



# APPENDIX 1:

## ERADICATE STIGMA, ISOLATION AND DISCRIMINATION

### STIGMA, ISOLATION AND DISCRIMINATION

We know that the lack of public awareness of brain, mind and pain (BMP) disorders feeds into patient stigma, isolation and discrimination. According to a survey conducted by the European Federation of Neurology Associations (EFNA) in 2020, 92% of those living with a neurological disorder feel affected by stigma, and the lack of understanding is perceived as the biggest cause of this<sup>1</sup>. Most people living with BMP conditions experience some level of stigma and, given the isolation and discrimination this can lead to, stigma must be recognised as a legitimate barrier to patient health and delivery of care.

**In a 2020 survey conducted by the BMP Interest Group to gather patient insights, 80% of respondents agreed that the COVID-19 crisis has contributed to the increase in stigma, isolation and discrimination<sup>2</sup>.**

Within the context of the COVID-19 pandemic, eradicating stigma, isolation and discrimination has emerged as a key issue for patients. The government restrictions and social shielding during the pandemic has imposed further social exclusion for patients living with BMP disorders. This in turn has had a tremendous impact on the well-being of both BMP patients their carers and families, adding to their burden of the illness.

BMP patients face a variety of physical, social and cognitive barriers which hinders their ability to complete education or find and maintain work. Professional inclusion is fundamental to well-being, and effective efforts to reduce stigma would be of great benefit to economic productivity. Patients also experience discrimination in terms of access to health and social care services, which may represent a barrier for groups that are socially disadvantaged due to gender, immigration, race/ethnicity or age.

**In 2019, Pain Alliance Europe consulted the pain patients about the existence, forms and manifestations of stigma perceived, related to their condition and statute. The level of stigma felt in the home and in various social groups was high, with 59% feeling stigma in the wider family levels and 42% feeling stigma with their partners. The situation is similar for the work environment: 67% of participants feel a high level of stigma from work colleagues, and 64% feel this from their bosses or managers<sup>3</sup>.**

## KEY CHALLENGES

BMP patients face stigma, isolation and discrimination in different forms, and social and economic factors can have an impact on their experience with the disorders. It is often perceived that people with BMP disorders are people of old age, however young people are also at risk, and as a result of this gap in knowledge, they often face discrimination within their own communities. In EFNA's 2020 survey, almost half of the respondents who lived with a neurological disorder during childhood found it difficult to make friends or maintain friendships, and the same amount were excluded from school events due to their conditions<sup>4</sup>.

Stigma encourages people to hide and represents a clear barrier to diagnosis, treatment, support and advocacy, with groups such as the black, Asian and minority ethnic (BAME) communities tending to experience greater isolation and discrimination with a similar trend being seen in relation to gender. A recent survey conducted on Migraine by Teva Pharmaceuticals illustrates this issue with almost half of the 12 545 respondents (44%) stating that they have hidden their migraine from their family and their employer (2 out of 3)<sup>5</sup>. The same study reveals that 85% of respondents believe that the disease is not taken seriously by society, women (88%) claiming this more so than men (78%)<sup>6</sup>. The lack of awareness and recognition of BMP disorders results in less social awareness and a lack of understanding in society as a whole. Equally, although some people may be affected with well-known neurological and chronic pain diseases, there is a need for further recognition of the true burden of these disorders.

The true scale and burden of neurological and chronic pain conditions is not fully recognized, from prevalence to the economic impact. More than three quarters of respondents to the 2020 BMP Interest Group survey, pointed out that the lack of understanding, awareness and recognition of BMP disorders are closely linked with the underestimated prevalence and impact of BMP disorders. As a result, Member States are unlikely to allocate sufficient national budgets, develop policies and initiatives that support the management of these conditions and combat stigma, discrimination and isolation.

As noted in the Book of Evidence, neurological disorders and chronic pain conditions have struggled in the past to be included in initiatives and policy debates on chronic or non-communicable diseases (NCDs) at national, EU and global level<sup>7</sup>. As a result, stigma related issues for people with BMP disorders have low visibility when compared to other NCDs such as cancer, presenting a challenge in addition to an opportunity for stakeholder engagement.

## ADVOCACY OPPORTUNITIES

There are a number of specific policy hooks at EU level which hold great potential for improving the inclusion of BMP patients and reducing levels of stigma, isolation and discrimination. In particular, engaging with EU policy-makers on disease and disability strategies, as well as social policies will remain a focus of the BMP Interest Group.

Calls for a new and ambitious **EU Disability Strategy post 2020** represent an opportunity to promote inclusivity and combat stigma through efforts to ensure people with BMP disorders are not disproportionately affected by the pandemic, support equal access to employment and lifelong education for people with disabilities.

Additionally, European legislation such as the **European Pillar of Social Rights** will require consistent implementation by Member States to ensure that people with BMP disorders have their fundamental rights protected. The **European Semester** will also play a key role in protecting the interests of BMP patients, as well as the coordination of economic policy developments at EU level which should be informed by the need for investment to tackle major public health challenges, such as the impact of NCDs, including BMP disorders.

The European Commissions' **COVID-19 Recovery Plan** will be key to the BMP community as it will help repair the economic and social damage brought by the coronavirus pandemic, kick-start European recovery, and protect and create jobs. Furthermore, the Recovery Plan also envisages a new **EU4Health programme**, which will make a significant contribution to the post-COVID-19 recovery by making the EU population healthier and addressing inequalities in health status among population groups, countries and regions. EU4Health also represents an

opportunity to deliver on the expectations for better mental health and wellbeing in Europe. Integrating mental health into the Recovery Plan and the long-term funding and policies is key to ensure social inclusion and access to the right services and support.

The activities of the BMP Interest Group will also align with the **WHO's Sustainable Development Goals (SDGs)**, with a specific focus on Goal 3.4, the reduction of premature mortality linked to NCDs. On a global level, the current mental health challenges associated with stigma, isolation and discrimination have now become a priority during the pandemic, and offer scope to anchor this theme in current global priorities. The Commission created the Steering Group on Health Promotion, Disease Prevention and Management of NCDs. The Group assists and advises the Commission in taking initiatives to promote coordination between Member States in addressing the challenges caused by NCDs.

## KEY ASKS TO SUPPORT PROGRESS IN ERADICATING STIGMA, ISOLATION AND DISCRIMINATION

The BMP Interest Group will continue providing a platform to reach out to policy-makers on the key issues and asks on behalf of patients who are calling for the eradication of stigma, isolation and discrimination. Key asks include:

- ✓ Fostering the further education of the general population and healthcare professionals about the burden of BMP conditions and the impact of stigma
- ✓ Improving access to flexible employment and education opportunities, adapting work conditions as well as facilitating access to care and treatments to mitigate the social and economic impact of stigma
- ✓ Improving access to psychological and social support for patients, carers and families affected by BMP disorders
- ✓ Supporting partnerships with patient groups and organisations working on relevant social care related issues to develop or initiate mutually beneficial collaborative relationships with policy makers, employers and medical societies on issues of stigma and social exclusion
- ✓ Encouraging patients, families and carers to initiate mutually beneficial collaborative relationships with policy makers, employers and medical societies on issues of stigma and social exclusion

## TRANSLATING ASKS INTO ACTION

The Roadmap to Change outlines the agreed steps that the BMP Interest Group and affiliated stakeholders will take to pursue the actions in the area of stigma, isolation and discrimination.

**"During the past few months, stigma, discrimination and isolation have increased exponentially because of the COVID-19 pandemic. This worsens the burden of BMP disorders and prevents people from seeking the support they need. As policy-makers, we have an obligation to deliver for citizens by supporting policy change to secure the long-term health and wellbeing of people living with BMP disorders, and ensuring that they are re-integrated in society and back to work post-pandemic."**

**MEP Marisa Matias (Portugal, GUE/NGL)**

## REFERENCES

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3. Pain Alliance Europe (PAE), Report on the Pain Europe Survey, 2019. Find here: <https://pae-eu.eu/wp-content/uploads/2019/08/PAE-Survey-2019-Pain-And-Stigma.pdf>
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5. Teva, Migraine & The Case of Change, 2020
6. Teva, Migraine & The Case of Change, 2020
7. Brain, Mind and Pain Interest Group, Book of Evidence, 2018, Find here: <http://www.brainmindpain.eu/wp-content/uploads/2019/04/BMP-Book-of-Evidence-%E2%80%93-2019-2024-web.pdf>

This appendix was created in November 2020, following a landscape analysis and stakeholder consultation to review the changing public health landscape due to the Covid-19 pandemic.

The aim was to update the existing central policy document of the MEP Interest Group on Brain, Mind and Pain: The Book of Evidence.

This appendix sets out current challenges and arising advocacy opportunities to be pursued now.

To read the full Book of Evidence, access the Roadmap to Change or learn more about the MEP Interest Group, please visit: [www.brainmindpain.eu](http://www.brainmindpain.eu)