



Patient Involvement in brain health – A call to action

Alzheimer Europe, the European Federation of Neurological Associations (EFNA) and the Global Alliance of Mental Illness Advocacy Networks - Europe (GAMIAN-Europe), have come together to issue a call to action for improved patient involvement in brain health in Europe.

To safeguard the future of brain health for patients, it is imperative that all stakeholders ensure the priorities, needs and expertise of those living with brain disorders are considered and included. United, the brain health patient voice of Europe calls on all stakeholders to be accountable for patient involvement and shared decision making.

We call on national and EU governing bodies to develop and, where developed, implement policies to ensure early and meaningful engagement and involvement of patients to:

1. Promote a human rights based approach in all policies and research affecting people living with brain health conditions
2. Prioritise patient needs in research agenda setting
3. Review funding proposals for research
4. Access, review and report on access to diagnosis, therapeutic intervention and care pathways
5. Support access to and design of clinical trials, and the design and use of patient reported outcome measures
6. Support approval processes for therapeutic interventions
7. Contribute, with industry, to patient-centric design in research, development and commercialisation
8. Optimise data sharing for patients and society

What is the Brain Health Burden?

Each year, approximately 1 in 3 Europeans are affected by a brain disorder. Across Europe, two thirds of people with brain disorders receive no treatment. It is estimated that EUR 295 billion a year is spent directly on healthcare for neurological and brain disorders, making them “the number one economic challenge for European health care, now and in the future”.

According to figures from 2017¹, brain health disorders:

- Caused 1.2 million deaths, representing 24.3% of those associated with NCDs.
- Accounted for 34.6 million DALYs, representing 26.9% of those associated with NCDs.

¹ Raggi, A., & Leonardi, M. (2020). Burden of brain disorders in Europe in 2017 and comparison with other non-communicable disease groups. *Journal of neurology, neurosurgery, and psychiatry*, 91(1), 104–105.
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- Constitute the most prevalent, disabling and burdensome disease among NCDs in the European population.

Furthermore, it is estimated that the total [economic cost of brain disorders in Europe](#) is approximately EUR 798 billion per year².

Why is it important to involve patients in brain health?

People with lived experience of a condition are uniquely placed to provide insights into what matters most to them and what would most improve their quality of life. These considerations should be the starting point for decision makers across all fields, in developing policy, designing health services or planning research.

As such, the patient voice is vital in research – when involvement is done in a truly collaborative way, patients and researchers ensure that the most meaningful and impactful findings are produced. In basic research initiatives, it starts with developing a shared research agenda and ends at better evaluations of research projects and their impact on patients. Furthermore, patient involvement not only has the potential to reduce the considerable amount of time research takes – it can also improve the efficiency of research, ensure better enrolment in clinical trials and better adherence to therapies.

EU funded research, especially projects funded through programmes such as the Innovative Medicines Initiatives (IMI), EU Joint Programme – Neurodegenerative Disease Research (JPND), ERA-NET NEURON and, we expect, the Innovative Health Initiative (IHI), have increasingly involved patients in research, as shown by the involvement of patient organisations in various EU projects.

The foundation for such positive and meaningful collaboration is well-established – it requires strong partnership working between patients, academia and industry.

What are the outstanding issues of patient involvement?

There are many long-standing challenges in patient involvement, which can only be addressed through collaborations which recognise and value patient involvement. Some of the challenges include:

1. Patients, informal carers and their representatives are often not meaningfully involved in the planning, design and governance of research (either in individual research

² Olesen, J., Gustavsson, A., Svensson, M., Wittchen, H.U., Jönsson, B., CDBE2010 Study Group and European Brain Council, 2012. The economic cost of brain disorders in Europe. *European journal of neurology*, 19(1), pp.155-162.



projects or in strategic research programmes) – too often patients are involved after decisions on subjects, governance etc. have been taken.

2. Involving patients in decisions that concern them in a meaningful way is challenging as it requires ensuring that resources, information and meetings etc. are accessible, balancing the need to address scientific, research and regulatory questions as well as treatment options, with what patients can and wish to talk about.
3. Recruitment and retention of patients in research, especially in clinical trials, is difficult especially as there is significant variation across Europe in relation to opportunities to participate in research.
4. Duplication of efforts in involving patients in different research – some projects have overlapping aims and objectives (in relation to patient involvement), yet projects will often establish their own distinct approaches and ways of involving patients.

Why are we issuing this call for action now?

In the next few years, many EU-level flagship brain-related projects will come to an end. However, the need to continue the focus on brain health research, coordinated at a European level, is evident.

Discussions are already underway for a European Brain Health Partnership, in an effort to align existing projects and ensure their findings are used as the basis for future scientific collaborations.

This is of course to be welcomed. However, the voice of the patient is still insufficiently included in these discussions, with the focus often predominantly on basic science, data sharing and clinical trials. These are undeniably important and the progress which has been made in these fields in recent years is to be celebrated, as they have improved our understanding of brain health and the underlying mechanisms which cause different disorders.

However, less attention is given to the day to day impact on and quality of life of people living with brain conditions. Research focused on how best to support people to continue to live as well as possible or develop models of care and support, both of which would have an immediate benefit for the quality of life of individuals (and carers) is still lacking. Whilst few disease-modifying or curative treatments exist for many brain health conditions, ensuring that people are able to live well with the condition must be prioritised as a key focus of the brain health research agenda alongside the search for better treatments and cures.

For policies and actions on brain health to have the greatest benefit for the people who live with such conditions, there must be a coordinated and collaborative approach, across the



domains of health and research, involving patients, carers, decision makers, researchers, clinicians and civil society.

With the transition into the Innovative Health Initiative (IHI) partnership underway, the emergence of the EU NCD initiative, as well as progress in the discussions for the future European Brain Health Partnership, the current policy context provides a perfect opportunity to transform not only our understanding of brain health, but to develop new ways to improve the quality of life of individuals living with brain conditions, as well as creating structures which give them meaningful involvement in setting the brain health agenda.

What are the key asks of the Call for Action?

Based on the reflections above, our organisations wish to see a brain health environment in Europe which meaningfully involves patients throughout the entire process, from strategic planning and development of research programmes and partnerships, through to the involvement in individual projects.

EU and national policy makers, regulators, funders and researchers must recognise the value of patient involvement in research and act on this recognition, not just in the research projects themselves, but in the development, governance and monitoring of research programmes, to ensure their focus remains relevant for people with lived experience.

Our organisations and our members have demonstrated over many years our commitment to ensuring that the patient voice is heard in policy-making processes in health, social affairs and research, often playing leading roles in EU funded projects. We remain committed to ensuring that the voices of patients are heard and wish to see a stronger commitment from decision makers, funders and researchers to allow a strong patient voice in priority setting in the brain health agenda in a practical and concrete way.

Therefore, we call for the following:

- Patients should be formally represented in setting the agenda of the European Brain Health Partnership, with a clear and recognised role for patient organisations in its governance and monitoring structures
- Research funders should place a greater emphasis on the role of and need for the patient voice in applications and the extent to which patients have been/are being involved in the development of the project proposal(s)
- The forthcoming European Brain Health Partnership must have a focus across the spectrum of research fields, reflecting a “care today, cure tomorrow” approach which will more likely benefit people living with brain health disorders today
- All stakeholders in the field of brain health, whether researchers, regulators, public health bodies, decision-makers etc. should ensure that resources and materials when involving people are accessible and in formats which meet the needs of patients.