



APPENDIX 3: PROMOTE PATIENT EMPOWERMENT FOR INCREASED INVOLVEMENT AND ENGAGEMENT

Empowerment plays a key role in ensuring meaningful patient involvement and engagement in decisions that impact research, treatment and care for people living with BMP disorders. Put simply, empowerment enables patients to gain further control of their lives and increases their capacity to act on issues that can improve health outcomes. Through advancing empowerment at an EU and national level, BMP patients can inform policies and transformations in healthcare which actively affect their day-to-day lives.

The digital transformation of healthcare is a key enabler of patient empowerment. However, systematic patient involvement and engagement in this sphere is critical for the BMP community - now more than ever. The COVID-19 pandemic has forced the adoption of new ways of healthcare service delivery, where there is a greater dependency on digital healthcare for solutions and services.

In a 2020 survey conducted by the Interest Group to gather BMP patient insights, 90% of the respondents acknowledged the increased role of digital health solutions as the world becomes more virtual¹.

The Interest Group recognises that the outcome of EU digital health policy discussions must enable care to be structured around a person's needs and preferences, promoting patient centeredness as a core component of high-quality healthcare and the provision of digital tools and resources to support diagnosis and disease management. A key aspect of unlocking the potential of digital health relates to the importance of ensuring health data accessibility through common and secured infrastructure in the EU, and generating and using data, such as real world evidence obtained outside of clinical trials, to inform more patient centric decision making.

In 2020, Pain Alliance Europe conducted a survey about the use that patients who are living with chronic pain may make of electronic health. Almost half of the respondents (46%) do not use electronic or mobile applications mainly because they do not know about them. 37% of participants who use health apps, do it because they want to better manage the pain themselves. Furthermore, 39% consider that these apps can improve their relationship with their physician².

KEY CHALLENGES

Prior to, and during, the COVID-19 pandemic, some BMP patients faced difficulty in making informed decisions about their health where access to the necessary information is limited and the use of medical terms difficult to understand. In the current pandemic context, where the benefit and value of digital tools has been elevated, BMP patients lack the necessary educational resources to properly access and benefit from the availability of these tools. According to a 2020 BMP Interest Group survey 50% of respondents highlighted that as the world adapts to new ways of working, there is a concern around the lack of digital literacy of patient organisations¹. In addition to this, 73% of patient respondents consider that patients do not have meaningful involvement in policy making, decision making and healthcare planning¹. This shows the importance of including patients at the core of all future decisions which affect them in digital health and beyond. Policy-makers and the BMP community need to come together to work closely on these issues, and develop and promote the necessary tools and resources to support patient empowerment.

The lack of BMP patient involvement is also reflected in research, although patient-centered clinical and public health research and care models have demonstrated better quality of care and potential long-term cost-effectiveness. During, and in the recovery phase of COVID-19, it is critical that both EU Institutions and industry maintain their commitment to supporting BMP research and innovation, as well as investing in public health initiatives to support people living with BMP disorders.

ADVOCACY OPPORTUNITIES

In the past few years, there has been a shift to patient-centric care within the healthcare ecosystem, which calls for the collection of robust and high-quality **real-world evidence** in order to better inform decision making, as well as demonstrate the added value of innovative treatments. The pandemic has accelerated policy hooks and debates in the digital space, providing concrete opportunities to shape the digital transformation of care for the benefit of the BMP community. Digital solutions can empower patients with BMP conditions to undertake an active and responsible role for their health, enable a smarter interaction between patients and the healthcare system, and improve patient outcomes.

The future **European Data Strategy** will contribute in particular to empowering patients to own their data. As the Strategy highlights, data is at the core of digital transformation and it is the right moment to act to create a connected health data ecosystem, which will also ensure better planning and delivery of patient-centred care and personalised medicine. For the BMP community, this must translate into increased control and access to patients' data, enhanced digital health literacy and data literacy levels, development of new ways of communication between health care professionals and patients, more sustainable and interoperable data registries and electronic health records.

One of the top priorities of the European Commission in the health sector is the development of the **European Health Data Space**, which aims to improve the quality of care and reduce inequalities in the scope of data governance, based on GDPR. To fully harness the potential of the European Health Data Space, it is crucial to foster trust in transparent and legally sound data processing and develop tools to empower patients in sharing their data on a voluntary basis. Therefore, we need to set up a clear regulatory data framework that should promote a better exchange and access to different health data, such as the cross border electronic health records and data from patient registries.

The 2021-2027 Multiannual Financial Framework will play a role in the digital transformation of health, under **Recovery and Resilience Facility**, **European Regional Development Fund** and **European Social Fund+**, **InvestEU**, **EU4Health Programme** and **Horizon Europe**, this is an opportunity for patient organisations to tap into EU public health spending for the BMP community.

KEY ASKS TO SUPPORT PROGRESS IN THE AREA OF PATIENT EMPOWERMENT FOR INCREASED INVOLVEMENT AND ENGAGEMENT

The BMP Interest Group will continue promote meaningful and systematic patient empowerment through increased involvement and engagement in planning, policy and research, and calls upon policy-makers to ensure:

- ✓ Improve health care literacy and the quality of patient information on non-communicable diseases, with a focus on BMP disorders;
- ✓ Support a patient-driven approach towards the development of digital tools in order to address the lack of user-friendly technologies and services;
- ✓ Improve digital literacy and equitable access to digital tools; whilst ensuring that innovation is in line with patient preferences - with ongoing monitoring of health outcomes and user satisfaction;
- ✓ The development of an inclusive eco-system supported by a transparent regulated data framework that responds to the needs of BMP patients and patients in general;
- ✓ Allocate more resources to patient organisations involved in the delivery of healthcare services and support, also to encourage best practice sharing.

TRANSLATING ASKS INTO ACTION

The Roadmap to Change outlines the agreed steps that the BMP Interest Group and affiliated stakeholders will take to make progress in the area of empowerment, involvement and engagement.

“Patients should not be merely receivers of health services, they should become their co-creators. This is particularly true in the time of Covid when the digitalization of healthcare systems is accelerating. The EU must ensure meaningful patient involvement in its push for the digital transformation of healthcare”.

MEP Isabel Wiseler-Lima (Luxembourg, EPP)

REFERENCES

1. Brain, Mind and Pain Interest Group Survey, 2020
2. Pain Alliance Europe (PAE), Chronic Pain, 2020. Find here: https://pae-eu.eu/wp-content/uploads/2020/10/PAE-2020-Survey-long_report_final.pdf

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