

EPILEPSY

A public health imperative

SUMMARY



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EPILEPSY

A public health imperative



Foreword

Epilepsy is one of the most common neurological diseases worldwide, affecting around 50 million people of all ages around the world. The risk of premature death in people with epilepsy is up to three times that of the general population. The lives of people with epilepsy are often impacted by stigma, discrimination and human rights violations.

We know that while 80% of people with epilepsy live in low- and middle-income countries, most of them do not have access to treatment. This is despite the availability of effective antiseizure medicines, which can cost as little as US\$ 5 per year. A lack of action to address the epilepsy treatment gap has dire consequences for people's lives and well-being, and impacts social and economic development.

This report presents encouraging evidence that almost a quarter of epilepsy cases are preventable and 70% of people with epilepsy can live seizure free with low-cost and effective medicines. As evidence from multiple countries shows, it is feasible to integrate epilepsy into primary health care and thereby ensure that all people with epilepsy have access to quality and affordable treatment and services.

If we are to achieve the health-related Sustainable Development Goals (SDGs), it is imperative that we substantially scale up global efforts to address epilepsy. The SDGs include the targets of reducing premature deaths from noncommunicable diseases and promoting mental health and well-being; as well as achieving universal health coverage with access to quality services and effective, affordable essential medicines. The importance of addressing epilepsy was also underlined in a World Health Assembly (WHA) resolution on the global burden of epilepsy in 2015. The resolution requests that WHO provide technical support to countries for epilepsy management, especially those with the lowest access to services and resources, where the burden of epilepsy is greatest.

This is the first global report on epilepsy produced by WHO and key partners. It highlights the available evidence on the burden of epilepsy and the public health response required at global, regional and national levels. The report is also an important milestone in re-energizing and translating the WHA resolution into action as it provides guidance to governments, policy-makers and stakeholders as they seek to reduce the disease burden as part of the universal health coverage agenda.

I encourage all WHO Member States and partners to build on the findings and recommendations of this report and to share it widely.



Dr Ren Minghui

Assistant Director-General for Universal Health Coverage/
Communicable and Noncommunicable Diseases
World Health Organization

Preface

Epilepsy is a brain disease characterized by abnormal electrical activity causing seizures or unusual behaviour, sensations and sometimes loss of awareness. It carries neurological, cognitive, psychological and social consequences and accounts for a significant proportion of the world's burden of disease. Despite availability of effective and low-cost antiseizure medicines, more than 75% of people with epilepsy in low-income countries do not have access to treatment.

This report is the product of a long-standing collaboration between WHO and leading nongovernmental organizations working in the area of epilepsy, the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). Together we have made substantial progress in encouraging countries to prioritize epilepsy in public health agendas.

Epilepsy: a public health imperative presents a comprehensive picture of the impact that the condition has on people with epilepsy, their families, communities and societies. Epilepsy has a high risk of disability, psychiatric comorbidity, social isolation and premature death. Across the world, people with epilepsy and their families suffer from stigma and discrimination. Many children with epilepsy do not go to school; adults are denied work, the right to drive or marriage. The human rights violations faced by people with epilepsy around the world are unacceptable.

It is time to highlight epilepsy as a public health imperative, to strongly encourage investment in reducing its burden, and to advocate for actions to address gaps in epilepsy knowledge, care and research.

Raising epilepsy on the global public health agenda cannot be done alone. The adoption of the World Health Assembly resolution on epilepsy by Member States drew attention to the need for coordinated action at country level. The resolution provides a powerful tool to engage governments and civil society in taking concrete action to promote access to care and to protect the rights of people with epilepsy.

Epilepsy: a public health imperative is a call for sustained and coordinated action to ensure that every person with epilepsy has access to the care and treatment they need, and the opportunity to live free from stigma and discrimination in all parts of the world.



Dévora Kestel
Director
Department of Mental Health
and Substance Abuse
World Health Organization



Samuel Wiebe
President
International League Against
Epilepsy



Martin Brodie
President
International Bureau for Epilepsy

Overarching messages



BURDEN

The burden of epilepsy is high and often neglected in public health agendas. Epilepsy is one of the most common neurological diseases, affecting nearly 50 million people of all ages around the world. The risk of premature death in people with epilepsy is up to three times that of the general population. Roughly half of adults with epilepsy have at least one other health condition. Psychiatric conditions, such as depression and anxiety, make seizures worse and reduce quality of life. Epilepsy has significant economic implications in terms of health care needs and lost productivity at work.



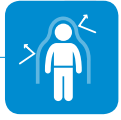
STIGMA AND DISCRIMINATION

In all parts of the world, people with epilepsy are the target of discrimination and human rights violations. The stigma of epilepsy can discourage people from seeking treatment and has consequences for quality of life and social inclusion. Improving knowledge and raising awareness of epilepsy in schools, work places, and communities is needed to reduce stigma. Legislation based on internationally accepted human rights standards can prevent discrimination and rights violations, improve access to health care services, and raise the quality of life for people with epilepsy.



TREATMENT GAP

Three-quarters of people living with epilepsy in low-income countries do not get the treatment they need. Yet, up to 70% of people with epilepsy could become seizure free with appropriate use of cost-effective antiseizure medicines. A significant proportion of the burden of epilepsy could be avoided by scaling up routine availability of antiseizure medicines, possible at an annual cost as low as US\$ 5 per person. It is feasible to integrate epilepsy treatment into primary health care – training nonspecialist providers, investing in continuous supplies of antiseizure medicines and strengthening health systems can substantially reduce the epilepsy treatment gap.



PREVENTION

An estimated 25% of epilepsy cases are preventable. The major modifiable risk factors for epilepsy are: perinatal insults, central nervous system infections, traumatic brain injury and stroke. Preventing epilepsy is an urgent unmet need. Effective interventions for prevention are available and delivered as part of broader public health responses in maternal and newborn health care, communicable disease control, injury prevention and cardiovascular health.



THE TIME TO ACT IS NOW

Sustained and coordinated action to prioritize epilepsy in public health agendas is required at global, regional and national levels. World Health Assembly resolution WHA68.20 on the global burden of epilepsy and the need for coordinated action at the country level to address its health, social and public knowledge implications sets the framework for increasing investment in epilepsy. There is a pressing need for increased investment in research and to address the burden of epilepsy through integration in primary health care, ensuring that all people with epilepsy have access to quality and affordable care.

Executive summary

Introduction

Epilepsy is a brain disease characterized by abnormal brain activity causing seizures or unusual behaviour, sensations and sometimes loss of awareness. It carries neurological, cognitive, psychological and social consequences and **accounts for a significant proportion of the world's burden of disease, affecting around 50 million people worldwide**. The number of people with epilepsy is expected to increase further due to rising life expectancy worldwide and an increasing proportion of people surviving insults which often lead to epilepsy, such as birth trauma, traumatic brain injury (TBI), infections of the brain, and stroke. The physical, psychological and social consequences of epilepsy impose significant burdens on people living with the condition and their families. Around the world, people with epilepsy and their families suffer from stigma and discrimination, often facing serious difficulties in education, employment, marriage and reproduction. Nearly 80% of people with epilepsy live in low- and middle-income countries (LMIC), where treatment gaps exceed 75% in most low-income countries and 50% in most middle-income countries. This is despite the effectiveness and low cost of antiseizure medicines.

The Sustainable Development Goals (SDGs), which seek to achieve global economic, social and environmental sustainable development by 2030, will not be realized without investment in physical and mental health for all people, including those living with epilepsy. This report calls for accelerated action to highlight epilepsy as a public health priority and support investment in reducing the burden it places.

At the Sixty-eighth World Health Assembly (WHA) in 2015, 194 Member States unanimously adopted resolution WHA68.20 on epilepsy which called for the need for coordinated action at the country level to address its health, social, and public knowledge implications. The third High-level Meeting on the prevention and control of noncommunicable diseases (NCDs) in 2018 highlighted the importance of mental health conditions, drawing the attention of policy-makers to integrate epilepsy into action on NCDs and mental health. This report represents a collaborative effort between the World Health Organization (WHO), the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE) to provide technical support to countries in addressing the needs of people with epilepsy.

The objective of this report is to raise the prioritization of epilepsy on the global agenda; to describe a public health approach that addresses its high burden; and to advocate for crucial actions that address gaps in epilepsy knowledge, care and research. It is written for not only policy-makers and public health experts and health care providers, but also for people living with epilepsy, their families and civil society organizations.

Global burden of epilepsy

Epilepsy accounts for over 13 million disability-adjusted life years (DALYs) and is responsible for more than 0.5% of the global burden of disease (GBD). It affects people of all ages, sexes, races, income groups and geographical locations. Around 7.6 per 1000 persons have epilepsy during their lifetime. It has a bimodal distribution according to age with peaks in the youngest individuals and in those over 60 years of age. Epilepsy has a variety of causes, ranging from genetic, metabolic, infectious, structural, immune and unknown. There is a higher incidence of epilepsy in LMIC (139 per 100 000 person-years) compared with high-income countries (HIC) (48.9).

Epilepsy carries a significantly increased risk of premature mortality, compared with the general population. Among deaths directly attributable to epilepsy, important immediate causes include sudden unexpected death in epilepsy (SUDEP), status epilepticus – characterized by seizure duration of over 30 minutes or seizures occurring close together without recovery in between, unintentional injuries, and suicide.

In LMIC, early death among people with epilepsy is significantly higher than in HIC. Excess mortality in LMIC is more likely to be associated with causes attributable to lack of access to health facilities and preventable causes such as drowning, head injuries, and burns. This could be substantially reduced with education about the risk of death and improved access to treatments, including antiseizure medicines.

Roughly half of the people with epilepsy have coexisting physical or psychiatric conditions. Physical and psychiatric comorbidities in people with epilepsy are associated with poorer health outcomes, increased health care needs, decreased quality of life and greater social exclusion. The most prevalent psychiatric comorbidities are depression (23%) and anxiety (20%). Intellectual disability is the most common comorbidity in children with epilepsy (30–40%). Epilepsy is also commonly associated with neurodegenerative diseases.

Epilepsy is a treatable condition. Up to 70% of people with epilepsy could become seizure free with appropriate diagnosis and use of cost-effective, and commonly available, antiseizure medicines. This can lead people with epilepsy to continue, or return to, a full and productive life. Despite the very low cost of antiseizure medicines, more than 75% of people with epilepsy in low-income countries do not receive treatment. Left untreated, **people living with epilepsy face devastating social consequences**, including stigma, discrimination and human rights violations.

Leadership and governance for epilepsy

Given the burden of epilepsy, **a broad public health approach is needed to improve the care and quality of life of people with epilepsy.** This requires governments to provide universal coverage through health and social care services, as well as policies and legislation to address stigma, discrimination and barriers to civil rights.

In many countries, laws impacting the lives of people with epilepsy are outdated and fail to protect and promote their human rights. Legislation for epilepsy, where it exists, sometimes actively violates the rights of people with epilepsy. This leads to unmet needs in the areas of education, employment, residential and community services, and access to appropriate and affordable health care.

Leadership and governance are critical levers for addressing these challenges and to improve care and support for people with epilepsy. **The implementation of policies and plans for epilepsy requires strong leadership and intersectoral collaboration.**

While significant steps forward have been made in recent years under the leadership of WHO/ILAE/IBE, more action is needed globally as well as oversight for implementation in every country, to reduce the burden of epilepsy. Legislative initiatives, public campaigns and social programmes are needed to guarantee the social and human rights of people with epilepsy. These should align with international human rights standards and global health agendas such as SDGs. Appropriate and integrated treatment of people with epilepsy requires that governments allocate sufficient funds towards epilepsy care and adopt a public health approach. Better data and information systems are needed to make the case for prioritizing epilepsy in global public health agendas.

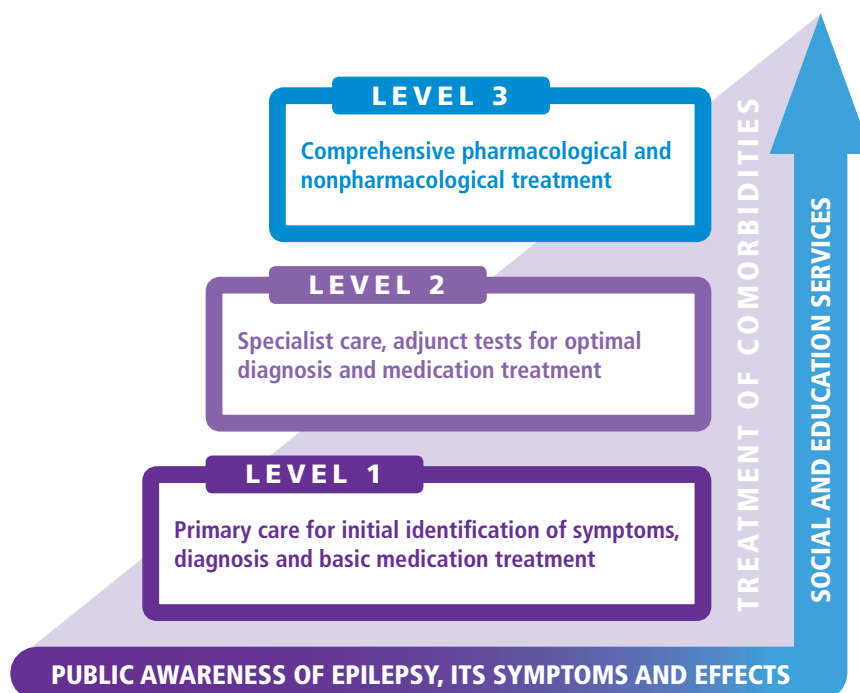
Comprehensive health care response to epilepsy

Health care for people with epilepsy involves providing health care and social services to decrease morbidity, premature mortality and adverse psychosocial outcomes associated with the condition. Providing quality epilepsy care is a challenge because of its complexity, chronicity and considerable comorbidity.

The care needs of people with epilepsy are multifaceted and should be a matter of great concern for policy-makers in all countries, as there are considerable gaps in policies and care available for epilepsy worldwide. **Access to care for people with epilepsy varies considerably across and within countries and unmet needs exist in every country, but particularly in LMIC.**

The spectrum of health care needs for people with epilepsy and their families can be viewed as a stepped model: starting with the initial diagnosis and continuing, as necessary, through to nonpharmacological therapies (e.g. surgery) for drug-resistant epilepsy (see figure below). **The management of comorbidities should be an essential component at all levels of care.** Multidisciplinary health care teams that emphasize person-centred care are also important in the stepped model (e.g. physicians, nurses, pharmacists, therapists and social workers). Community-based care should be emphasized to increase access to all people in need of epilepsy services. Social and educational services should provide individualized support to people with epilepsy, throughout the levels of care and should continue, as needed, even when the person is no longer having seizures.

Stepped model to improve quality of care for people with epilepsy



Policy-makers need to ensure that there are sufficient population and health care system data to determine the need for and evaluation of epilepsy care, identify appropriate training for providers, provide guidelines for quality health care, and allocate the required resources to ensure those living with epilepsy have access to adequate health and social services.

Country examples of comprehensive care for epilepsy do exist. The WHO Programme on reducing the epilepsy treatment gap has shown that epilepsy care can be cost-effectively integrated into the primary health system in low-resource settings. Through pilot projects in Ghana, Mozambique, Myanmar and Viet Nam the programme has meant that 6.5 million people now have access to health facilities where epilepsy care is available.

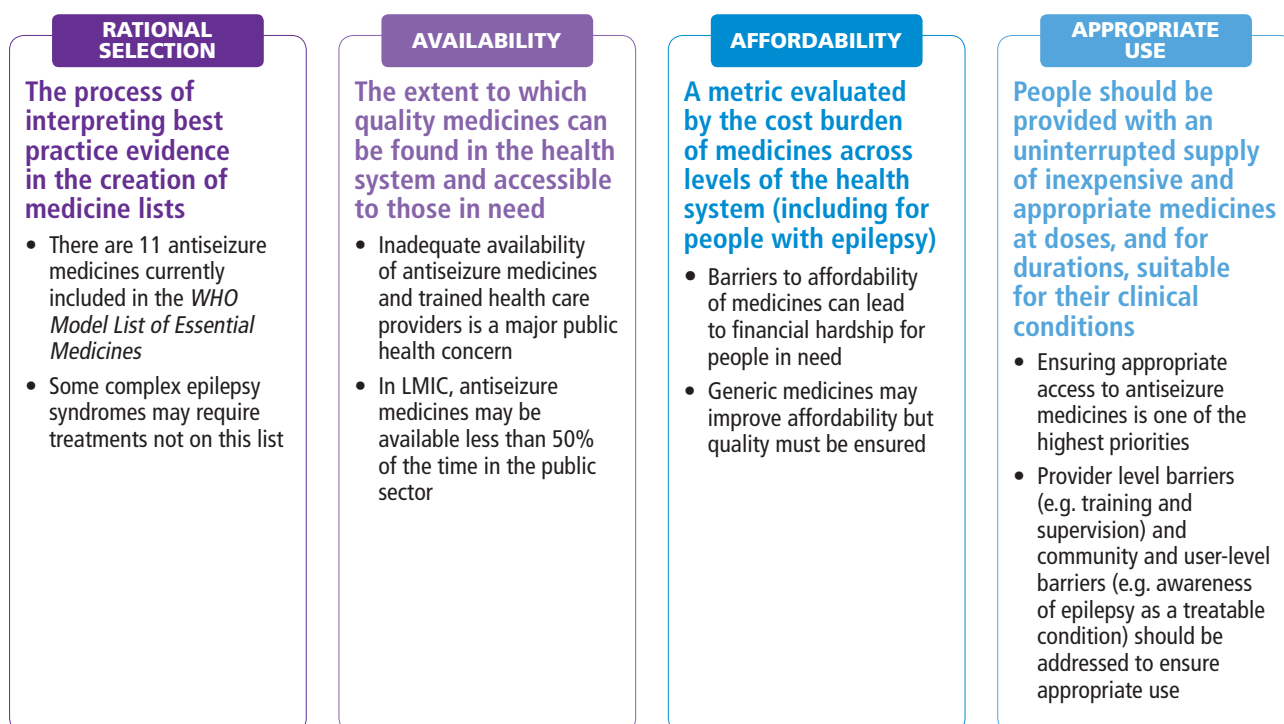
Access to antiseizure medicines

Various terms are used to describe medicines used to manage acute seizures (e.g. antiseizure, anticonvulsant, and antiepileptic medicines/drugs); antiseizure medicines is the broadest possible term for this class of medicines (not all seizures are convulsive, nor do all seizures constitute epileptic conditions).

People with epilepsy require treatment with antiseizure medicines for many years, sometimes for a lifetime. The abrupt withdrawal of antiseizure medicines may result in life-threatening consequences, including status epilepticus. Therefore, it is essential to ensure that access to these medicines is sustained over time to ensure uninterrupted treatment.

The imperative to increase access to essential medicines was highlighted in the United Nations SDGs in goals 3.4 and 3.8. The key components of access are: **rational selection, availability, affordability and appropriate use of essential medicines** (see figure below).

Framework for understanding access to medicines for epilepsy



Ensuring uninterrupted supply of appropriate access to antiseizure medicines is one of the highest priorities. Policies should be in place to monitor supply chains and stock-outs in health facilities and address possible disruptions.

Access to antiseizure medicines offers the potential for approximately 70% of people with epilepsy to live seizure free (on medicines), with an opportunity to impact their quality of life and participation in society. Understanding the myriad of financial, educational and sociocultural barriers to accessing antiseizure medicines is crucial for the adequate planning of financial, health system and clinical interventions to help improve access to treatment for people with epilepsy.

Actions to improve access to medicines should be addressed at the international, national, district, community and individual levels. There are different options when establishing health policies impacting access to antiseizure medicines. The optimal model to be adopted depends on the local context, and opportunities to integrate an epilepsy action plan within broader public health objectives. Transparent policies that involve all stakeholders – from suppliers to government acquisition – need to be developed.

The social response: misconceptions and stigma in epilepsy

Stigma is a significant contributor to poor physical and mental health in people with epilepsy and will not be improved with a single approach. A multipronged strategy, which is culturally appropriate, multisectoral and collaborative, is needed.

Misconceptions and poor understanding about the nature of epilepsy contribute to the burden of disease and lead to stigma. This includes the perception of epilepsy as a form of insanity, ruining people's lives, and being untreatable or contagious. Misconceptions and negative attitudes cause people with epilepsy to feel shame, embarrassment and disgrace. The impact of feeling socially excluded contributes to the physical, psychological and social burden of epilepsy. **Stigma can delay appropriate health care seeking, access to care, health financing and availability of treatment.**

Institutionalized discrimination in epilepsy affects employment, education, marriage and childbearing, and driving regulations. Discriminatory laws exist in a number of countries. Most were repealed decades ago, but the legacy of these laws can still lead to misconceptions and discrimination.

Direct investments in health care do not necessarily lead to improvements in epilepsy-related stigma. To reduce stigma, funds need to be directed toward epilepsy awareness and stigma-reduction programmes. Policy-makers can reduce stigma by changing laws that are punitive to people with epilepsy. A multisectoral public health response needs to include interventions that improve the knowledge of individuals and their families, teachers, employers, health care providers, disability service providers, care providers, first responders, traditional healers, media, community and policy-makers.

Prevention of epilepsy

The high global burden of epilepsy requires prevention where possible. The major modifiable risk factors for epilepsy are: perinatal risk factors, central nervous system (CNS) infections, TBI and stroke, which, together, account for an estimated 25% of epilepsy cases.

- **Perinatal risk factors** related to epilepsy include gestational age at delivery, birth weight, maternal health conditions such as nutritional status, pre-eclampsia, the presence and skill of birth attendants,

method of delivery, perinatal infection (e.g. human immunodeficiency virus [HIV]), and other adverse events and conditions.

- **Central nervous system infections**, according to population-based studies, comprise three main categories: bacterial meningitis, viral encephalitis and neurocysticercosis. Bacterial meningitis and viral encephalitis combined account for approximately 2–3% of epilepsies in HIC and about 5% of epilepsies in LMIC. In some LMIC where the *Taenia solium* (pork tapeworm) is endemic, roughly one-third of epilepsies are attributed to neurocysticercosis. Malaria is one of the most common parasitic diseases worldwide. Its neurological form, known as cerebral malaria, is a potential cause of epilepsy in malaria-endemic regions of the world.
- **Traumatic brain injury** is the cause of epilepsy in 4% of LMIC and 5% of HIC. Road traffic injuries, falls and violence are the most common causes of TBI. The risk of epilepsy is higher in people with severe versus mild TBI (increased almost 20-fold).
- **Stroke**, including ischaemic and haemorrhagic types, is also a common potentially preventable cause of epilepsy, representing 12% of epilepsies in HIC and 2.7% in LMIC. Seizures after stroke are associated with increased premature mortality, disability, and higher resource allocation and costs. In population-based studies, stroke was identified as a common cause of status epilepticus (12–40% in HIC, 5–15% in LMIC).

Estimates of the burden of epilepsy attributable to preventable causes are at best approximate and the true burden undoubtedly varies between regions and localities. The **primary prevention** of these causes has a substantial impact on the development of epilepsies and requires improving maternal health care and obstetrical services, communicable disease control, injury prevention, and cardiovascular and cerebrovascular health with reduction of the major risk factors of NCDs. An understanding of the development of epilepsy after a brain insult or parasitic infection is critical to the development of **secondary preventive strategies**.

Epilepsy research

Epilepsy research has enabled remarkable progress in deepening our understanding of the etiologies and mechanisms leading to epilepsy and associated comorbidities. It has also brought interventions and treatments to improve the management of seizures and their comorbid conditions or consequences. There remains, however, a **dramatic inequality in access to and utilization of research resources and expertise across the globe**.

Investment in research for epilepsy is insufficient. Even in HIC, where significant investments in epilepsy research have been made, funding for epilepsy only represents a small proportion of overall funding. In the United States of America, the National Institutes of Health (NIH) support for epilepsy research accounted for less than 0.09% of the total NIH budget dedicated to research and has stagnated over the last 3 years, unlike other neurological conditions which have attracted increasing research support, e.g. Alzheimer disease research, autism and rare diseases.

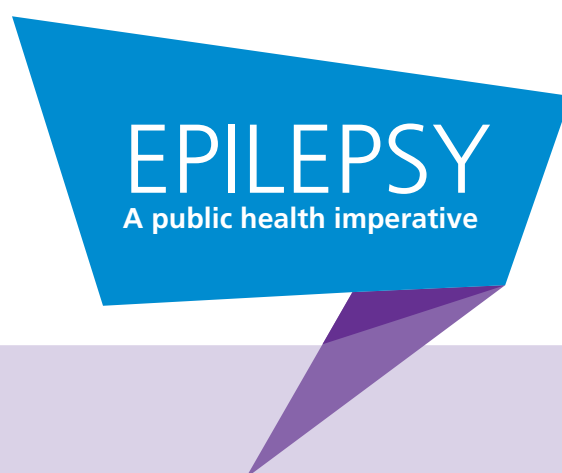
The **barriers in funding epilepsy research are higher in LMIC**, where financing comes from domestic organizations and most funding is directed towards communicable diseases and little towards epilepsy. Whether research is preclinical, clinical or at the population level, it is important to engage and sustain the best pool of researchers in the field, at all career stages, and enrich the available resources by maintaining collaborations within and beyond the epilepsy community to facilitate this.

Developing epilepsy research priorities around the world may be a vehicle to improve research support and advocacy. Recognizing the need to determine possible areas of research priority, and as a response to regional declarations on epilepsy, taskforces combining regional expertise from ILAE and IBE were established to address research priorities in their region. A significant role in the advocacy for epilepsy research has also been played by organizations led by families that have experienced epilepsy, e.g. Citizens United for Research in Epilepsy (CURE).

The way to advance epilepsy research is through capacity building, especially research partnerships between HIC and LMIC; increased funding and infrastructure for epilepsy research; optimization of research process standardization; establishment of global, regional and national research priorities; enhanced efforts to translate research findings into policies and programmes; and fostering stakeholder collaboration and partnership.

The way forward

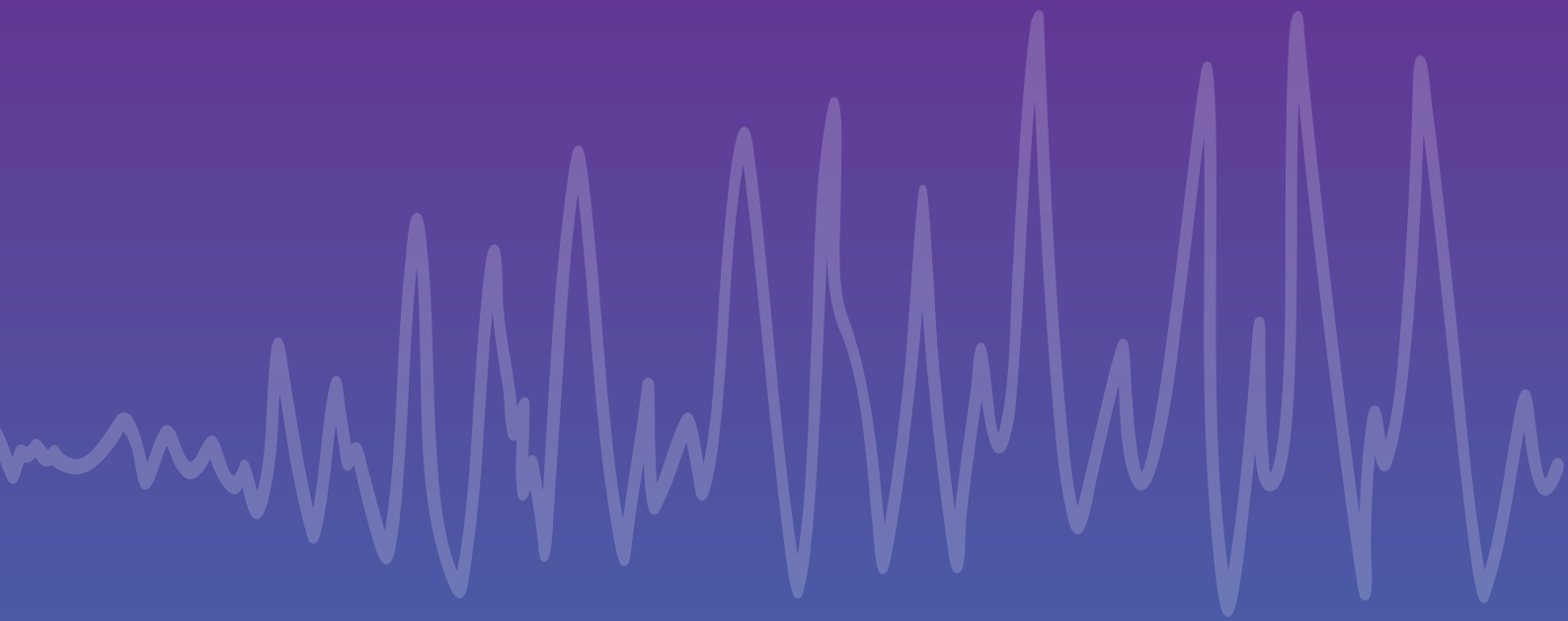
Major gaps in awareness, diagnosis and treatment of epilepsy impose a significant global burden on the lives of people with epilepsy. *Epilepsy: a public health imperative* raises epilepsy as a public health priority to address these gaps through a cost-effective, coordinated response. People with epilepsy and their families are asking that this unique opportunity not be lost, and that global action be taken.



The time to act is NOW.

Urgent actions are needed, and these include:

- **Promote** epilepsy as a public health priority to reduce its burden.
- **Improve** public attitudes, reduce stigma and promote protection of the rights of people with epilepsy.
- **Invest** in health and social care systems to improve accessibility to epilepsy care.
- **Enhance** access to cost-effective antiseizure medications globally.
- **Prevent** acquired epilepsies through improved care for common causes, such as perinatal injury, central nervous system infections, stroke and traumatic brain injuries.
- **Increase** priority given to epilepsy in research agendas.



For more information, please contact:

Department of Mental Health and Substance Abuse
World Health Organization
Avenue Appia 20
CH-1211 Geneva 27
Switzerland

Website: www.who.int/mental_health/neurology/epilepsy/report_2019/en