

EFNA 2023 POSITION PAPER ON THE IGAP TARGETS RELATING TO NATIONAL PLANS AND AWARENESS CAMPAIGNS

1. Introduction

Neurological disorders are a significant public health challenge and addressing them has become a global priority with the adoption of the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022–2031 (IGAP) in 2022. The European Federation of Neurological Associations (EFNA) recognizes the critical importance of implementing the IGAP and calls attention to two specific IGAP targets that are essential prerequisites for the successful rollout of the plan. This position paper highlights the importance of these two targets and provides recommendations for achieving them comprehensively.

2. The Global Challenge of Neurological Conditions

Neurological conditions are the leading cause of disability adjusted life years (DALYs) and the second leading cause of death globally. In Europe, they are the third leading cause of mortality and DALYs. More than half of countries have seen an increase in the risk of dying from neurological disorders, making them the fastest-growing cause of death among non-communicable diseases. By 2040, neurological conditions are projected to contribute to an increase of approximately 50% in DALYs.

3. The Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022–2031 (IGAP)

To address this challenge, over 190 countries, including all EU countries, supported the adoption of the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022–2031 (IGAP) in 2022. This marks a turning point and a revolution in neurology as the WHO and its member states are now committed to prioritizing brain health and addressing the burden of neurological conditions at global, regional, and national levels.

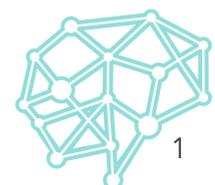
All the EU countries have expressed support to the Plan since its early days. It is now time for Europe to lead the way in implementing the IGAP.

4. Two Essential IGAP Targets for Successful Rollout

The IGAP has ten global targets and countries can set their own national targets, taking into account national circumstances and challenges. In this position paper, EFNA calls attention to two IGAP targets that are essential prerequisites for the successful rollout of the whole plan. The targets are:

1. *Adapting or updating existing national policies, strategies, plans or frameworks to include neurological disorders*
2. *At least one functioning awareness campaign or advocacy programme for neurological disorders*

Implementing these two targets comprehensively will be essential to the success of the IGAP.



5. Awareness Campaigns to Reduce Stigma and Discrimination

The first step to achieving these targets is raising awareness about the IGAP itself as well as the collective burden of neurological conditions and a need to prioritize them within the context of brain health. Education should address the impact of neurological conditions and the opportunities to optimize brain health for everyone so that the brain health is valued and protected as our most vital asset, to the benefit of all society. Widespread awareness is needed to dispel the immense stigma surrounding neurological conditions. Currently, 92% of those living with neurological conditions report feeling affected by stigma, which is mainly caused by a lack of understanding, myths, and misconceptions about these disorders and their often invisible nature. Awareness campaigns can improve understanding and reduce stigma and discrimination against people with neurological conditions. The objective of these campaigns should be to foster an accurate understanding of neurological conditions, reduce stigmatization and discrimination associated with them, educate people about the human rights of people with neurological disorders and the UN Convention on the Rights of Persons with Disabilities, and enhance the general population's ability to recognize early symptoms and signs of neurological conditions.

6. Bundled Approaches for Comprehensive National Neurological and Brain Health Plans

Countries need to take a holistic and comprehensive approach to neurological conditions and brain health by formulating national neurological and brain health plans that take a bundle approach to neurological conditions. This means addressing their common challenges and solutions rather than fragmentation in separate medical "silos". Such bundled approaches are effective in other areas such as cancer, even though there are more than a hundred distinct types of cancer, which can vary substantially in their behaviour and response to treatment.

Implementing such strategies at a population level can be the most impactful, cost-effective approach to address the massive burden of neurological ill-health and can generate substantial health and wellbeing gains. National neurological and brain health plans will be the best instrument to drive systemic change.

7. Factors for the Development, Implementation, and Sustainability of National Neurological and Brain Health Plans

A national neurological health plan should examine the gaps and needs related to neurological conditions in a particular country and identify policy solutions to address them, tailored to the unique culture and demographics of that country. Furthermore, such plans can create a vehicle to consider a range of issues from improving the quality of health and social care to expanding support provided to caregivers to increasing research funding. When issued by the government, a national neurological health plan establishes an infrastructure and accountability that can lead to a continued assessment and evaluation of progress on, and outcomes of, the plan.

A range of factors should be considered for the development, implementation, and sustainability of national plans. These factors include political leadership and strong commitment, involvement of multiple stakeholders, meaningful engagement of patients in plan development and implementation, allocation of dedicated resources for implementation, retention of flexibility, and learning from experience through monitoring and evaluation, as well as cross-border learning. To achieve real success, we must ensure that plans can be monitored and evaluated by developing information systems with adequate capacity to measure health outcomes resulting from such interventions. The plan's development can be informed by a situation or needs assessment based on available baseline data.

8. The Crucial Role of Multiple Stakeholder Involvement



Multiple stakeholder involvement, particularly through the representation of people with lived experience, will be a crucial catalyst for the development, implementation, and sustainability of neurological and brain health plans. Lessons from other disease groups clearly show that patient groups played a central role in developing other national plans and were key to the successful adoption and implementation of such plans. If a country prefers to develop a wider plan, such as a strategy addressing brain health including both mental and neurological conditions, or a non-communicable diseases plan, a dedicated section on neurological conditions, including specific targets from the neurological IGAP, should be incorporated into those plans alongside with a ringfenced budget.

9. Regional Coordination between Global and National Targets

Regional coordination between the global (IGAP) and national (national targets) dimensions can provide tremendous added value in achieving the best results in individual countries. In this regard, DG SANTE is well placed to provide a platform that can facilitate the development and implementation of national neurological and brain health plans in a synergistic way and develop a European guide for quality national neurological and brain health plans. Successful examples exist in other disease areas such as cancer and diabetes, e.g., CanCol Joint Action, European Guide for Quality National Cancer Control Programmes, or Guide for National Diabetes Plans - CHRODIS+.

In this regard, the NCD Initiative Healthier Together, with mental and neurological conditions among its priority areas, is timely. The European community now has a unique window of opportunity to provide an integrated and cross-sectoral response to neurological health. Investing in this holistic model can bring measurable health and economic gains to European countries, including decreasing the incidence of neurological disorders, improving survival rates, reducing complications and disability, lowering treatment costs, and ultimately ensuring a better quality of life for all those affected.

In view of the above, the NCD Initiative's activities addressing neurological disorders should fully align with the targets of the IGAP, which provides a comprehensive framework for national action. This synergistic approach will be the most efficient use of resources, which are limited and need to be spent wisely.

10. Central role of a coordinated patient involvement

Patient involvement in the implementation of the IGAP and the NCD Initiative will be best achieved by involving national neurological coalitions that bring together different neurological disorders. However, in many countries, such alliances do not exist, and there is instead a patchwork of national organizations dedicated to individual neurological disorders. Building the organizational capacity of neurology patient groups at a national level should be supported by the NCD Initiative. These groups can become focal points and critical enablers, contributing significantly to the implementation of the IGAP targets and NCD Initiative projects. EFNA can assist in creating or strengthening these national groups by leveraging its extensive membership covering all major disease areas in all EU member states and other European countries.

