BRAIN HEALTH IN UNCERTAIN TIMES: A STRATEGIC INVESTMENT FOR EUROPE'S FUTURE

Report

July 2025

Focus Epilepsy
Headway
A new roadmap in Brain Health
TEHA
Angelini Pharma

This document was conceived and produced by TEHA Group, a subsidiary of The European House – Ambrosetti, in partnership with Angelini Pharma. The document was prepared by the TEHA Working Group composed of: Daniela Bianco, Elisa Milani, Irene Gianotto, Iacopo Del Panta Ridolfi, and Nicola Cosentino.

Acknowledgements

The Headway – A New Roadmap in Brain Health initiative, launched in 2017 by the Think Tank TEHA Group in collaboration with Angelini Pharma, is a comprehensive platform dedicated to the analysis of brain health policies, access to care, and societal inclusion, advocating for evidence-based interventions.

Operating within a **multisectoral framework**, Headway engages institutional representatives at the European and national levels, healthcare professionals, civil society organizations, patient associations, and the private sector, fostering collaboration among all stakeholders to ensure a **holistic approach to brain health** (in particular epilepsy) and mental disorders.

The initiative keeps the trajectory and works in continuity and coherence with programs, activities, and strategies of Governments and International Organizations (such as the WHO) and scientific societies, patient associations, advocacy groups (among others, ILAE, IBE, and Epilepsy Alliance Europe), as well as of European Institutions, to contribute to reducing the burden of epilepsy in Europe.

The 2025 edition of the "Headway – A new roadmap in Brain Health: Focus Epilepsy" initiative aims to position epilepsy as a critical component of brain health and a public health priority in the EU. Its main objectives include quantifying and highlighting the **socio-economic burden of epilepsy**, raising awareness about the **challenges faced by individuals with epilepsy** – mainly in terms of unmet needs, treatment gap, access to innovative treatments and employment opportunities – and promoting **strategies to improve epilepsy care and reduce stigma**, particularly in workplaces, and stimulating **policy debate**. Additionally, the initiative seeks to develop policy recommendations for securing funding and establishing common strategic priorities aligned with the Intersectoral Global Action Plan on epilepsy and other neurological disorders (IGAP).

The initiative, which culminated in a **Roundtable event at the European Parliament** in July 2025, was made possible through the collaboration of various experts. TEHA Group gratefully acknowledges the time, expertise, and valuable contributions provided by all those involved in the development of this Report. In particular, the 2025 edition has benefited from the input of a multidisciplinary, cross-country **Patient Expert Group**, whose insights helped highlight both common challenges and country-specific needs.

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Introduction: The invisible casualty of global uncertainty

Europe is facing the consequences of a profound geopolitical transition, shifting from a period of relative stability to one marked by heightened uncertainty, fragmentation, and tension.

While conflicts continue to displace millions globally – over 114 million in 2024, facing prolonged uncertainty, inadequate sanitation, and barriers to education and employment – the repercussions extend far beyond war zones. Rising nationalism and isolationism are reshaping global priorities, often undermining social cohesion and international cooperation. These dynamics are producing wide-ranging ripple effects that extend beyond global security, directly and indirectly influencing the health and well-being of populations.

The impact of geopolitical instability on health

The repercussions of this evolving geopolitical landscape on health are both deep and multifaceted. International conflicts and political instability disrupt healthcare systems on multiple levels, significantly impacting both the physical and mental health of the general population, especially the most vulnerable groups. Recent studies have highlighted the compounding effects of conflict on mental and neurological health, showing increased incidence rates, worsening disease progression, and elevated levels of stigma and social exclusion.

At a systemic level, regions directly affected by conflict often experience the collapse of health infrastructure and a severe loss of professional capacity. This leads to the interruption of essential services such as immunizations, maternal and child healthcare, and the management of non-communicable diseases. **Even in relatively "safe" areas, tensions can disrupt care continuity, interrupt medication supply chains, and cause shortages in diagnostic and therapeutic services** – all of which significantly compromise patient outcomes. These disruptions are particularly critical for conditions that require consistent, long-term access to life-saving medications, and specialized care.

Figure 1. The determinants of health and the impact of geopolitical instability - *Source: TEHA on WHO data, 2025*

When looking at Europe, this situation is especially evident in Ukraine, where the WHO has documented over 2,250 attacks on healthcare facilities since the full-scale war began 3 years ago, and where the conflict has intensified health needs, particularly in areas such as trauma care and rehabilitation.[1] **Geopolitical chaos and economic threats do not spare other European countries either,** increasingly depending on external sources for critical medicines and health technologies. The COVID-19 pandemic underscored the vulnerability of supply continuity and highlighted the need for autonomy in essential drug manufacturing. Today, all European countries continue to struggle with medicine shortages, largely due to fragile supply chains characterized by long, complex value chains and just-in-time deliveries.[2] Resilience in the pharmaceutical supply chain must therefore become a priority. The EU is undertaking positive steps to address these challenges by tackling medicine shortages and diversifying supply chains, particularly for products with limited manufacturing sources. By fostering greater self-sufficiency, Europe can mitigate supply disruptions, ensuring health security across Member States.

The threatening side effects of globalization are well visible when geopolitical tensions rise – as the ongoing frictions between the US and Europe show. **In a context marked by shifting political priorities, however, health cannot be treated as a secondary issue.** In February 2024, EU leaders presented the Readiness 2030 plan, originally labelled "Rearm Europe", a new strategic agenda focused on boosting Europe's defense capabilities, economic competitiveness, and crisis preparedness. Yet, the plan should also acknowledge health security as a core component of resilience. In response, in March 2024, health ministers from 11 EU Member States issued a joint statement warning that the omission of health from Europe's long-term strategic vision risks becoming an Achilles' heel.[3]

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[1] WHO (2025), "Three years of war: rising demand for mental health support, trauma care and rehabilitation".

[2] In this specific direction goes the Critical Medicines Act, proposed in 2023, by aiming to strengthen pharmaceutical autonomy.

[3] The open letter is available at this link: https://www.euronews.com/my-europe/2025/03/09/europes-dangerous-medicine-dependency-is-the-achilles-heel-of-its-defence-strategy

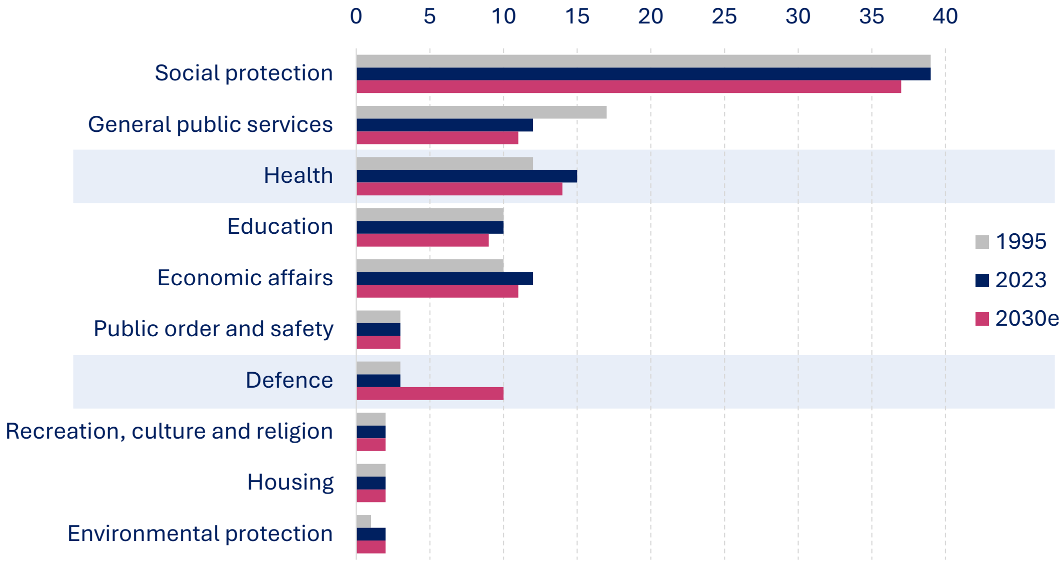

Figure 2. EU Government expenditure trend by function (% on total), 1995, 2023, 2030e - *Source: TEHA on Eurostat and European Commission data, 2025. The estimate is based on insights from the EU "Readiness 2030" Plan and under the assumption of a budgetary spending constraint.*

While health has emerged as a critical pillar of Europe's strategic resilience, with the COVID-19 pandemic exposing profound structural vulnerabilities in health systems across the continent and compelling a paradigm shift in how security is conceptualized, significant challenges remain. As highlighted in a recent editorial in The Lancet, Europe's health security framework requires a "reboot" by 2025 to ensure a more integrated and cohesive approach to future threats.[4] Former EU Health Commissioner Stella Kyriakides has explicitly stated that **"health must be considered an integral part of the EU's security strategy"**, warning that health vulnerabilities can undermine Europe's overall capacity to respond to crises. In this light, the resilience of European societies will increasingly depend on the ability to protect and promote population health – both as a matter of public welfare and as a foundation of collective security.

Investing in health and inclusion as a social "stability" strategy

In light of these dynamics, health must be redefined as a cornerstone of Europe's broader strategy for security and resilience. Recent reports – including the Global Risks Report 2024[5] – highlight how **health is deeply interconnected with key domains such as economic competitiveness, national security, and social stability.** Specifically in today's context of growing social fragmentation and political polarization across Europe, investing in health and social inclusion is therefore not only a moral imperative but a strategic necessity. Unequal access to healthcare, unmet mental health needs, and widening health disparities often mirror and deepen existing divides, fueling distrust in institutions and contributing to civic disengagement.

In this context, it must not be forgotten that **unaddressed health conditions are responsible for significant societal costs – ranging from absenteeism and early**

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[4] The Lancet (2024), "European health security needs a reboot in 2025".

[5] World Economic Forum (2024), "Global Risks Report 2024".

retirement to long-term disability and dependency. The revised EU Economic Governance Framework, adopted by the European Commission in April 2023, marks a paradigm shift in how public spending is assessed. No longer focused solely on deficit control, the new approach recognizes the role of strategic investments – including in public health and brain health – in strengthening a country's economic and social resilience. This opens a window of opportunity for Member States to prioritize health not as a cost to contain, but as a pillar of long-term sustainability, in a vision in which rather than costs, investments represent value multipliers with tangible returns in productivity and social cohesion.

How investing in brain health saves costs

In this rapidly evolving geopolitical and socioeconomic landscape, brain health remains both underrecognized and critically important. While economic disruption and broader social challenges often dominate attention, the cognitive, emotional, and neurological consequences – whether driven by crisis, chronic conditions, or underlying health inequities – tend to receive far less visibility. **People living with brain disorders, regardless of their cause, risk being sidelined in times of competing priorities**. This Report aims to highlight how a population burdened by undiagnosed or untreated brain health conditions risks being less productive, less innovative, and more vulnerable to social fragmentation, and why we should keep the level of attention high and invest in brain capital.

While Europe is currently facing multiple economic pressures – from inflation and labor market uncertainty to rising social protection costs – the economic impact of under-addressed brain health conditions remains insufficiently considered. Conditions such as epilepsy, depression, or dementia contribute significantly to indirect costs, including absenteeism, early retirement, and reduced productivity.[6] Studies suggest that **early intervention and appropriate care pathways can reduce long-term public expenditure and support individual and societal resilience**.[7,8] Epilepsy, as a treatable and manageable condition, exemplifies how early diagnosis and inclusive policies can produce significant economic and social returns. In contrast, delays in care, stigma, and lack of access drive cycles of exclusion, poverty, and inefficiency.

Against this backdrop, *Headway – A New Roadmap in Brain Health: Focus Epilepsy* calls for a redefinition of brain health in times of uncertainty. **By framing epilepsy as a 'sentinel condition' – clinically relevant, socially sensitive, and economically impactful – the Report urges integrated, data-driven, and equity-oriented approaches.** The goal is to move beyond fragmented responses and place brain health at the core of policy agendas. The stakes are high but so is the opportunity: to build a Europe where resilience is not measured solely in economic terms, but also in our collective capacity to care for and empower all individuals, particularly those living with brain health conditions.

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[6] Olesen J et al. (2011), "The economic cost of brain disorders in Europe".
[7] Feigin VL et al. (2020), "The global burden of neurological disorders: translating evidence into policy".
[8] Nail-Beatty O et al. (2024), "Brain health is essential for smooth economic transitions: towards socio-economic sustainability, productivity and well-being".

What is epilepsy?

Epilepsy is one of **the most common chronic neurological disorders worldwide**. This noncommunicable brain disease is characterized by recurrent, unprovoked seizures, which result from sudden and excessive electrical discharges in groups of neurons and can arise from various regions of the brain. Seizures manifest in diverse forms, ranging from brief lapses in attention or muscle twitches to prolonged and severe convulsions. There are four main seizure classes of seizures: focal (originated in one side of the brain) generalized (originated in both hemispheres), unknown (whether focal or generalized), and unclassified. In some cases, these seizures may lead to loss of consciousness, lead to motor symptoms or not motor symptoms like loss of control over bowel or bladder functions.[9] The frequency of seizures can also vary significantly, from fewer than one per year to multiple episodes per day.

A single seizure is not sufficient for a diagnosis of epilepsy – up to 10% of the global population may experience an isolated seizure during their lifetime. For this reason, epilepsy is typically diagnosed when: two or more unprovoked seizures occur more than 24 hours apart; there is one unprovoked seizure and a probability of further seizures similar to the risk after two; a diagnosis of an epilepsy syndrome. The condition has been recognized for millennia, with documentation dating back to 4,000 BCE. Despite advances in medical understanding, epilepsy remains surrounded by stigma, fear, and misinformation in many societies, which significantly impacts the quality of life for individuals with the condition and their families.

Linking to this, it is important to underline that epilepsy is not a contagious condition. **Although various pathological mechanisms can cause epilepsy, the underlying etiology remains unknown in about 50% of cases worldwide.** Identified causes are typically classified as genetic, structural, infectious, metabolic, immune, or unknown. Genetic factors may involve single-gene mutations, chromosomal abnormalities, or complex interactions between multiple genes and environmental triggers. Structural causes, one of the most important for the onset of epilepsy in adults, include, among the others, malformations of cortical development, vascular malformations, traumatic brain injury and tumors.[10] Establishing the cause is essential for guiding treatment and prognosis. Advances in diagnostics, particularly imaging and genetic testing, are improving our ability to identify underlying etiologies, although access remains uneven across health systems.

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[9] ILAE (2025), “Updated classification of epileptic seizures”. Available at: https://www.ilae.org/updated-classification-epileptic-seizures-2025.

[10] ILAE (2024), “Diagnostic Manual”. Available at: https://www.epilepsydiagnosis.org/aetiology/structural-groupoverview.html.

1. The urgency of investing in brain health in a changing world

In today's world, brain health should be seen as a starting point and an essential condition for building resilient, inclusive, and forward-looking societies.

The lifelong importance of brain health

Even, and especially, in uncertain times, supporting brain health is not optional: it is the foundation for individual well-being and collective stability.

Brain health, in fact, plays a fundamental role throughout the entire life course of every single person. As the most complex organ in the human body, the brain governs not only how we think, feel, and behave, but also how we learn, connect with others, and respond to challenges. Its functioning shapes every aspect of daily life and overall health.

The World Health Organization defines brain health as a state of functioning across cognitive, sensory, emotional, behavioral, and motor domains, allowing individuals to realize their full potential, regardless of whether a disorder is present.[11] This definition underscores the need to promote brain health throughout the entire life course. In children and adolescents, a healthy brain supports cognitive development, learning, and social interaction, laying the foundation for tomorrow's citizens and workforce. Among working-age adults, it underpins productivity, adaptability, and meaningful economic participation. For older adults, especially in an ageing Europe, it is essential for preserving independence, cognitive abilities, and quality of life.

Optimizing brain health across all stages of life has therefore tangible benefits, improving physical health, reducing long-term care needs, and contributing to greater social cohesion. Most importantly, **it is a powerful enabler of sustainable economic growth, lowering avoidable costs while unlocking both individual and societal potential**.

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[11] WHO (2022), "Optimizing brain health across the life course".

The increasing burden of brain disorders

Brain health conditions, including both neurological and mental health disorders[12], represent one of the most pressing global health challenges of our time, being responsible for over 18% of all health loss worldwide[13]. Their impact moves from loss of independence and increased healthcare costs to reduced productivity, strained social relationships, and elevated suicide risk.

The dimension of this issue is well clear looking at the numbers: **1 in 3 people will experience a neurological condition in their lifetime, while 1 in 8 lives with a mental health disorder**.[14] Globally, neurological disorders affect an estimated 3.4 billion people globally (equivalent to 43% of the world population)[15], and nearly 1 billion people are living with mental health disorders. In Europe alone, 179 million individuals are affected by mental or neurological conditions. In terms of global disability, brain health conditions are among the leading contributors: in 2021 alone, they accounted for more disability-adjusted life years (DALYs) than commonly acknowledged threats such as cancer or cardiovascular disease.[16]

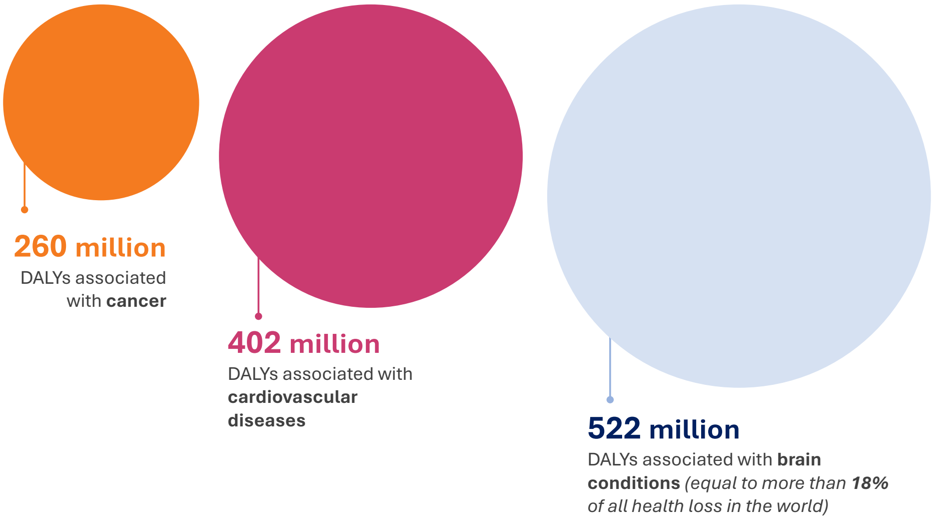

Figure 3. Global burden of brain conditions vs. cancer and cardiovascular diseases (million DALYs), 2021 - *Source: TEHA elaboration on Global Burden of Disease data, 2025*

The urgency of recognizing brain health as a global health priority stems from its rapidly growing burden and the relevant mismatch in resource allocation. Demographic shifts, particularly population ageing, are driving a sharp increase in age-related neurological conditions such as Alzheimer's disease and other dementias, alongside a general rise in chronic conditions among older adults. These trends are expected to accelerate in the coming years, placing increasing pressure on families, health systems, and economies. Left

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[12] Winkler AS et al. (2024), "Global brain health-the time to act is now".

[13] Institute for Health Metrics and Evaluation (2022), "Findings from the Global Burden of Disease Study 2019".

[14] WHO (2022), "World mental health report: transforming mental health for all".

[15] The Lancet Neurology (2024), "Global burden of conditions affecting the nervous system". This analysis includes stroke among neurological conditions.

[16] According to GBD, in 2021, brain conditions caused 522 million DALYs vs. 260 million DALYs of cancer and 402 million DALYs of cardiovascular diseases.

unaddressed, these conditions will contribute to straining healthcare systems, reduce workforce participation, and erode social cohesion.

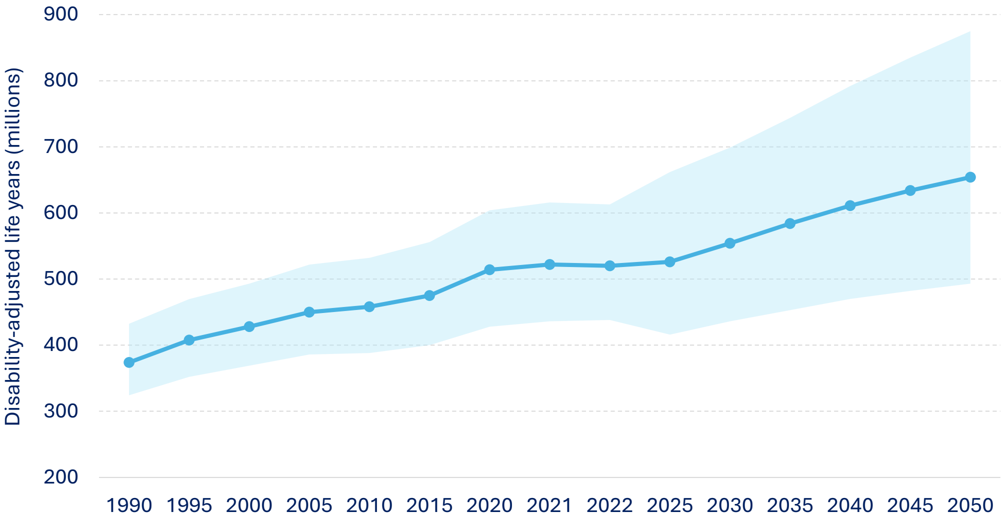

Figure 4. Global burden of brain conditions (million DALYs), 1990-2050e - *Source: TEHA on Global Burden of Disease – Brain Health Atlas data, 2025*

The economic toll is equally alarming: brain health currently costs the global economy an estimated $2.5 trillion each year, a figure expected to rise to $6 trillion by 2030[17]. These costs are not limited to direct healthcare expenses; they include lost productivity, early retirement, long-term disability, and unpaid caregiving responsibilities.

Compounding this challenge is the actual inadequate and uneven access to care.

Many individuals living with brain health conditions face barriers to timely diagnosis, treatment, and ongoing support, especially in rural or underserved areas. Families are often left to fill the gap, with caregivers providing extensive, unpaid support that comes with its own emotional, psychological, and financial burden. The toll is particularly high for those caring for individuals with chronic, complex conditions and varies depending on whether they care for children, adolescents, or adults.

The rise of the Brain Economy

As the global burden of brain disorders becomes increasingly evident – affecting hundreds of millions globally, undermining individual potential and placing immense pressure on health systems and economies alike – recent shifts in global health governance suggest that brain health remains insufficiently prioritized.

A positive milestone came in 2022 with the adoption of the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (IGAP) by the World Health Assembly (WHA). Developed and led by the WHO, IGAP aims to provide a comprehensive and coordinated framework for improving the prevention, diagnosis, treatment, care, and rehabilitation of neurological conditions. The plan covers a ten-year period (2022–2031) and represents a formal commitment by Member States to integrate neurological disorders into national public health agendas. It also seeks

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[17] McKinsey and Company, “What is brain health?”, Available at: https://www.mckinsey.com/featured-insights/mckinsey-explainers/what-is-brain-health#/. Accessed June 2025.

to foster intersectoral collaboration and align countries around shared priorities, contributing to greater visibility and momentum for brain health across both global and European health agendas.

Despite its strategic potential, the implementation of IGAP faces substantial challenges, with the current geopolitical and economic climate likely to cause considerable delays in its application across Europe.[18] These include both sectoral systemic and barriers. On the sectoral side, implementation is slowed by **fragmented service delivery, uneven distribution of specialized workforce (such as neurologists or nurses), and a lack of integrated care pathways** tailored to chronic neurological conditions, with epilepsy care remaining siloed and underprioritized, with insufficient coordination between primary, specialized, and social services. Moreover, disparities in access to diagnostic tools, treatment options, and follow-up services persist between and within countries, exacerbating health inequalities and undermining IGAP's vision of equitable brain health.[19]

On the systemic side, **fiscal constraints and pressure to reduce national deficits are limiting the allocation of resources to healthcare services**, including those for people living with epilepsy and other neurological conditions. Political instability and frequent turnover in Government leadership further hinder long-term planning and policy continuity, weakening the ability to embed IGAP's objectives into national health strategies. WHO's new organizational structure for 2025 underscores these constraints. In the new organigram, neurology falls within a broader "Non-communicable Diseases & Mental Health" department, with no dedicated structure. This reorganization is partly driven by financial pressures following the U.S. withdrawal – previously WHO's largest donor. This change has contributed to a projected $600 million budget shortfall in 2025 and a $1.7 billion gap for the 2026–2027 biennium. As part of a cost-saving strategy, the number of headquarter departments and directors will be cut by more than half.

This limited attention is also reflected in high-level policy discourse. The zero draft of the upcoming UN Political Declaration on Non-Communicable Diseases, expected from the High-Level Meeting in September 2025, barely mentions neurological conditions.[20] Without explicit policy recognition and dedicated investment, brain health risks will continue to fall through the cracks of fragmented health agendas.

At the same time, however, **momentum is beginning to build from the economic and innovation sectors, rather than from traditional healthcare sectors,** which are increasingly recognizing the strategic importance of brain health. A new paradigm is emerging: one that positions brain health not only as a public health concern but as a key driver of economic and social progress. This approach revolves around the Brain Economy concept: an emerging vision where brain health and brain skills are central to building resilient, innovative, and inclusive societies.

At the heart of this framework is the concept of brain capital, a form of human capital that integrates brain health with key cognitive, emotional, and social skills such as analytical thinking, adaptability, creativity, and empathy. In this view, **investing in brain capital is not only good for health and disease prevention, but also for the**

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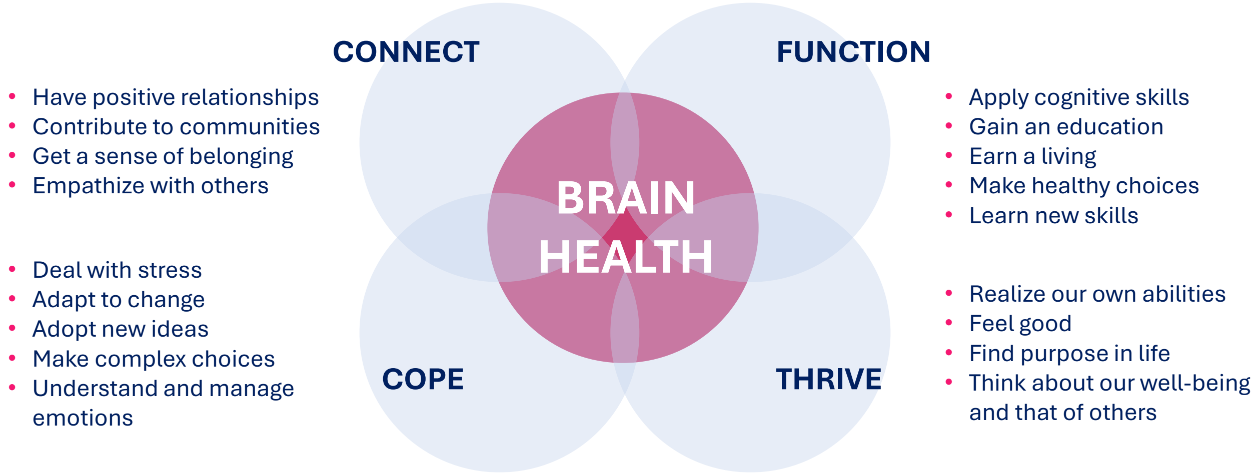
[18] This topic will be further developed in last section of the Report.

[19] These critical dimensions will be explored in greater depth in the following sections.

[20] United Nations (2025), "Zero draft. Political declaration of the fourth high-level meeting of the General Assembly on the prevention and control of noncommunicable diseases and the promotion of mental health and well-being.".

economy, with optimal brain functioning enabling individuals to thrive, innovate, and contribute meaningfully to society.

Besides focusing on the preservation of good health and adopting a life-cycle approach, in fact, the Brain Economy responds to the rising global demand for brain-based skills across all sectors of the modern workforce, driven by rapid technological change, demographic shifts, and evolving labor market needs. According to recent estimates, prioritizing brain health and brain capital could unlock up to $26 trillion in global economic value by boosting workforce productivity, sparking innovation, and reducing years lost to disability.[21]



- Have positive relationships
- Contribute to communities
- Get a sense of belonging
- Empathize with others

- Apply cognitive skills
- Gain an education
- Earn a living
- Make healthy choices
- Learn new skills

- Deal with stress
- Adapt to change
- Adopt new ideas
- Make complex choices
- Understand and manage emotions

- Realize our own abilities
- Feel good
- Find purpose in life
- Think about our well-being and that of others

Figure 5. Brain health intrinsic and instrumental value - *Source: TEHA on WHO data, 2025*

Moreover, brain capital offers a unifying policy objective, cutting across health, research, education, labor, and social sectors. It provides a shared goal for collaboration between traditionally siloed policy domains, recognizing that sustainable development depends as much on mental and neurological well-being as it does on environmental or financial stability.[22]

While Europe is the first continent where **national brain health plans** have emerged, some of which, as is the case in Finland, have a strong brain capital component, new interesting advancements are coming also from the global South. This is the case of the Yaoundé Declaration on Brain Economy, Brain Health & Brain Capital[23,24], adopted in July 2024 and strongly endorsed by the Government of Cameroon (Chair of the 79th United Nations General Assembly), which outlines a comprehensive roadmap for building a brain-healthy economy. Launched with strong leadership from Africa and endorsed globally, the Declaration calls for a rapid shift away from brain-unhealthy systems toward a model that nurtures wellbeing, productivity, and creativity. It urges governments and institutions to invest in the brain capital of their populations, not only to treat disease, but to prepare societies for the complex challenges ahead.

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[21] McKinsey Health Institute (2025), “Promoting the brain economy transition”.

[22] Eyre H et al. (2024), “Brain capital is crucial for global sustainable development”. The Lancet Neurology.

[23] Njamnshi A et al. (2024), “The Yaoundé Declaration”. The Lancet Neurology.

[24] Njamnshi A et al. (2025), “African leadership in brain diplomacy: The Yaoundé declaration advances the global brain economy playbook for better brain health”. Neuroscience.

Prevention as an urgent unmet need

Brain health must be redefined not merely as the treatment of existing disorders, but as the active prevention of diseases and the long-term preservation of cognitive, emotional, and social well-being. Yet, in practice, most health systems concentrate resources on clinical interventions and care, with limited attention and funding directed toward prevention. This imbalance is especially striking given that **nearly a quarter of an individual's health outcomes are shaped by socio-economic determinants, factors that rarely receive adequate support or strategic focus.**[25]

This gap is particularly critical in the context of neurological conditions, many of which have no cure and require long-term, multidisciplinary care. Identifying modifiable risk factors and reducing the preventable burden of disease must become a strategic priority in public health planning.

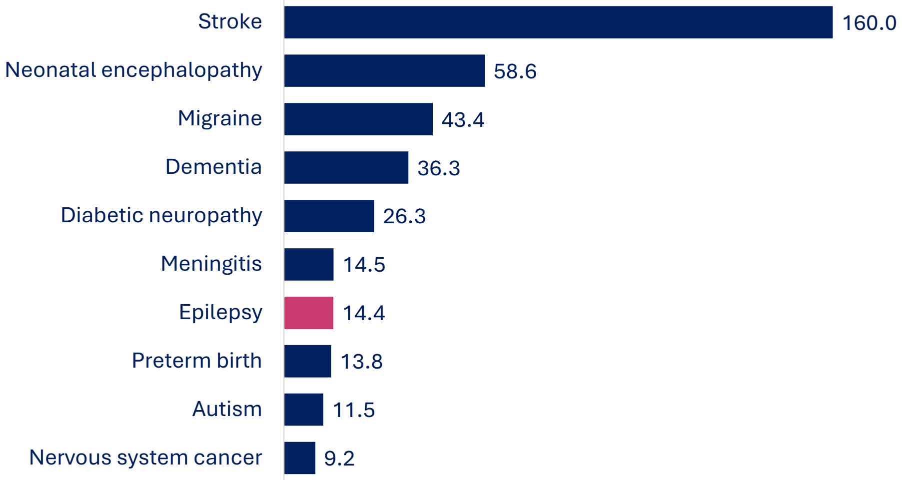

Figure 6. Global top 10 neurological conditions in terms of DALYs (millions), 2021 - *Source: TEHA on Lancet Neurol 2024; 23: 344–81, 2025*

This prevention gap, however, is reflected in the research field as well. **Research efforts, in fact, tend to mirror the reactive nature of health systems, focusing predominantly on managing disease progression rather than sustaining brain health throughout life.** This leaves a significant opportunity gap: investing in prevention could dramatically reduce disease burden and associated costs. The COVID-19 pandemic has, in some ways, catalyzed a rethinking of this model. The shift to virtual work created new possibilities for interdisciplinary collaboration, bringing together neurologists, psychiatrists, psychologists, policymakers, and citizens.[26] This convergence has the potential to better understand how brain health is shaped by a wide range of physical, mental, environmental, and socio-economic factors.

In this broader perspective, **a life-course approach to brain health emerges as one of the most promising individual, societal, and global investments**.

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[25] As an example of the potential shift from a reactive to a preventive approach in the neurological field, consider: Farina F et al. (2024), "Next generation brain health: transforming global research and public health to promote prevention of dementia and reduce its risk in young adult populations". The Lancet Healthy Longevity.

[26] Avan A. et al. (2021), "Brain health: Key to health, productivity, and well-being".

2. A specific focus on epilepsy: The state of the art from a healthcare perspective

Within the broader effort to advance brain health across Europe, epilepsy stands out as a condition that is both emblematic of current challenges and illustrative of untapped opportunities.

It is one of the most prevalent neurological disorders, affecting over 50 million people worldwide, yet it continues to be under-recognized, underfunded, and often overlooked in national health strategies. Despite the availability of cost-effective treatments, significant treatment gaps persist, particularly among vulnerable populations such as children, older adults, and those living in rural or low-resource settings.[27] **Treatment gap varies from over 75% in low-income countries and 50% in most middle- and upper middle-income countries**,[28] often due to late diagnosis, limited specialist access, and socioeconomic barriers. At the same time, the disorder carries a substantial societal and economic burden, from direct healthcare costs to indirect impacts such as stigma, educational disadvantage, and lost productivity.

Epilepsy also provides a strategic entry point for broader neurological care, as it can be secondary to other neurological conditions, such as stroke or traumatic brain injury and it frequently co-occurs with conditions such as migraine and cognitive impairment. Moreover, **psychiatric comorbidities – particularly depression and anxiety – are highly prevalent** across neurological disorders. By addressing epilepsy more effectively, it is possible to generate a positive ripple effect along the entire brain health continuum, improving outcomes and care pathways for a wide range of interconnected conditions, including those previously mentioned.

The epidemiology and health burden of epilepsy

The global burden of epilepsy is considerable, not only in terms of its clinical and neurological implications, but also in its broader social and economic impact. The prevalence of active epilepsy, defined as ongoing seizures or the requirement for treatment, affects between 4 and 10 per 1,000 individuals at any given time.

Each year, an estimated 5 million people are newly diagnosed with epilepsy, with an incidence that varies significantly by region: in

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[27] Szaflaraski M (2014), “Social determinants of health in epilepsy”.
[28] Meyer AC et al. (2010), “Global disparities in the epilepsy treatment gap: a systematic review”.

high-income countries, approximately 49 per 100,000 individuals are diagnosed annually, whereas in low- and middle-income countries (LMICs), incidence rates can reach up to 139 per 100,000. This disparity is largely attributed to higher exposure to risk factors such as endemic infectious diseases (e.g., malaria, neurocysticercosis), perinatal complications, road traffic injuries, and limited access to healthcare infrastructure, preventive services, and timely treatment.

In Europe, epilepsy is the 4th most common neurological disorder, affecting over 6 million individuals, with a prevalence around 6-8 per 1,000 individuals, while 15 million citizens of all ages, ethnicity and social class have one seizure at some time in their lives. In the European population, the probability of developing epilepsy is between 0.3-0.5%, but increases to around 5% if one parent has idiopathic epilepsy (genetically determined) and reaches 10-12% if both parents have epilepsy. Overall, there are ~400,000 new cases in Europe each year, that is, one new case every minute; 100,000 are children and adolescents, whereas 1 in 4 are aged 65 and above.

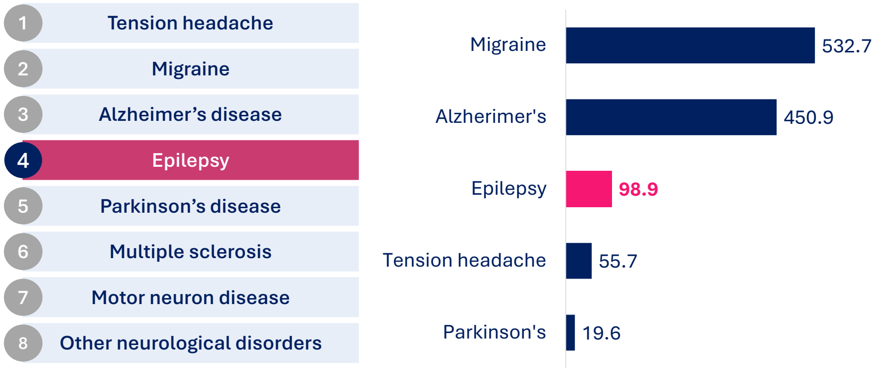

Figure 7. Left: Top neurological disorders in Europe by prevalence, 2021. Right: Age-standardized Years Lives with Disability (YLDs) of the main neurological disorders in Europe (per 100,000 inhabitants), 2021 – *Source: TEHA on GBD 2021 Nervous System Disorders Collaborators (2024), "Global, regional, and national burden of disorders affecting the nervous system, 1990–2021: a systematic analysis for the Global Burden of Disease Study 2021", 2025*

The impact on the quality of life of patients with epilepsy in the EU is significant: over 411,000 YLDs and 729,000 DALYs (0.46% of the total) are caused by epilepsy – the 3rd most disabling neurological disorder, after headache disorders and Alzheimer's disease[29]. Nevertheless, **in some European countries, epilepsy is not recognized as a brain disorder, and up to 40% of people with this condition may be untreated,**[30] contributing to a considerable share of neurological disability. Despite its high prevalence and chronic nature, in fact, epilepsy remains widely under-prioritized in many healthcare and welfare systems.[31]

However, as previously mentioned, its implications remain relevant. **Individuals with epilepsy have a more than twofold increased risk of premature death compared to the general population**, and their life expectancy is reduced by approximately 10 to 12 years. This elevated risk is particularly pronounced in younger individuals and in those residing in rural areas,

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[29] Global Burden of Disease, 2025.

[30] IBE, ILAE, WHO (2011),"Epilepsy in the WHO European Region." and European Parliament (2011), "Proceedings of the workshop 'Treating and living with Epilepsy'".

[31] As an example, please refer to Norton AC et al. (2025), "Top Ten epilepsy research priorities: A UK priority setting partnership" and Meador KJ et al. (2011), "Disparities in NIH funding for epilepsy research".

where the risk of mortality can be up to 247% higher than in the general population.[32] The risk of death associated with epilepsy is strongly influenced by the type of epilepsy, the timing of diagnosis and the degree of seizure control achieved with current antiepileptic therapy (with a 40-fold higher risk in patients with uncontrolled epilepsy vs. those in remission). Notably, the highest mortality rates are observed in the initial years following diagnosis, underscoring the critical role of early and effective management.[33]

Key risk factors include age, sex, history of status epilepticus, seizure frequency and severity, and adherence to antiepileptic drug (AED) regimens. One of the leading causes of epilepsy-related mortality is Sudden Unexpected Death in Epilepsy (SUDEP), defined as the sudden and unexplained death of an individual with epilepsy, in the absence of trauma or drowning, and with no toxicological or anatomical cause found post-mortem. The incidence of SUDEP is estimated at approximately 1 per 1,000 people with epilepsy per year, translating to around 50,000 deaths annually worldwide[34].

Risk is particularly elevated in individuals with drug-resistant epilepsy and those experiencing frequent, severe generalized tonic-clonic seizures. Despite its significance, SUDEP remains an underrecognized and often uncommunicated risk. Studies indicate that patients and their families are frequently not informed about SUDEP by healthcare professionals, a critical oversight given that up to 70% of SUDEP cases may be preventable through risk-adapted behaviors, seizure control strategies, and prompt emergency intervention.[35]

In addition to SUDEP, mortality in epilepsy can result from seizure-related accidents such as drowning, aspiration, or fatal head injuries during convulsive episodes. Moreover, individuals with epilepsy are at increased risk of suicide, which is likely linked to a higher prevalence of comorbid psychiatric conditions such as depression and anxiety. Research suggests that the risk of suicide in people with epilepsy is 2.6 to 5 times higher than in the general population.[36]

Recent epidemiological data underscores the multifaceted burden of epilepsy – not only in terms of its direct neurological manifestations, but also through its interconnectedness with both physical and mental health.[37] According to a recent study published in Seizure[38], it is highly prevalent among individuals with epilepsy, affecting approximately 60-70% of adults and up to 80% of children. In pediatric populations, neurodevelopmental disorders – particularly autism spectrum disorder and attention-deficit/hyperactivity disorder – are frequently observed, along with developmental delays and cognitive impairments. Among adults, common comorbidities include cardiovascular disease, cancer, and neurodegenerative conditions.

Mental health disorders, including depression and anxiety, are pervasive across all age

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[32] Thurman DJ et al. (2014), "The burden of premature mortality of epilepsy in high-income countries: A systematic review from the Mortality Task Force of the International League Against Epilepsy". Epilepsia.

[33] Neligan A & Sander JW (2011), "The mortality of epilepsy". Epilepsia.

[34] Devinsky O et al. (2016), "Sudden unexpected death in epilepsy: Epidemiology, mechanisms, and prevention". The Lancet Neurology.

[35] Shankar R et al. (2018), "Preventing SUDEP: Evidence-based recommendations". Seizure.

[36] Hesdorffer DC et al. (2006), "Epilepsy, suicidality, and psychiatric disorders: A bidirectional association". Annals of Neurology.

[37] Keezer MR et al. (2016), "Comorbidities of epilepsy: Current concepts and future perspectives". The Lancet Neurology.

[38] Gaitatzis A & Majeed A (2023), "Multimorbidity in people with epilepsy". Seizure: European Journal of Epilepsy.

groups: according to recent studies, people with epilepsy have a 2-5 times increased risk of developing any psychiatric disorder, and 1 in 3 patients with epilepsy have a lifetime psychiatric diagnosis. Psychiatric comorbidities represent a poor prognostic marker as they have been associated with a poor response to treatment (drugs and surgery), increased morbidity, and mortality.[39] Furthermore, children with epilepsy often experience learning difficulties and reduced social functioning, while older adults are at increased risk of accelerated cognitive decline and functional impairment.

As data shows, the presence of multiple comorbidities in people with epilepsy is associated with increased risks of premature mortality, higher rates of hospitalization, and reduced health-related quality of life. These findings underscore **the need for a shift from a traditional single-disease approach to a more holistic, person-centered model of care**.

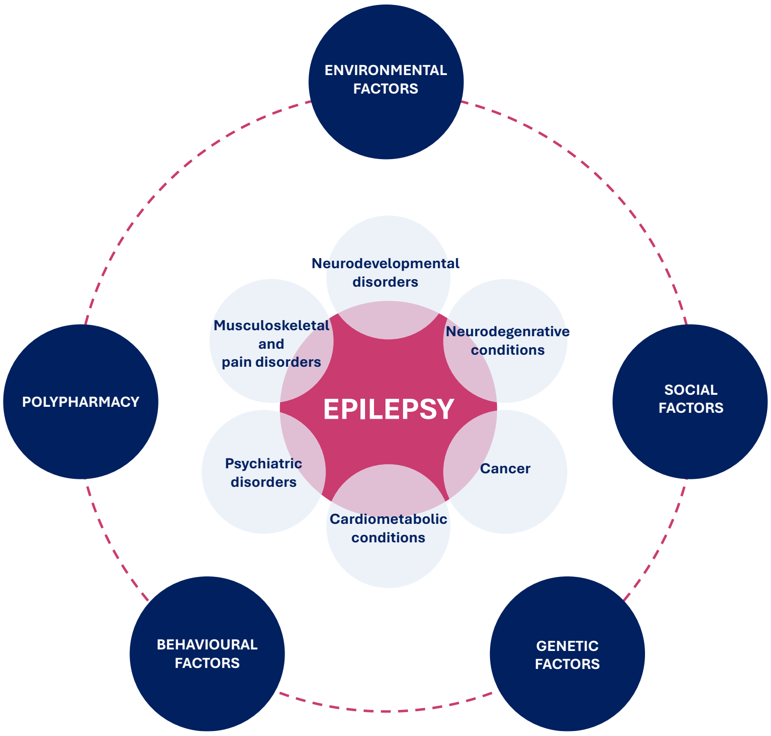

Figure 8. Conceptual framework of multimorbidity classification in people with epilepsy – *Source: TEHA on Gaitatzis A & Majeed A (2023), "Multimorbidity in people with epilepsy" data, 2025*

Reports increasingly highlight the need for a holistic and life-course approach to epilepsy, recognizing it not merely as a neurological disorder but as a chronic condition with pervasive effects on brain health, social integration, and functional independence.[40] Broader brain health narratives reinforce the importance of integrating epilepsy management into mental health and primary care systems, reducing the silos that currently fragment care delivery.[41]

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[39] Mula, M., Kanner, A. M., Jetté, N., & Sander, J. W. (2021), "Psychiatric comorbidities in people with epilepsy". Neurology: Clinical Practice.

[40] Baulac M et al. (2015), "Epilepsy priorities in Europe: A report of the ILAE-IBE Epilepsy Advocacy Europe Task Force".

[41] Spanos S et al. (2024), "Integrated Care in Epilepsy Management: A Scoping Review of the Models and Components of Health and Social Care Delivery".

Key challenges in the healthcare sector

Despite growing awareness, several critical barriers continue to hinder the effective management of epilepsy across Europe.[42] **Unequal access to care remains one of the most pressing concerns.** Socioeconomic status, geographic location, and gender significantly influence access to timely diagnosis, anti-seizure medications, and specialist care. For instance, research indicates that pregnant women with epilepsy from lower-income backgrounds are considerably less likely to receive appropriate treatment and follow-up care. This raises serious concerns about maternal and fetal health and underscores persistent inequities in access to neurological services.

The overall burden of epilepsy in Europe is substantial. As mentioned before, it affects approximately 6 million people, yet access to quality care remains inconsistent and often inadequate. According to the European Brain Council, around **70% of individuals with epilepsy could live seizure-free with appropriate treatment**.[43] However, nearly 40% across Europe do not receive the care they need – a figure that rises to 90% in certain underserved areas. This treatment gap is particularly evident in regions with limited health infrastructure or in rural communities, where specialist services are scarce or absent.

A recent study conducted in Spain[44] has underscored the **heterogeneous nature of epilepsy care delivery**, which involves both specialist and non-specialist centers. Within this framework, a multidisciplinary team comprising neurologists, nurses, patients, and caregivers identified key barriers hindering the provision of high-quality care for individuals with epilepsy across various stages of their journey within the Spanish National Health System. The analysis delineated six critical phases along the patient pathway: emergency care, diagnosis, pharmacological treatment, follow-up, referral to specialist services, and interventional procedures. Among these, follow-up emerged as the most influential phase in determining the overall quality of care, followed by pharmacological treatment and diagnostic processes. Emergency care was identified as a critical juncture, with implications that extend across the entire continuum of care.

Several barriers were highlighted, including suboptimal communication - both among healthcare professionals and between professionals and patients - which was particularly evident during the phases of drug therapy, follow-up, referral, and interventional treatment. Resource limitations also posed significant challenges, particularly in confirming diagnoses, ensuring the availability of appropriate medications, and facilitating timely referrals. These were often compounded by a shortage of specialized personnel, limited access to dedicated centers, and prolonged waiting times. The study concluded that ensuring high-quality care for people with epilepsy requires targeted actions, including specialized training for healthcare providers, adequate allocation of resources for diagnostic and therapeutic services, and the establishment of effective communication channels throughout the care process.

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[42] Pellinen J (2022), “Treatment Gaps in Epilepsy”. Frontiers in Epidemiology.

[43] Marson AG et al. (2017), “Barriers to Best Management of Epilepsy” and National Institute for Health and Care Excellence (2016), “Epilepsies: diagnosis and management”.

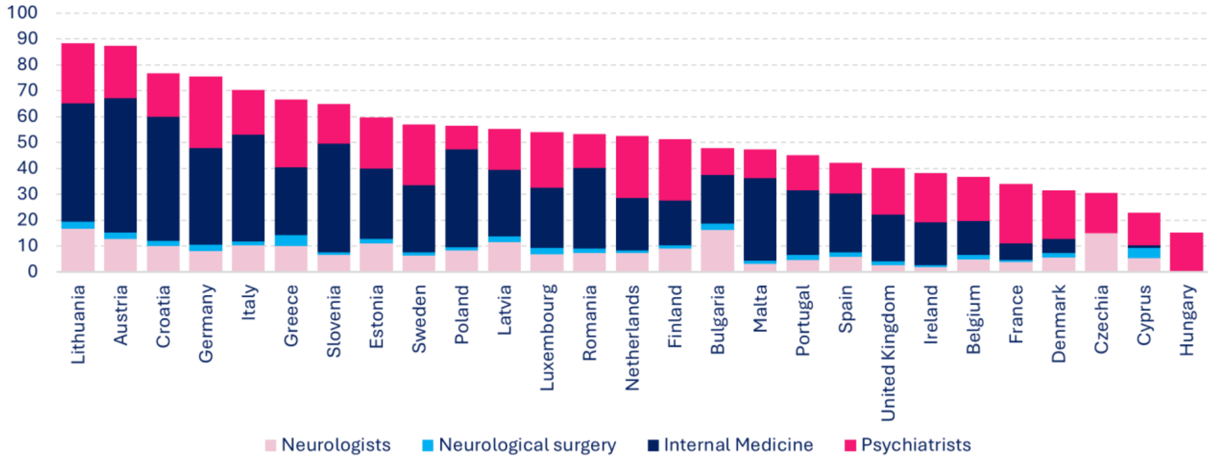
[44] Poza JJ et al. (2024), “Key steps and barriers in the journey of patients with epilepsy through the National Healthcare System in Spain: The EPIPASS qualitative study”. Epilepsia.

Differences in access between countries are not surprising, considering the variability in national income, life expectancy, and the organization of healthcare systems. Nonetheless, significant disparities also exist within countries, often shaped by the level of urbanization, regional resource allocation, and broader socioeconomic factors. The result is an uneven landscape in which the quality of epilepsy care can vary dramatically based on where a person lives or their economic circumstances.

This deeply concerning situation reflects a broader and systemic issue: the insufficient recognition of epilepsy as a public health priority by governments, communities, and even healthcare providers. A lack of political attention and strategic planning contributes to gaps in awareness, early detection, and access to comprehensive care. For people living with epilepsy and their families, this translates into not only a heightened clinical burden but also increased social isolation, financial strain, and reduced quality of life.

In general, wide treatment gaps are driven by a combination of systemic factors, including limited capacity within health services, an inequitable distribution of resources, and a consistently low prioritization of epilepsy care within national health agendas. **This is compounded by workforce shortages, particularly in neurology and specialist care, as well as by constrained access to anti-seizure medications.**

A 2019 study analyzing the provision of epilepsy care across Europe highlighted significant variability in the availability of healthcare professionals involved in epilepsy management. Most adults with epilepsy are generally treated by neurologists, yet the number of neurologists per capita differs markedly between countries. For example, Ireland reports only 1.8 neurologists per 100,000 inhabitants, whereas countries like Italy and Austria report over 10 neurologists per 100,000 inhabitants. The availability of neurosurgeons – particularly relevant for epilepsy surgery – is even more limited and unevenly distributed. Figures range from 0.69 per 100,000 inhabitants in Ireland to 4.2 per 100,000 in Greece. This variation is concerning, especially considering that the limited availability or underutilization of epilepsy surgery is frequently cited as a major shortcoming in several European countries, despite evidence supporting its effectiveness for selected drug-resistant cases. For pediatric populations, children with epilepsy are typically managed by pediatric neurologists.



(*) In some countries, complete data is not available.

Figure 9. Healthcare professionals involved in the treatment of epilepsy at European level (per 100,000 inhabitants), 2019 or last available data - *Source: TEHA on Zelano J et al. (2019), "The provision of Epilepsy care across Europe 2017: A 17-year follow-up survey" and Eurostat data, 2025*

However, comprehensive data on the availability and distribution of these specialists across Europe remain scarce, making it difficult to assess the adequacy of pediatric epilepsy care. This lack of data further complicates efforts to ensure equitable access to appropriate expertise for younger patients, with a smooth transition from pediatric to adult care remaining critical. In many settings, especially outside urban centers, healthcare and social workers lack adequate training and confidence to manage epilepsy effectively. This often results in delayed diagnoses, insufficient follow-up, and limited access to advanced therapies. Misconceptions and stigma continue to surround the condition, further discouraging people from seeking help and perpetuating social exclusion.

Moreover, **fragmentation of care pathways leads to inconsistencies in treatment protocols and poor coordination between primary, secondary, and tertiary levels**. In several countries, a lack of national epilepsy plans and registries further hampers the ability to monitor outcomes, allocate resources effectively, and implement quality standards. Even in countries with well-established treatment systems, challenges persist.

In France, for example, access to core medical services is generally strong, but complementary services are lacking. These include specialized management of comorbidities, access to a ketogenic diet, and targeted inclusion programs within schools. A notable gap also exists in the diagnosis of epilepsy among the elderly, many of whom go undiagnosed because their symptoms are mistaken or added to those of other neurological conditions.

Socioeconomic and structural factors also play a central role in shaping epilepsy outcomes. Individuals from lower socioeconomic backgrounds experience significantly higher rates of first unprovoked seizures, face wider treatment gaps, have limited access to advanced therapies, and are less likely to receive specialist care from neurologists. These disparities are further compounded by lower educational attainment and higher rates of unemployment. A recent study highlighted the inequity in access to care, showing that in 2019, the average annual cost per person with epilepsy ranged from $204 in low-income countries to $11,432 in high-income countries[45].

Affordability remains a significant barrier to epilepsy care, particularly in relation to anti-seizure medications (ASMs), whose supply chains may be vulnerable to disruptions. Within the European Union, the cost of medical services can vary by a factor of up to 24 – ranging from the highest in the United Kingdom to the lowest in Portugal – while the price of ASMs differs by up to 4.4 times, from Belgium (highest) to Spain (lowest)[46].

Additional barriers to equitable care include income and wage disparities, variations in healthcare system structures (e.g., where epilepsy care is primarily managed by general practitioners), limited per capita healthcare spending, persistent social stigma, and uneven distribution of specialized services.

A 2015 study[47] highlighted substantial cross-country differences in the availability of anti-epileptic drugs (AEDs), particularly between high-income and non–high-income countries.

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[45] Begley, C., Wagner, R. G., Abraham, A., Beghi, E., Newton, C., Kwon, C. S., ... & Winkler, A. S. (2022), “The global cost of epilepsy: a systematic review and extrapolation”
. *Epilepsia*, *63*(4), 892-903.

[46] Heaney DC et al. (2001), “Comparing the cost of epilepsy across eight European countries”. Epilepsy Research.

[47] Baftiu A et al. (2015), “Availability of antiepileptic drugs across Europe”. Epilepsia.

Notably, the most recently developed AEDs were entirely unavailable in the 12 non–high-income countries surveyed. Availability was significantly higher in countries with public reimbursement systems, though policies varied widely – from full reimbursement for all AEDs to complete exclusion. The main obstacles to AED access included lack of regulatory approval and reimbursement limitations. These disparities in access to AEDs across European countries - especially for newer therapies - raise serious concerns about the overall quality and equity of epilepsy care.

Compounding these issues is the underfunding of epilepsy research and care, which continues to lag behind that of other chronic conditions with similar prevalence and societal burden. **Epilepsy remains chronically underfunded, not only when compared to other diseases but even within the field of neurology itself.** For example, in the UK public research funding is equal to £234 per patient for Alzheimer's disease, £97 per patient with dementia and only £21 per patient for epilepsy.[48] This underfunding is partly attributable to the complexity of epilepsy, which poses challenges in both communication and public awareness. The multifaceted nature of the condition makes it difficult to convey its societal and healthcare impact in simple terms, which, in turn, affects its visibility on policy agendas. Epilepsy research, in fact, is remarkably broad and complex, largely due to the intricacies of normal brain function and the heterogeneity of epilepsy itself, encompassing numerous types, each with distinct causes, manifestations, and consequences.

Clinical research in epilepsy focuses on a wide array of priorities: from uncovering the underlying causes and improving diagnostic accuracy, to understanding comorbidities and refining treatment approaches. This is occurring in parallel with the advancement of personalized epilepsy management, which aims to tailor interventions based on individual genetic, neurobiological, and clinical profiles. Over the past three decades, these efforts have contributed to the development and approval of more than 20 new ASMs, expanding the therapeutic arsenal available to clinicians. Despite this progress, a significant proportion of people with epilepsy – approximately one-third – do not achieve seizure control. For these individuals, continued research is critical to develop more effective and better-tolerated therapies.

In addition to pharmaceutical advances, non-pharmacological therapies are also gaining ground. These include innovative approaches such as minimally invasive brain surgery, wearable and implantable seizure detection devices, and novel methods of electrical brain stimulation. Together, these developments hold promises for improving quality of life, reducing seizure burden, and ultimately moving toward disease-modifying or even curative interventions.

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[48] Epilepsy Research UK, 2023.

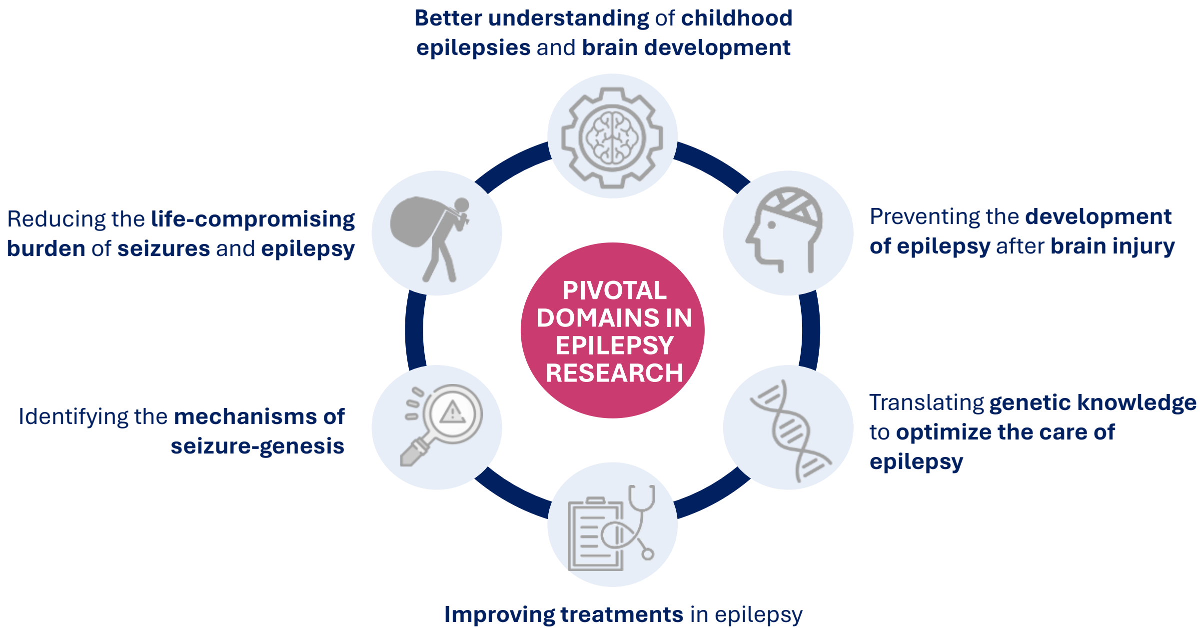

Figure 10. Pivotal domains in epilepsy research – *Source: TEHA on Perruca E et al. (2013) "Epilepsy Research Priorities in Europe", Chen Z et al. (2020), Krasowski (2010), EpiCARE and EBRA data, 2025*

Moving forward: Priorities for action

The future of epilepsy care must be shaped around 4 key pillars: prevention, early detection, innovation, and patient empowerment. Recent studies emphasize the need for upstream policies that promote awareness, reduce stigma, and facilitate timely diagnosis. Public health campaigns, school-based programs, and training for non-specialist providers are all essential to expanding the reach of epilepsy services.

On the diagnostic front, research into biomarkers and neuroimaging technologies is helping to reduce the time from symptom onset to diagnosis. Early intervention is critical, especially in drug-resistant cases where delayed treatment is associated with poorer outcomes. It is estimated that up to 30% of people with epilepsy do not respond to first-line treatments, highlighting the need for continued innovation.

Next-generation therapies, including novel anti-seizure medications and surgical interventions, offer new hope for patients with refractory epilepsy. Achieving seizure control and freedom – the ultimate goal of treatment – is critical, as uncontrolled seizures are associated with increased risks of premature death, comorbidities, and substantial healthcare and societal costs.[49] Seizures, in fact, often lead to emergency care, injury management, and hospitalization, while also disrupting daily life, emotional wellbeing, and social participation. Because of their unpredictability, each seizure carries a significant burden while causing brain damage and cognitive decline.[50] In contrast, people who achieve seizure freedom experience better overall health, greater autonomy, and improved quality of life. In this context, new pharmacological treatments have demonstrated improved efficacy in

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[49] Sveinsson O et al. (2020), "Clinical risk factors in SUDEP: A nationwide population-based case-control study". Neurology.

[50] Kovac S et al. (2014), "Seizure activity results in calcium- and mitochondria-independent ROS production via NADPH and xanthine oxidase activation". Cell Death & Disease.

seizure reduction and a better tolerability-safety profile resulting in fewer side effects. However, these advances must be matched by investments in infrastructure and workforce capacity to ensure that innovations translate into real-world benefits.

Equally important is patient empowerment. Studies consistently show that individuals who are engaged in their care decisions report higher satisfaction, better health outcomes, and increased adherence to treatment. Digital health tools, peer support networks, and personalized care planning are emerging as key enablers of empowerment. In this context, even before addressing healthcare itself, one major barrier must be acknowledged: driver's license regulations for people with epilepsy. Limits on driving often mean limits on access to care.[51] To ensure equitable access to care, two complementary solutions could be considered: the guarantee of accessible and high-quality public transportation, and the provision of monetary allowances or bonuses to support individuals in covering transport costs.[52]

Ultimately, the evolving landscape of epilepsy care in Europe calls for a paradigm shift – one that elevates epilepsy from a neglected condition to a central concern within the broader agenda for brain health and health system resilience. Coordinated action, sustained investment, and patient-centered policies will be essential to closing the gaps and transforming outcomes for million people affected by epilepsy across the continent.

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[51] This topic will be further developed in Chapter 3.

[52] In this regard, the Personal Independence Payment (PIP) in the United Kingdom represents a good practice, which helps mitigate such disadvantages. Further information is available in Chapter 3.

3. Moving beyond: The socio-economic opportunity of investing in epilepsy

Key challenges and hidden barriers in the social and work environments

Although epilepsy is a neurological condition, its impact reaches far beyond the clinical management of the disease. It is, in fact, a disorder with multifactorial consequences, deeply affecting multiple aspects of daily life of patients, often in ways that remain hidden from public view or are not widely recognized. **Beyond the immediate health implications, people with epilepsy – especially those with uncontrolled seizures – routinely encounter barriers in education, employment, social participation, mobility, and emotional well-being**, many of which stem not from the condition itself[53], but from the way society perceives and responds to it. Understanding and addressing these hidden obstacles is crucial not only for improving individual outcomes but also for unlocking the full social and economic value of investment in epilepsy treatment and care.

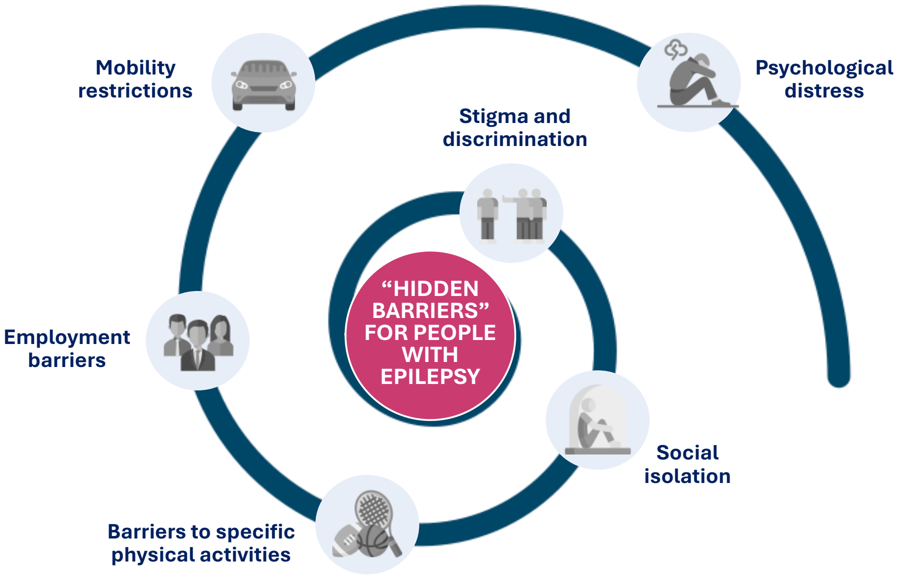

Figure 11. Hidden barriers faced by individuals with epilepsy (illustrative) – *Source: elaboration by TEHA, 2025*

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[53] Especially when linked to mental health disorders, learning difficulties or mental impairment.

In part, the magnitude of the impact on patients' lives can be attributed to epilepsy itself (especially in presence of uncontrolled seizures) and to the numerous comorbidities it is often associated with – already discussed in Chapter 1 – but an additional factor that shapes how patients interact with their social and economic environment is the **stigma, fear of unpredictable seizures and incomprehension that accompany them, representing a "silent" comorbidity**. The less visible effects that it produces - exclusion, marginalisation, emotional distress - can prove as disabling as the seizures themselves, undermining well-being, limiting opportunities, and in some cases compromising medical treatment.

Stigma takes many forms, such as discrimination or verbal abuse. Despite major advances in therapeutics, and more limited improvements in social understanding of this condition, many individuals with epilepsy continue to experience significant social rejection. Public understanding of this issue would be a first step for breaking the wall of stigma; however, in a 2023 cross-national survey conducted across five European countries (France, Germany, Italy, Spain and the UK), 34% of respondents with epilepsy stated that stigma around the condition remains "strong," compared to just 13% of individuals without epilepsy.[54] This highlights a striking perception gap that marks the disconnect between patient experience and broader societal awareness.

Such findings confirm earlier data: stigma consistently ranks among the top concerns reported by patients, often outweighing worries related to driving and education.[55] This highlights the limited progress that has been achieved so far, despite the significant efforts put in place by patient organizations. Some clinicians have described stigma as a "second illness", which burdens patients on top of their condition and produces economic losses for society by limiting job opportunities and efficient allocation of resources.

One of the clearest manifestations of stigma is concealment. Many individuals with epilepsy, particularly in professional settings, feel unable or unwilling to disclose their condition. In most cases, this decision reflects a calculated attempt on behalf of patients to avoid discrimination. Data from surveys suggest that between 15% and 48% of workers with epilepsy do not inform their employers and colleagues of their condition, depending on the country and context.[56] This not only affects patients' safety, as people around them are unaware of their condition and unprepared to manage a potential seizure, resulting in avoidable workplace incidents, but can also contribute to a vicious cycle of discrimination as the condition continues to be concealed and, therefore, misunderstood.

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[54] Strzelczyk et al. (2023), "The impact of epilepsy on quality of life: Findings from a European survey". Epilepsy & Behavior.

[55] Baker CA et al. (2000), "The Stigma of Epilepsy: A European Perspective". Epilepsia.

[56] EpilepsyPOWER, 2021.

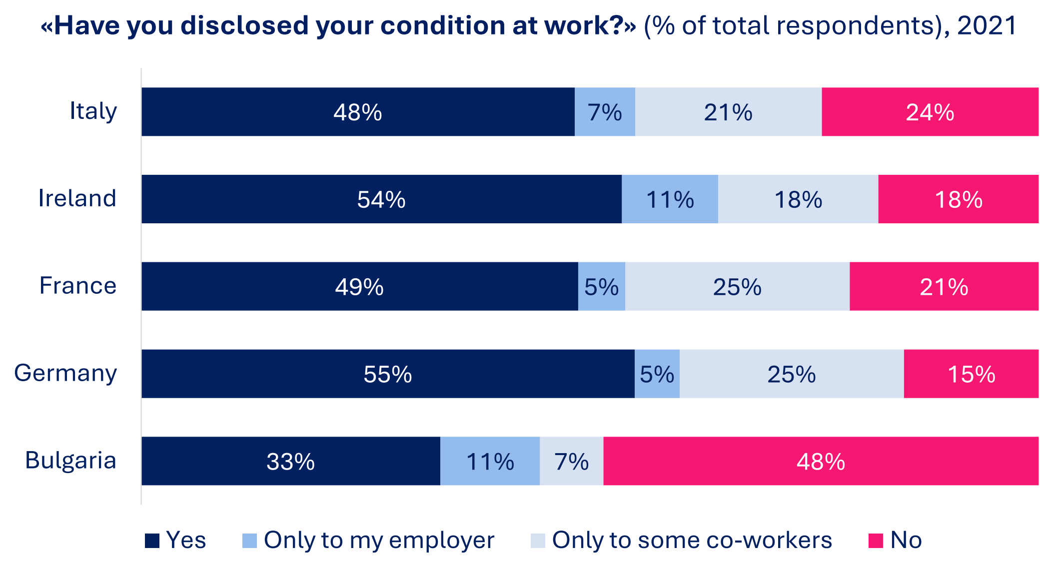

Figure 12. Disclosure of the condition by people with epilepsy to their employers and employees (%) – *Source: TEHA on EpilepsyPOWER data, 2025*

On the other hand, **despite being capable and qualified, individuals with epilepsy are too often overlooked due to unfounded concerns about safety or performance**. This results in limited access to quality employment contracts, particularly when seeking part-time or flexible solutions. Many employers still hold misconceptions about the productivity and reliability of workers with epilepsy, which restricts professional opportunities and reinforces social exclusion. Research on workplace incidents involving people with epilepsy remains limited, and most claim that epilepsy increases such risks are anecdotal. A European cohort study, for example, found that 3.5% of workers with epilepsy reported accidents over a 1-3-year period, compared to 1.5% of the general population.[57]

As shown, unemployment and underemployment in patients with epilepsy arise from a combination of multiple and different factors, both internal – such as individual characteristics, clinical features, and self-concepts – and external, including working environment, knowledge, and employers' attitudes. While data indicate that **seizure control is the most relevant internal factor influencing the possibility of getting and maintaining a good job**, highlighting the importance of continuous follow-up and optimal medical care, studies emphasize **employers' attitude as the most significant external factor**. This underlines how employability is shaped by a complex interplay of clinical, psychological, and social elements and supports the need to explore, in addition to solutions to keep as many workers seizure-free as possible, also non-clinical barriers to employment. Developing targeted legislation and inclusive workplace programs could play a key role in supporting the professional integration and social inclusion of people with epilepsy.[58]

Experts agreed that many of these issues stem from a fundamental lack of communication and comprehension of the condition. At the root of the issue lies

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[57] Cornaggia C et al. (2006), "Accidents at work among people with epilepsy. Results of a European prospective cohort study".

[58] Narducci et al. (2025), "Epilepsy and Employment in Europe: A Systematic Review of Literature". European Journal of Neurology.

ignorance and fear, rather than "bad intentions", which often create invisible but pervasive barriers. More awareness initiatives could be introduced in the workplace, as is increasingly the case for other health conditions or social issues. Often, experts are only brought in after an incident has occurred – rather than proactively, as part of prevention and education.

Stigma and challenges related to inclusion extend beyond working life and should also be addressed during transitional life phases – such as university years, when individuals face heightened stress and complex social dynamics, **and retirement**, a stage often overlooked despite its own set of vulnerabilities.

As mentioned in the previous Chapter, restrictions on driving licences represent another significant barrier for people with epilepsy.[59] While these rules are rooted in legitimate safety concerns – to protect both patients and those around them – in the absence of alternatives, they can have significant economic repercussions in terms of lost autonomy, flexibility, and in some cases, the possibility to continue working. The impact is especially acute in rural areas, where public transport options are limited, and sometimes non-existent. Without alternative mobility options, individuals with epilepsy may face long-term unemployment or be forced to accept underpaid, less stable work closer to home, or in some cases they may not disclose their seizures, thus putting their life at risk. From a broader perspective, this hidden cost carries significant economic implications. **When individuals with uncontrolled seizures have limitations or are unable to access transportation, a substantial portion of the workforce is prevented from reaching their full productive potential.** This not only reduces overall economic output and tax contributions, but also increases reliance on welfare systems, leading to greater public expenditure and lost human capital.

The challenge of limited mobility, in turn, often intersects with another hidden barrier: social isolation. The inability to access workplaces, educational opportunities, or even informal social settings due to transportation restrictions or fear of seizures can gradually lead individuals to withdraw from broader social life. In this sense, achieving seizure control is a critical milestone not only from a clinical viewpoint, but also to improve the emotional wellbeing of patients.[60] This withdrawal, moreover, is rarely a mere consequence of practical limitations, and is frequently amplified by the misunderstanding and lack of awareness that still surrounds epilepsy, which goes back to the issue of stigma already discussed. According to a large European survey[61], 25% of individuals with epilepsy reported feeling "extremely isolated" in the preceding three months, nearly double the rate observed among people without epilepsy (13%).[62] This finding points to a broader failure of social inclusion. **Isolation, like stigma, becomes a self-reinforcing barrier**: it undermines confidence, reduces access to support networks, and limits the

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[59] According to EU Directive 2006/126/EC (as amended by Directive 2009/113/EC), individuals with epilepsy may obtain a driving license if they have been seizure-free for a defined period, typically at least 12 months without seizures for private vehicles, subject to medical evaluation. Member States may adopt more detailed or stricter rules regarding eligibility, monitoring, and reassessment.

[60] According to Josephson CB et al. (2017) "The impact of seizures on epilepsy outcomes: A national, community-based survey", people with epilepsy who become seizure-free are 2.5-fold more likely to consider their health as 'excellent' compared with those who had experienced a seizure in the prior 5 years.

[61] Strzelczyk et al. (2023), "The impact of epilepsy on quality of life: Findings from a European survey". Epilepsy & Behavior.

[62] Interestingly, this finding was registered despite the fact that, in the analyzed sample, more individuals with epilepsy lived with someone in the same house or apartment (29%) compared to the control group (22%).

informal interaction that are often key in resulting in access to educational or professional opportunities.

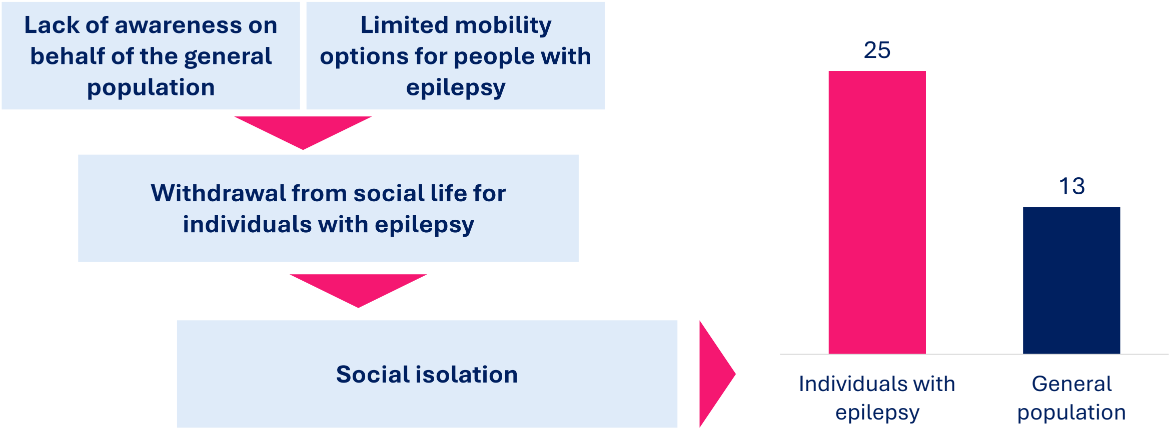

Figure 13. Individuals with epilepsy feeling "extremely isolated" vs general population perception (in %), 2023 – *Source: TEHA on Strzelczyk et al. (2023), "The impact of epilepsy on quality of life: Findings from a European survey", 2025*

The same societal misunderstanding that fuels stigma also extends its impact to **other dimensions of daily life such as access to sports and engagement in physical activity**. Sports are known to benefit not only physical health in people with epilepsy (both adults[63] and children[64]), but also cognition and mental health[65]. However, many individuals remain excluded from these opportunities. A recent study[66] found that almost one in five adults with epilepsy (19.7%) avoid physical activity for fear of having a seizure, underlining the broader social value of a life without the constraints of uncontrolled seizures. Another 21.4% of patients reported lack of transportation options as a key obstacle to doing sports.

Taken together, these hidden barriers create a complex set of disadvantages for individuals with epilepsy which result in significant social and economic losses. Their cumulative effect is profound, gradually eroding individuals' ability to participate fully in society, both socially and economically. These barriers therefore have measurable consequences in terms of income, job security, and long-term financial well-being. As such, they become a broader economic cost affecting society as a whole, which add to the direct costs in terms of disease management.

In this context, **achieving seizure freedom becomes a key goal not only from a clinical standpoint, but also as a means to improve broader social and economic inclusion**. Beyond health, seizures disrupt education, work, mobility, and emotional well-being, deepening stigma and exclusion.[67,68] The ability to live seizure-free can thus restore

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[63] Arida RM et al. (2008), "Physical activity and epilepsy: proven and predicted benefits". Sports Medicine.
[64] Alfonso D et al. (2024), "Effects of physical activity on cognition and psychosocial functioning in pediatric epilepsy: A systematic review".
[65] Bhatt G et al. (2023), "Impact of Physical Activity on Epilepsy". Journal of Datta Meghe Institute of Medical Sciences University.
[66] Alexander HB et al. (2023), "A single-center survey on physical activity barriers, behaviors and preferences in adults with epilepsy". Epilepsy & Behavior.
[67] Glauser T et al. (2024), "Short-Term Impact of Seizures and Mitigation Opportunities". Current Neurology and Neuroscience Reports.
[68] Hu C et al. (2024), "Effects of stigma on the quality of life in patients with epilepsy". Acta Epileptologica.

confidence, enable participation in the workforce, facilitate mobility, and reduce the psychological burden on both patients and caregivers[69].

The economic burden arising from the barriers described in this Chapter is well documented in the academic literature. According to recent estimates, the employment rate for individuals with epilepsy ranges between 49% and 58%[70] in Europe, markedly lower than the 77.5% employment rate observed in the general population[71]. These findings are reinforced by longitudinal research on childhood-onset epilepsy (COE), which shows that 37% of individuals with COE never entered the workforce, compared to only 4% of matched controls without epilepsy. Even among those without additional disabilities, the share of individuals who never entered the workforce was nearly twice as high as in the control group (7.7% vs. 4%).[72]

The following section provides an estimate of the economic burden of epilepsy, taking into account both direct healthcare costs and indirect costs such as those described above so as to capture the full economic impact of the condition in the EU-27 + UK countries.

From burden to opportunity: The socio-economic burden of epilepsy across Europe and the potential return on investment

The socioeconomic burden of epilepsy

As mentioned above, **the economic impact of epilepsy extends beyond the costs of medical treatment alone**. Like many chronic neurological conditions, epilepsy generates both direct costs (such as hospitalisations, outpatient visits, diagnostics and drug related expenses) and indirect costs (loss of productivity due to unemployment, underemployment, premature retirement and time spent by caregivers.[73]

These **costs are substantially higher in individuals with uncontrolled seizures and those requiring multiple anti-seizure medications**, often reflecting more severe or drug-resistant forms of epilepsy. In particular, drug-resistant epilepsy is associated with significantly greater healthcare resource use, higher out-of-pocket costs, and lower quality of life, making timely diagnosis and access to effective treatments even more critical for patients and health systems alike.[74]

Several efforts have been made in the past to estimate the overall economic burden of epilepsy in Europe. In 2006, Andlin-Sobocki et al. estimated the total annual cost at approximately €12.5 billion across the EU. This figure was later revised upwards to €13.8 billion in 2011 by the European Brain Council, while a joint report by the WHO, ILAE and IBE released the same year suggested that the burden likely exceeded €20 billion annually. However, these estimates can now be

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[69] According to Soare IA et al. (2022), “Quality of life study for caregivers of people with uncontrolled focal-onset seizures”, caregivers spend between 15 and 24 hours per week caring for people with uncontrolled epilepsy, most frequently types of offering psychological support, staying with the individual after a seizure, and aiding with everyday tasks.

[70] Narducci et al. (2025), “Epilepsy and Employment in Europe: A Systematic Review of Literature”. European Journal of Neurology.

[71] Eurostat, 2025.

[72] Starck C et al. (2024), “Education and employment among patients with childhood-onset epilepsy in adulthood: A population-based cohort study”. Epilepsy & Behavior.

[73] Willems LM et al. (2021), “Multicenter, cross-sectional study of the costs of illness andcost-driving factors in adult patients with epilepsy”. Epilepsia.

[74] Villanueva V et al. (2013), “Quality of life and economic impact of refractory epilepsy in Spain: The ESPERA study”. Neurología.

updated by taking into account the evolving demographics of the region, the rising prevalence of epilepsy, advances in treatment modalities and new evidence on the burden on caregivers.

For this reason, a new estimation of the economic burden of epilepsy in the EU-27 countries and the United Kingdom, applying a comprehensive methodology that incorporates both direct and indirect costs, can provide significant added value to the public discourse on epilepsy and provide policymakers with the tools to identify areas of intervention to reduce this burden.

The estimation of the economic burden of epilepsy in the EU-27 and the United Kingdom realized by Headway is based on comprehensive research to factor in the most relevant and up-to-date data available within the academic literature. Importantly, the costs associated with the numerous comorbidities have not been included in the estimates, making the overall assessment conservative and narrowly focused on epilepsy alone, in order to maintain a high level of accuracy and reliability of the results.

Direct costs include all medical expenses related to the management of epilepsy, such as hospitalisations, specialist consultations, diagnostic tests, and anti-seizure medications. The starting point for the calculation is the 2019 cost data available from the literature for 11 European countries (including Germany, France, Spain, Italy, the UK, and others).[75] These data were updated to reflect 2024 prices using the European healthcare inflation rate.[76]

To estimate costs for countries lacking direct data (e.g. Austria, Belgium, Finland, ...), figures were extrapolated using the strong correlation between epilepsy-related healthcare costs and voluntary or out-of-pocket health spending per capita. Countries were grouped into four regional clusters (Eastern, Northern, Western, and Southern Europe), and cluster-specific coefficients were applied to refine the estimates in order to account for different healthcare models throughout the continent. In addition to patient-related healthcare costs, the model also included out-of-pocket expenses borne by caregivers, such as transport and out-of-pocket medical costs.[77]

Indirect costs were estimated by quantifying the productivity losses associated with epilepsy, using data on both the prevalence of the condition and the disability burden as measured by Disability-Adjusted Life Years (DALYs). The most recent figures from the Global Burden of Disease Study (GBD) and associated literature[78] were used to determine the number of DALYs for both primary and secondary epilepsy in each country.

To translate DALYs into economic terms, each country's value added per capita was used in combination with its employment rate. A reduction factor equal to 24% was applied to reflect the difference between the employment rate of the general population and that of individuals with epilepsy[79]. This allowed to adjust the loss of economic productivity to epilepsy-specific employment rates. An additional refinement was introduced to calibrate indirect costs by age

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[75] Begley C et al. (2022), "The global cost of epilepsy: A systematic review and extrapolation". Epilepsia.

[76] Europea Central Bank, 2025.

[77] Strzelczyk et al. (2015), "Costs of epilepsy and cost-driving factors in children, adolescents, and their caregivers in Germany". Epilepsia.

[78] GBD Epilepsy Collaborators (2025), "Global, regional, and national burden of epilepsy, 1990–2021: a systematic analysis for the Global Burden of Disease Study 2021". The Lancet Public Health.

[79] Narducci F et al. (2025), "Epilepsy and Employment in Europe: A Systematic Review of Literature". European Journal of Neurology.

group. Since economic output is only generated by people of working age, the indirect costs were reduced by 51.2% to reflect the fact that only 48.8% of people with epilepsy fall within the 20–64 age bracket.

Finally, the model accounted for productivity losses associated with informal caregivers. Drawing on estimates from Strzelczyk et al. (2015), which quantified caregiver burden in Germany, the costs were adjusted for inflation to reflect 2024 values and then recalibrated across countries to reflect differences in value added per capita. The model only applies indirect costs of caregiving to 67% of people with epilepsy, which reflects the proportion that requires some level of care on behalf of relatives or friends according to recent academic evidence.[80]

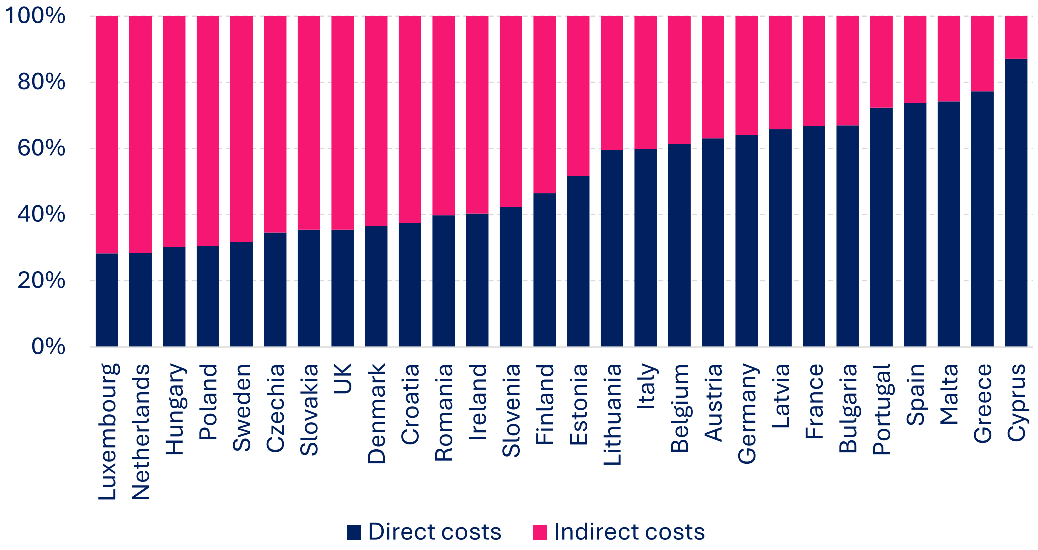

Figure 14. Composition of epilepsy costs in EU-27+UK (% share of direct and indirect costs over total) – *Source: elaboration by TEHA on various sources, 2025*

The updated estimation of the economic burden of epilepsy across the EU-27 and the United Kingdom reveals a substantial and persistent impact on both healthcare systems and the wider economy. **The total burden is estimated to range between €41.1 and €49.2 billion per year, corresponding to approximately 0.24% to 0.28% of the combined GDP of EU-27+UK countries.**

As mentioned above, this burden is composed of both direct and indirect costs. Direct costs, linked to hospitalisations, specialist consultations, diagnostic testing, and anti-seizure medications, are estimated at €16.9 to €20.1 billion per year, accounting for 41% of the total burden. Indirect costs, which capture productivity losses due to unemployment, underemployment, premature retirement, and the time demands on informal caregivers, represent most of the economic impact. These are estimated between €24.3 and €29.0 billion per year, making up 59% of the total burden.

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[80] Yeni K et al. (2024), “Caregiver burden and its predictors in adult epilepsy patients”. Epilepsy & Behavior.

DIRECT COSTS

€16.9 – 20.1 billion per year
(41.0% of total costs)

INDIRECT COSTS

€24.3 – 29.0 billion per year
(59.0% of total costs)

The **overall economic burden of Epilepsy** is estimated at **€41.1 – 49.2 billion euros per year**, equal to **0.20 – 0.24% of GDP** of EU-27+UK countries

Figure 15. Overall economic costs of epilepsy in EU-27 + UK countries – *Source: elaboration by TEHA on various sources, 2025*

A breakdown of the direct costs of epilepsy reveals that hospitalisation and rehabilitation represent the largest expenditure, accounting for 43.8% of total direct medical costs. This is followed closely by drug costs (41.2%), highlighting the significant contribution of long-term pharmacological treatment to overall costs. Other components, such as specialist consultations (11.2%), diagnosis, and laboratory testing, account for a smaller share.

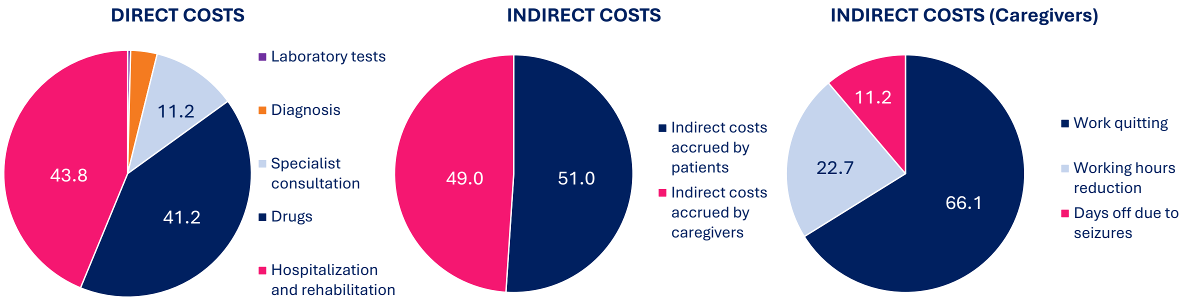

Figure 16. On the left: Direct costs by cost component (% over total). In the middle: Indirect costs by costs accrued by patients and costs accrued by caregivers (% over total). On the right: Caregiver costs by cost component (% over total) – *Source: TEHA on Begley C et al. (2022), "The global cost of epilepsy: A systematic review and extrapolation", Strzelczyk et al. (2015), "Costs of epilepsy and cost-driving factors in children, adolescents, and their caregivers in Germany", and Willems LM et al. (2021), "Multicenter, cross-sectional study of the costs of illness andcost-driving factors in adult patients with epilepsy", 2025*

With respect to indirect costs, the burden is evenly split between patients and informal caregivers, who respectively absorb 51% and 49% of the total. Among caregivers, the most significant contributor is work quitting (66.1%), followed by reduction in working hours (22.7%) and days off due to seizures (11.2%). These data reflect the profound impact epilepsy has on household income and workforce participation, reinforcing the need for better workplace policies, caregiver support systems, and broader social protection measures to mitigate long-term economic consequences.

These figures underline **the multidimensional nature of epilepsy's economic impact, which extends far beyond clinical care to affect labor markets, social welfare systems, and long-term productivity.** As the largest share of the burden stems from reduced employment and productivity, both for people living with epilepsy and for caregivers, this distribution highlights how epilepsy is not only a medical condition but also a social and economic challenge. At the same time, it points to a significant, often overlooked economic opportunity for Europe.

If individuals with epilepsy receive timely diagnosis and effective treatment, they are more likely to remain in or return to work. Similarly, when caregivers are adequately supported, their participation in the labour market can also be sustained. Investing in prevention, optimal care pathways, and inclusive support systems is therefore not just a matter of health and impact on patients' quality of life and support: it is a strategic lever for productivity, workforce participation, and long-term growth.

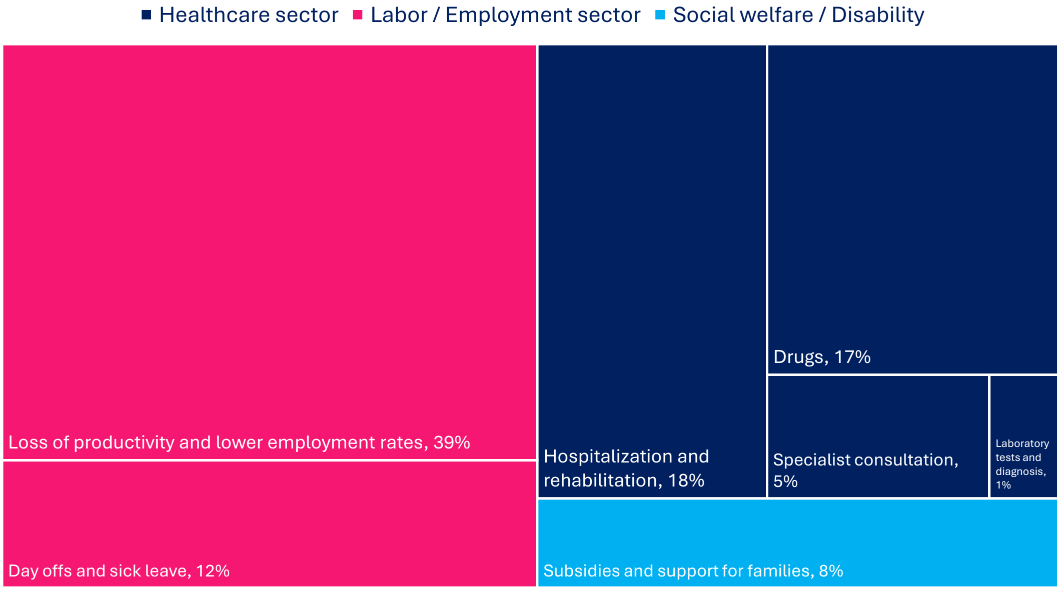

Figure 17. Break-up of the economic burden of epilepsy in EU27+UK by sector and type of cost (% over total) - *Source: elaboration by TEHA on various sources, 2025*

The Return on Investment (ROI) of epilepsy treatment and prevention

Return on Investment is a framework used to assess the value of an investment by comparing its costs with the expected benefits. In healthcare, ROI is particularly relevant as it helps policymakers and stakeholders understand how targeted spending on prevention, diagnosis, and treatment can generate long-term savings and broader societal gains. Rather than focusing solely on immediate financial returns, healthcare ROI also accounts for improved health outcomes, increased productivity, reduced disability, and better quality of life for individuals.

In the case of epilepsy, this approach highlights the significant value of investing in a comprehensive approach. The burden of epilepsy, in fact, while representing a challenge for healthcare systems and the broader economy, also presents a critical opportunity: by investing in the prevention, early treatment and optimal care of epilepsy, including its comorbidities, European countries could improve population health and, at the same time, reduce healthcare expenditure and drive economic growth. In fact, high-quality care not only reduces the frequency and severity of seizures but also helps mitigate the broader social and economic consequences of the condition, such as unemployment, loss of productivity, and the long-term costs of untreated comorbidities.

To quantify this opportunity, three distinct return-on-investment (ROI) models were developed, each targeting a specific area of intervention.

1. **Closing the treatment gap**

   This model estimates the ROI of ensuring that all individuals with epilepsy receive appropriate treatment according to international clinical guidelines. A significant proportion of patients across Europe remain untreated or undertreated and thus develop uncontrolled epilepsy, which results in significantly higher direct and indirect costs. Therefore, an initial investment in the improvement of treatment, for example by accelerating diagnoses, identifying the optimal therapy and improving adherence to anti-seizure medication, can result in lower costs for the healthcare system.

   In advanced economies, according to the literature[81], the treatment gap is equal to 9.8% of the total population with epilepsy. Considering direct and indirect costs of epilepsy, the burden of uncontrolled epilepsy is estimated to cost over 30% more.[82,83] On this basis, an initial investment to bring patients with uncontrolled epilepsy back onto an optimal clinical pathway (i.e. a clinical pathway able to close the treatment gap) is estimated to produce a positive return on investment equal to 1.9.

2. **Minimizing the risk, preventing and treating psychiatric comorbidities**
   Mental health conditions such as anxiety and depression are common among people with epilepsy and are often unaddressed within standard care pathways. These comorbidities significantly impact quality of life, increase healthcare resource utilisation, and contribute to lost productivity. Furthermore, they are more frequent in patients with uncontrolled seizures, and vice versa, with the presence of depression being associated with poorer seizure control. By using more effective anti-seizure medications in earlier treatment line, people with epilepsy will not only have a better control of their seizures but will reduce their risk of suffering from anxiety and depression. At the same time, by early recognizing and treating psychiatric comorbidities like depression, the odds of uncontrolled seizures and their consequences can be reduced.

   Specifically, this model evaluates the costs[84] and benefits[85] of integrating psychotherapy into treatment pathways, estimating the potential returns arising from the reduction in healthcare costs and by the increased participation in the labour market. The model adopts a conservative assumption by considering the benefits of psychotherapy for patients and healthcare systems to accrue only during the active treatment period, even

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[81] Kwon C et al. (2022), "The worldwide epilepsy treatment gap: A systematic review and recommendations for revised definitions – A report from the ILAE Epidemiology Commission". Epilepsia.

[82] De Zélicourt M et al. (2014), "Management of focal epilepsy in adults treated with polytherapy in France: The direct cost of drug resistance (ESPERA study)". Seizure.

[83] Willems LM et al. (2022), "Multicenter, cross-sectional study of the costs of illness and cost-driving factors in adult patients with epilepsy". Epilepsia.

[84] Dewhurst E et al. (2015), "A prospective service evaluation of acceptance and commitment therapy for patients with refractory epilepsy". Epilepsy & Behavior.

[85] TEHA Group elaboration on OECD data and Fleishman JA et al. (2006), "Using the SF-12 health status measure to improve predictions of medical expenditures". Medical Care.

though in reality, these benefits are likely to persist beyond the conclusion of therapy. Even under these assumptions, the model yields a return on investment equal to 1.5.[86]

3. **Prevention of epilepsy through public health interventions**

While not all cases of epilepsy are preventable, 24% of the total prevalence in high-income countries is attributable to modifiable risk factors, particularly stroke, traumatic brain injury, central nervous system infections and complications in the perinatal period.[87]

This ROI model explores the economic gains associated with investing in upstream prevention strategies, addressing two of the most common non-genetic causes of epilepsy: stroke (responsible for 12% of epilepsy cases in industrialized countries) and inadequate perinatal care (responsible for a further 5% of cases).[88]

Starting from the first, NHS data provides the number of strokes that can be prevented through a prevention programme in high-risk populations. At the same time, the academic literature has found the probability of developing epilepsy following a stroke[89], which allows to calculate the number of cases of epilepsy that can be avoided by acting on cardiovascular prevention. Calculating the 10-year benefit over the costs incurred in the same years[90], in order to provide enough time to absorb the initial investment, yields a return to investment equal to 1.8.

In parallel, a second model focused on perinatal care interventions, particularly the screening of pregnant women at risk of preterm birth. Children born preterm have a 2.16 times higher risk of developing epilepsy compared to those born full-term.[91] By preventing a share of these preterm births through low-cost measures such as cervix screening, several future epilepsy cases can be avoided.[92] When the long-term savings[93] are compared with the cost of these interventions, the estimated return on investment is 1.6.

Overall, assuming a balanced investment into both prevention strategies, the overall ROI would be equal to 1.7, confirming the value of integrating prevention into broader strategies to reduce the burden of epilepsy.

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[86] The model focuses specifically on psychotherapy, reflecting the scope of available data and evidence. Further analyses could expand its scope to include, for example, pharmacological treatment.

[87] WHO, ILAE and IBE (2019), “Epilpesy. A Public Health Imperative”.

[88] Ibid.

[89] Galovic M et al. (2021), “Seizures and Epilepsy After Stroke: Epidemiology, Biomarkers and Management”. Drugs & Aging.

[90] Costs and benefits factored into the model assuming a discount rate equal to 2%. Initial costs include the cost of the screening programme, while long term costs include the cost of hypertension medication. Benefits are derived from data used to compute the burden of epilepsy in the previous section.

[91] Li W et al. (2019), “Do premature and post term birth increase the risk of epilepsy? An updated meta-analysis”. Epilepsy & Behaviour.

[92] Zechmeister-Koss I et al. (2014), “Affordability of programmes to prevent spontaneous preterm birth in Austria: a budget impact analysis”. European Journal of Public Health.

[93] The model takes into account avoided costs until the 18th year of life of babies whose preterm birth was avoided. A 2% discount rate is applied.

Together, these three models offer a structured framework to assess the value of investing in epilepsy prevention and treatment. Each highlights the economic efficiency of targeted interventions and the broader societal benefits they bring. **Investing €1 in each of them would not only repay for itself but also yield an additional €0.50-€0.90 in terms of reduced healthcare spending and increased productivity of patients and caregivers.** In a context of strained healthcare budgets compounded by demographic ageing, such evidence-based models can help policymakers prioritise cost-effective strategies that maximise both health outcomes and economic value.

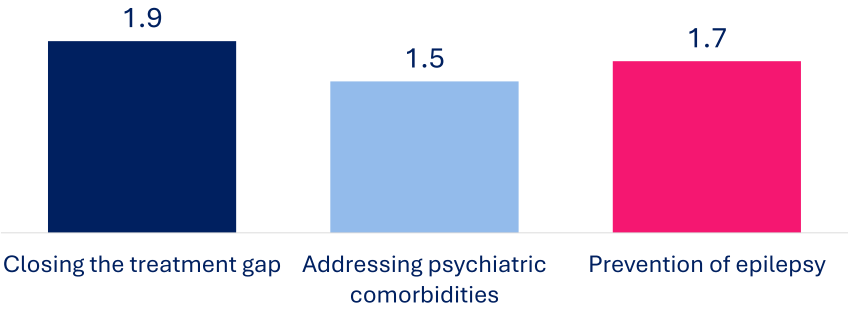

Figure 18. Return on Investment (ROI) results from three different interventions on epilepsy management – *Source: elaboration by TEHA on various sources, 2025*

Moving forward: Priorities for action

The socioeconomic burden of epilepsy, as outlined in this Chapter, is not simply the sum of clinical expenses and lost productivity, but rather the tangible outcome of unmet needs, fragmented care, persistent stigma, and preventable barriers in daily life. Limited mobility, rigid workplace environments, and delayed access to adequate care are central drivers of the human and economic costs associated with epilepsy.

This burden, however, is not inevitable. The return-on-investment analyses demonstrate that targeted action can yield substantial gains for both individuals and society. **Encouraging inclusive employment policies, fostering social understanding, and equipping patients with the tools and support they need to navigate their condition** is key not only for their wellbeing, but to reduce the burden of this condition and thus drive economic growth.

What might be needed is targeted training and support to help patients confidently and effectively communicate about their condition. This would not only foster greater inclusion but also improve access to policymakers, who often overlook epilepsy simply because they do not fully understand it. In reframing the narrative around epilepsy, a powerful sensibilization point is the reminder that ‘everyone has a brain’ – highlighting that neurological conditions can affect anyone, at any stage of life. Moreover, epilepsy is not only a medical issue but a matter of representation: people with epilepsy are citizens and voters, and their needs and rights deserve greater attention in political and public discourse.

Best practices on the management of epilepsy from Europe

While the challenges associated with epilepsy are significant, numerous experiences from throughout Europe demonstrate the important margins for improvement in the management of epilepsy that exist. These best practices, ranging from national Brain Health plans to policies aimed at promoting inclusion, demonstrate that **progress is not**

only possible but already underway. **It is therefore important to share and disseminate these experiences** to support the adoption of effective strategies whose impact on the quality of life of patients was demonstrated.

This section presents a selection of diverse and transferable approaches that have delivered measurable benefits in the management of epilepsy. Together, they offer valuable insights and potential pathways for other health systems seeking to reduce the burden of epilepsy for patients, caregivers and society as a whole.

- One of the most tangible ways to support people with epilepsy is to help them overcome the daily functional limitations imposed by the condition. In the United Kingdom, the **Personal Independence Payment (PIP)** represents a best practice in this regard, enabling greater autonomy and inclusion through financial support calibrated to the individual's specific needs. PIP is a non-means-tested benefit available to individuals with long-term health conditions or disabilities, including epilepsy, which can provide support for up to £184.30 per week.[94] As of 2023, over 63,000 people with epilepsy received PIP, making it one of the most awarded conditions under the scheme. Significantly, 31% of recipients with epilepsy receive an enhanced rate for both the daily living and mobility components. Also, 96% of those awarded PIP for epilepsy receive support for mobility needs, which also grants access to the UK's Motability scheme. Together, these policies help individuals with epilepsy to overcome mobility challenges, one of the hidden challenges addressed in this chapter.
- Remaining in the UK, the **establishment and integration of Epilepsy Specialist Nurses (ESNs) into the healthcare system** stand out as a best practice in ensuring continuity of care, improving patient outcomes, and supporting families and caregivers. Recognized by the UK's National Institute for Health and Care Excellence (NICE) guidelines, the presence of ESNs is now considered essential by treatment guidelines. ESNs fulfil a broad range of functions, including patient education, medication management, seizure monitoring, and coordination of care across different providers. They serve as a consistent point of contact for patients navigating complex health and social systems and offer guidance tailored to individual needs – a critical resource in managing a condition marked by unpredictability and stigma. Organizations such as Epilepsy Nurses Association (ESNA) play a key role in supporting the professional development of these nurses and facilitating peer learning across the UK and internationally. The collaborative model underlying the ESN system also promotes integration across care settings, enhancing the delivery of holistic, person-centered care.
- While many challenges persist, some countries also offer valuable examples of how structured, patient-centered approaches can enhance epilepsy care. The **Finnish care pathway model** provides a compelling case study: it emphasizes early intervention, continuity of care, and robust integration between primary and specialist services. As a result, Finland has achieved measurable improvements in seizure control, quality of life,

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[94] UK Government, 2025.

and healthcare utilization, highlighting the importance of standardized treatment protocols, multidisciplinary care teams, and interoperable data systems.

- Ireland, as well, offers a strong example of how integrated care pathways can lead to measurable improvements in epilepsy management. Through its **national Model of Care for Epilepsy**, launched in 2017, health outcomes of patients have experienced significant improvement. One of the most striking outcomes of this approach has been a significant reduction in epilepsy-related hospital admissions, from 45.9% to 28.7%.

- The **EpilepsyPOWER project**, co-funded by the EU Health Programme, aimed at improving opportunities of inclusion in job market for people with epilepsy in five countries: Italy, Germany, Bulgaria, Ireland and France. The initiative developed an e-learning platform, collaborative labs with stakeholders to share best practices, and multilingual training modules tailored to employability needs. Participant institutions who successfully completed the online training modules (e.g. Universities, businesses, ...) could earn a Certificate of Achievement for communication purposes.

- Public awareness campaigns represent a powerful tool to combat stigma and misinformation surrounding epilepsy. A notable example comes from Croatia, where the **Out of the Shadows campaign**, active from 2002 to 2010, sought to improve public understanding and reduce discriminatory attitudes toward people with epilepsy. The initiative was mainly conducted in high schools in Zagreb. Over the campaign period, substantial progress was recorded. For example, the share of adolescents expressing positive attitudes toward employment of individuals with epilepsy rose from 68.1% in 2002 to 82.8% in 2010.[95] These outcomes underscore the long-term value of sustained, targeted communication in reshaping public attitudes and enhancing social inclusion for people with epilepsy.

- In terms of institutional best practices, Norway has been in the forefront of brain health efforts and was the first country to devise a national brain health strategy and provide resources to implement it. The **Norwegian Brain Health Strategy** (updated to 2020–2025) establishes concrete objectives for improving the lives of people with neurological conditions. The strategy prioritizes early intervention, equitable access to specialist services, and stronger coordination between the health, education, and social sectors. It also mandates new evidence-based epilepsy guidelines prepared jointly by a specialist epilepsy hospital and health authorities, with patient representatives on the steering committee. By implementing an overarching approach, the country managed to decrease age-adjusted incidence rates of dementia by 5.4%, ischemic heart disease by 30.0%, and stroke by 35.3% between 1990 and 2019.

- Finland also has a well-established national brain health plan, which is now incorporating **impact-investing approaches**, notably through the procurement of services based on outcomes rather than outputs, such as social impact bonds. The **Finnish National Brain Health Plan** is drawing on lessons learned from previous impact bond initiatives in areas like occupational wellbeing, rapid employment and immigrant integration, child welfare, employment advancement, type 2 diabetes prevention, and support for independent

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[95] Bielen I et al. (2012), “Changes of attitudes toward epilepsy in college-preparatory high school students population: An indicator of global campaign successfulness?”. Seizure.

living among the elderly. This evolving strategy reflects a broader shift toward value-based healthcare, where public investment is increasingly aligned with measurable improvements in health and social outcomes.

- Similarly, **Germany's 2022 National Brain Plan** represents an effort to systematically address the challenges of brain health conditions, tackling the common challenges that they entail. Developed with input from patients, clinicians, and researchers, the Plan calls for the integration of brain health into national health policy, improved access to specialized services, and the reduction of disease burden through early diagnosis, continuity of care, and social inclusion. It explicitly includes epilepsy among its target conditions and supports intersectoral collaboration to break down care silos, an approach that is especially relevant for epilepsy given its many comorbidities and impacts on social life.
- Another recent example comes from Switzerland, which in 2023 launched a **National Brain Health Plan** (2023–2033) aimed at raising awareness of brain health as a whole and promoting the development of targeted prevention programs. The plan outlines five strategic objectives: increasing public awareness, fostering interprofessional education and training, advancing research on the determinants of brain health, strengthening prevention efforts, and empowering both patients and caregivers. This long-term strategy reflects a comprehensive and inclusive approach to brain health, addressing not only clinical aspects but also social and educational dimensions.
- A more recent development is the **Plan Español del Cerebro (PEC)**, Spain's first-ever national brain health strategy, launched by the government in April 2025. It marks a coordinated response to the growing societal and healthcare burden of brain conditions. The PEC was developed and presented by the Spanish Brain Council in light of recent data showing that over 21 million people in Spain (nearly 43% of the population) live with a neurological or psychiatric condition and that brain disorders are now the leading cause of disability and the 2nd cause of death in the country. The PEC outlines a multisectoral strategy aligned with WHO targets and the European Brain Council's call for national brain plans. It is structured around five pillars: strengthening epidemiological data and monitoring (data and impact); reducing territorial inequalities and improving access (equitable care); boosting investment in neuroscience and innovation (research); prioritizing early detection and risk reduction (prevention); and fostering patient and community engagement (social participation). It also includes plans to create an **Iberian Brain Observatory** in partnership with Portugal to promote cross-border collaboration.

Conclusion: Making brain health (and epilepsy) a public priority in the European Union

The need for a holistic approach

While considerable progress has been made, deepening the understanding of the brain and the value of brain capital is now more critical than ever. **Given the complexity and importance of brain health, it must be addressed through collaborative, integrated, and comprehensive strategies**, with effective and equitable solutions implemented at all levels – local, national, and European. In a context of limited resources, it is crucial to ensure their optimal use by supporting better coordinated brain research and promoting strategies focused on prevention, early detection, accurate diagnosis, timely treatment and care.

For the 6 million people living with epilepsy in Europe, **achieving seizure control and – ultimately – seizure freedom is the key therapeutic goal, as it reduces the risk of accidents and epilepsy related deaths, improves quality of life, social inclusion, and mental well-being**. As outlined in previous Chapters, epilepsy is a highly unpredictable condition, often accompanied by comorbidities, stigma, and significant economic burden. To improve outcomes for patients and their families and to unlock currently untapped social and economic potential, a holistic approach is essential. This means addressing the full spectrum of needs (medical, psychological, social, and financial) through integrated care pathways and responsive policy frameworks.

Epilepsy must therefore be recognized as a major brain disorder that requires coordinated action across healthcare systems, policy arenas, and public discourse. An inclusive approach is necessary to ensure a fulfilling and healthy life for people with epilepsy while promoting brain health for all.

Advancing the IGAP Agenda in Europe: State of the art and role of the EU Institutions

As described in Chapter 1, the Intersectoral Global Action Plan on Epilepsy and other neurological disorders (IGAP) is a 10-year roadmap launched in 2022 by the WHO to strengthen the response to neurological conditions, including epilepsy. Endorsed by all 194 Member States, **it is the first global action plan of its kind since the Global Campaign Against Epilepsy (GCAE) of 1997**.

The IGAP aims to reduce the stigma, impact, and burden of neurological disorders while improving the quality of life for affected individuals, their families, and caregivers. It sets out five strategic objectives, each comprising two global targets, with a specific focus on promoting a public health approach to epilepsy.

Among the ten global targets, target 1.1 is arguably among the most important: **by 2031, 75% of countries should have adopted a national plan, policy, or strategy for neurological conditions**. Establishing such frameworks is foundational, as it creates the governance and resource commitments needed to make progress towards other targets, such as expanding service coverage and implementing effective public-awareness initiatives.

Despite the IGAP's call for 75% of countries to adopt a national strategy for neurological conditions by 2031, progress across the EU-27 and the UK remains limited. As of mid-2025, **only 4 countries[96] - Finland, Germany, Ireland, and Spain - have a government-endorsed brain health plan currently in force[97]**. These plans vary in scope but share a common goal: to improve prevention, care, and research related to neurological conditions across the life course.

Spain is the most recent addition, having officially presented its Plan Español del Cerebro 2025–2035 in May 2025. The plan adopts a comprehensive, multi-pillar approach and allows Spain to join a small but growing group of European countries that have taken concrete policy steps to address the growing burden of brain disorders. Other developments suggest a slow but emerging momentum. NHS England is expected to launch a national brain health plan in the summer of 2025, building on public consultations carried out starting from October 2024. Meanwhile, Poland adopted a non-governmental brain plan in 2019, developed by experts and civil society stakeholders, which remains a valuable reference but lacks formal recognition or implementation by national authorities. The Italian Society of Neurology (SIN) has also proposed a National Brain Health Strategy with a time horizon (2024-2031) which, if adopted, would align Italy with the scope of the IGAP.

The limited number of existing plans stands in stark contrast to the scale of the challenge. As mentioned, brain disorders are among the leading causes of disability and economic loss in Europe, yet most European countries have yet to define a structured national response. The absence of formal strategies often results in fragmented services, delayed diagnoses, underinvestment in prevention, and insufficient research coordination. It is also important to note that **not all national plans are accompanied by dedicated funding or allocated human resources for implementation**, factors that can significantly limit their strategic effectiveness and long-term impact.

Looking forward, reaching target 1.1 will be crucial to laying the foundation for broader progress under the IGAP. Achieving all ten targets by 2031 is, in fact, essential not only for reducing the health and economic burden of neurological conditions, but also for building more resilient, inclusive, and equitable health systems across Europe and beyond.

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[96] Since IGAP allows target 1.1 to be achieved even when policies for neurological conditions are integrated into broader national strategies, such as those on noncommunicable diseases or maternal and child health, it is possible that other European countries have developed brain health policies without presenting them under the framework of a dedicated national plan.

[97] As previously mentioned, several countries, including Norway and Switzerland, are advancing brain health strategies. In the U.S., Congress is considering legislation (H.R. 10210/S. 494) to establish a National Plan for Epilepsy. These efforts increase pressure on the EU to take coordinated action on brain health.

Figure 19. Progress towards IGAP target 1.1 in EU-27 + UK countries – *Source: TEHA on various sources, 2025*

EU institutions have a critical role to play in advancing brain health, including epilepsy, by leveraging their ability to shape policy through legislation and strategic funding frameworks. While healthcare remains primarily a national competence, the European Union has, in fact, increasingly demonstrated its capacity to guide Member States through overarching programs and initiatives.

EU4Health, Horizon Europe, and the upcoming European Partnership on Brain Health[98] represent key instruments through which the EU can elevate epilepsy as a strategic health priority. This includes embedding epilepsy into the broader framework of non-communicable disease (NCD) policies, promoting patient-centred care approaches, and supporting coordinated data collection and outcome monitoring across countries. In this regard, **strategic EU funding – both for research and public health – can serve as a catalyst to help Member States adopt evidence-based interventions**, scale up innovative models of care, and invest in targeted research, especially in areas where treatment gaps and comorbidities remain unaddressed.

Moreover, **EU institutions can play a vital role in promoting rights as well as harmonization** of healthcare quality and service standards, including access to treatment, for example by reducing disparities in time-to-access for anti-seizure medications and ensuring equitable availability of effective and innovative therapies. Scaling up best practices across Europe – such as the deployment of epilepsy-specialist nurses, the adoption of national epilepsy action plans, and the reinforcement of cross-border reference networks like EpiCARE – is another key area where EU coordination can add value.

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[98] European Commission (2025), "European Partnership for Brain Health".
Available at: https://cordis.europa.eu/programme/id/HORIZON_HORIZON-HLTH-2025-02-DISEASE-01

A call to action: Elevating brain health and epilepsy on the European stage

Despite the formal adoption of the IGAP and significant national initiatives, implementation across Europe remains uneven. With a shared framework in place, time has come to translate ambitions and targets into concrete action through coordinated policies, dedicating funding, and services. Building on insights from patient communities and expert groups, an EU-coordinated action should now prioritize brain health through both strategic investment and public engagement.

10 strategic priorities emerge to embed epilepsy and broader brain health on Europe's policy agenda:

1. Establish a **dedicated funding line for epilepsy and related brain health** within both EU research and public health programs – including the upcoming EU Brain Health Partnership, Horizon Europe, and EU4Health – to ensure coordinated support for innovation, care delivery, and prevention strategies.
2. Include **epilepsy as a distinct priority in EU and Member States strategies on NCDs, mental health, and rare diseases**, with tailored indicators and goals.
3. Accelerate the achievement of public health objectives already defined and the full adoption of IGAP across Member States, including the elaboration of national Brain Health Plans or policies, with **EU coordination, peer review, and monitoring mechanisms**, to ensure its 2031 service coverage targets are met.
4. **Strengthen prevention efforts** by supporting early-life interventions, perinatal care, awareness of preventable causes of epilepsy (e.g. head trauma, infections), and targeted risk-reduction strategies to improve long-term outcomes.
5. Expand **access to anti-seizure medications and surgical and technological options** uniformly across Europe (with alignment to the EU Pharmaceutical Strategy), including epilepsy-monitoring infrastructure, while ensuring that basic enablers such as information, economic support, and transportation services are in place.
6. Strengthen the role of **people with epilepsy as experts by experience**, enabling structured involvement in policy co-design, with specific attention on raising employers' awareness and promoting supportive company policies. **Support and partner with patient organizations at the EU level** to advance these efforts collaboratively.
7. Increase **coordinated initiatives thought a joint European action** to address the multifaceted challenges of epilepsy, focusing on reducing stigma, promoting rights and inclusion, and supporting key life transitions (e.g., school and higher education, employment, ageing).
8. Facilitate **cross-border collaboration and cooperation** to improve access to highly specialized care and shared expertise across Member States. At the same time, launch a **coordinated action to overcome health workforce shortages** by training and deploying new epilepsy specialists (e.g., dedicated nursing professionals).
9. Strengthen **data and evidence to increase knowledge of epilepsy**, its symptoms and its specific health, economic and social impact, starting from standardized registries on epilepsy and seizure outcomes (integrated within the European Health Data Space), including patient-reported indicators and real-world evidence. Enhance the level of attention to the specific health needs of vulnerable groups and caregivers.
10. Promote an **intersectoral EU approach to epilepsy** by integrating it into broader frameworks on disability rights, employment, gender equity, and digital health – ensuring coordinated policies that address the full spectrum of challenges faced by people with epilepsy.

This strategic agenda calls upon EU institutions to catalyze a transformative approach to brain health that places disease prevention, equitable access, stigma reduction, and patient empowerment at its core. By committing to these priorities, the European Union can turn pledges into tangible progress, ensuring that individuals with epilepsy, and all citizens, stand to benefit from a healthier, more inclusive future.

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EBC – European Brain Council - www.braincouncil.eu

EFNA – European Federation of Neurology Associations - www.efna.net

EpilepsyPOWER – www.epilepsypower-project.eu

European Commission - www.ec.europa.eu

European Parliament - www.europarl.europa.eu

Eurostat - www.ec.europa.eu/eurostat/data/database

GBD - Global Burden of Disease - www.vizhub.healthdata.org/gbd-compare and brainhealthatlas.org

International Bureau of Epilepsy - www.ibe-epilepsy.org

International League Against Epilepsy - www.ilae.org

OECD - Organisation for Economic Co-operation and Development - www.stats.oecd.org

WHO – World Health Organization - www.who.int/news-room/fact-sheets/detail/epilepsy

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