagnosis and access to effective treatment**. These inequalities and limited access are caused by **significant underfunding of national health systems**, including HTA, reimbursement processes and clinical research together with the lack of a patient-centric approach

» The EU spends just over **three Euros a year per patient** on research into brain disorders⁵

Significant health disparities are documented as a **legitimate barrier interfering with patient health** and delivery of care

» An estimated **3 to 8 out of 10 people living with a brain disorder are inadequately treated or untreated** despite the fact that effective treatments exist⁶

» Given the complexity of BMP disorders, patients should be diagnosed by multidisciplinary expert teams and treated under integrated care

» In many Member States there is limited access to specialists, *eg: In Greece, people with chronic migraine have poor access to the needed expertise. Patients must travel to one of the big cities to reach a relevant specialist*

Better **health service organisation** on national level and **clinical research/health technology assessment processes** both at national and EU level would ensure better access to treatment, services and support

THE BMP INITIATIVE CALLS FOR:

» **National and regional governments to assess access to healthcare in their health systems, specifically in regard to:**

- Access to the right existing treatment at the right time, based on patient preferences
- The full recognition of the added value of innovative treatments, beyond purely clinical considerations, taking into account the socio-economic benefits of access to treatment
- The consistent implementation of guidelines on ensuring meaningful patient input in health policy, clinical research, regulatory matters and health technology assessment

» **The BMP initiative supports complex patient involvement in policy discussions and the final agreement on EU cooperation in the field of HTA and the nature of joint clinical assessments**

» **EU to fund more research on brain disorders aligned with the creation of Pan-European data registries, with the aim of identifying the unmet needs of patients and monitoring the implementation of research results**

OUR COMMITMENT

The BMP initiative commits to collect and share good practice in ensuring equitable access to treatment in the EU Member States – this includes the promotion and dissemination of National Brain/Pain Plans with the aim of supporting brain, mind and pain research and improving the quality of and access to treatment and care, including rehabilitation

⁵ European Brain Council, Value of Treatment for Brain Disorders, 2017, https://www.braincouncil.eu/wp-content/uploads/2017/06/EBC_white_policy_paper_DEF26072017_Low.pdf

⁶ Ibid

KEY MESSAGES PATIENT EMPOWERMENT FOR INCREASED INVOLVEMENT AND ENGAGEMENT



- » Patients with chronic conditions such as BMP disorders are considered **under-consulted resource** in the health system. Patient-centred care models contribute to better quality of care and potential long-term cost-effectiveness. Thus, **patient empowerment (better engagement and involvement in key areas such as research, HTA, policy and delivery of health services)** is vital to provide effective healthcare
- » **Patient involvement in policy discussions must be guaranteed** and any agreement must facilitate timely patient access to innovative treatments
- » The BMP initiative calls for a **“Horizon Europe” budget of at least €120 billion**. Once the text is finalised, **active patient engagement in the distribution of research funding proposals should be a key principle** and pre-requisite for successful funding policies
- » **Patient engagement and involvement is key to unleashing the potential of digital health.** Digital solutions can empower patients with BMP conditions to take control of their healthcare data, manage and personalise their care as well as interact with HCPs and other people with the same or similar conditions

THE BMP INITIATIVE CALLS FOR:

- » The development and dissemination of educational resources, considering language barriers, that allow patients to benefit from access to all the relevant information about BMP disorders, in an easily understandable format
- » Continued support for initiatives and programmes which raise awareness and provide knowledge empowering BMP patients to involve themselves and engage with decision-makers
- » The involvement of BMP patients, patient groups and policymakers in the development and implementation of the European Commission’s digital health actions as well as national discussions on how to best incorporate them into national policy

OUR COMMITMENT

The BMP initiative commits to providing trainings to patients/patient advocates to better understand and engage in R&D, policy and decision-making and the self-management of their own disease, including increased digital literacy



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The challenges facing people with neurological disorders and chronic pain conditions can only be overcome with your help. In order to implement the policy recommendations above, support from EU and national policymakers is critical if we are to build on the progress of the BMP group to date and make real progress in the next mandate. To this end, we ask you to pledge your support to the initiative and advocate actively for people with BMP disorders on EU and national level during the 2019-2024 mandate.

**“I pledge my support to the Brain, Mind and Pain MEP Interest Group
in the 2019-2024 European Parliament mandate”**

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(Insert signature/e-signature)

