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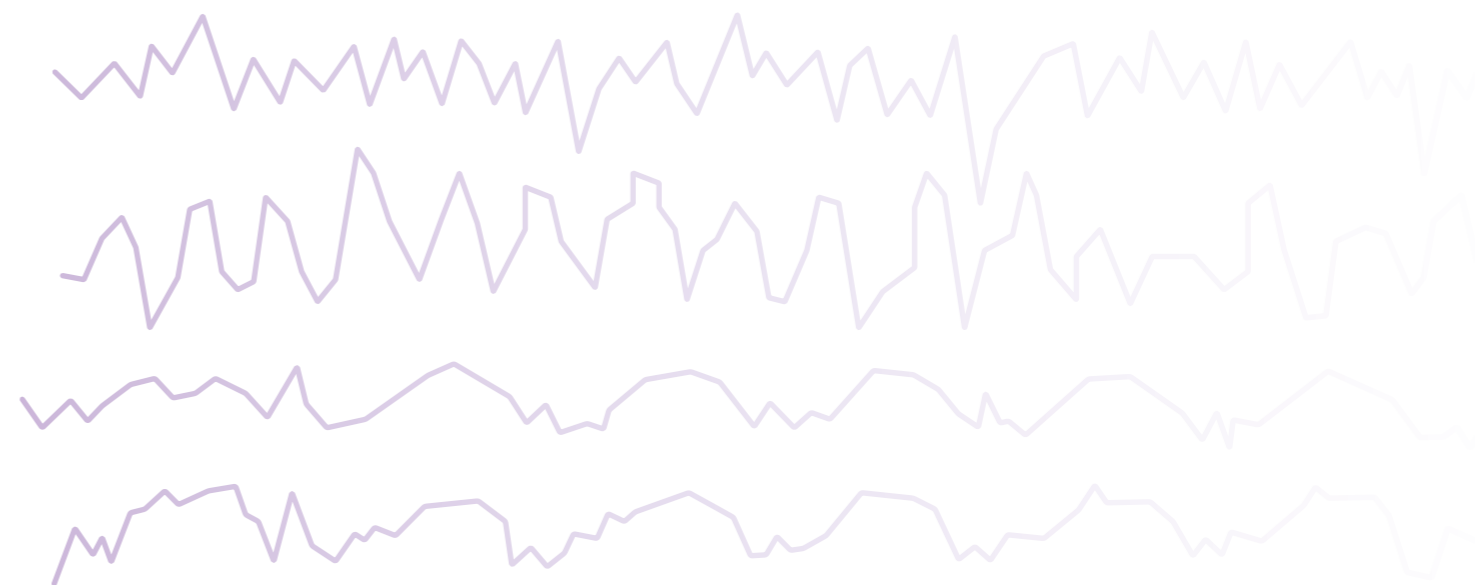
Improving the lives of people with epilepsy:

a technical brief



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Executive summary

Epilepsy, a disorder that manifests as recurrent seizures, has significant neurobiological, cognitive, social and economic consequences for individuals, communities and countries. More than 50 million people worldwide have epilepsy. People with epilepsy are about three times more likely to die than the general population, and an estimated 125 000 deaths per year globally are related to the condition. There are significant gaps in the provision of care for epilepsy around the world. Lack of diagnosis and care prevents people with epilepsy from realizing their full potential and poses a significant burden to countries' economic, health and social systems. Low- and middle-income countries are disproportionately affected.

The burden of untreated epilepsy can be reduced in several ways. Up to 70% of people with epilepsy could become seizure-free after appropriate diagnosis and with antiseizure medicines. They could lead productive lives and contribute fully to their societies. About one fourth of all cases of epilepsy could be prevented with greater attention and interventions by health systems, such as in perinatal risk, traumatic brain injuries, stroke and central nervous system infections. The stigmatization and discrimination experienced by people with epilepsy and their families can be countered by raising awareness in communities and ensuring respect for human rights in policy and practice. Evidence and tools are available to improve the knowledge of primary care health workers about epilepsy, which would increase access to diagnosis and treatment.



>50
million people
worldwide
have epilepsy



Continuous supply of antiseizure medicines is necessary to ensure people with epilepsy receive the treatment they need. The voices of people with epilepsy and their families and carers should be heard to guide person-centred care that responds to their needs and results in better, healthier societies.

The *Intersectoral global action plan on epilepsy and other neurological disorders (2022-2031)*, adopted in 2022 by the World Health Assembly, gives a fresh impetus to the work to reduce the burden and improve the lives of people with epilepsy. The plan is based on a multisectoral approach, in which various sectors of society such as health, social protection, labour and education work together to provide integrated care for people with neurological disorders throughout their life, ensuring their health and dignity. This technical brief describes the actions that are necessary to implement the approach, with levers to channel this change. National and local governments, policy-makers and programme managers across various sectors at national and local levels can conduct the proposed actions to restructure and strengthen their services for people with epilepsy. The levers and corresponding actions and resources will also be useful in planning and programming by civil society groups, professional associations, academic institutions, organizations of people with epilepsy and their families and carers, development partners, and global and national funding initiatives. Each country can customize its multisectoral approach to epilepsy according to the setting and its priorities to achieve significant gains for its society and improve the lives of people with epilepsy.



The Intersectoral global action plan on epilepsy and other neurological disorders (2022-2031) was adopted in 2022 by the World Health Assembly





Introduction

Epilepsy is a neurological disorder characterized by an enduring predisposition to recurrent seizures. The condition also has neurobiological, psychological, cognitive, social and economic consequences (1). More than 50 million people worldwide have epilepsy (2), with point prevalence of 6.38 persons with active epilepsy per every 1000, and 7.6 people per every 1000 will have epilepsy at some point in their life. Epilepsy ranks fifth among all neurological causes for disability-adjusted life years (DALYs) (3), disproportionately affecting low- and middle-income countries (LMIC) (3,4). Worldwide, an estimated 125 000 deaths each year are related to epilepsy (2), and more than 80% of all deaths due to epilepsy are reported from LMIC. The risk of premature death for people with epilepsy is estimated to be three times that of the general population (5), but this risk may be up to seven times higher in some low-resource settings (6-8). Many neurological and psychiatric disorders co-occur with epilepsy (9). Seizures after stroke or traumatic brain injury can drastically increase the mortality and burden of these conditions (10).

Epilepsy affects not only people with the condition but also their families and carers, through a range of significant personal, social, ecological, economic and policy issues that are directly or indirectly linked to the condition. It imposes direct costs on individuals and society due to the expense of health care and social services for assessment, treatment and rehabilitation and also creates indirect costs for disabling complications and premature mortality, which prevent people from reaching their full potential in school, employment or household activities. Stigmatization of people with epilepsy, their families and carers imposes a great social cost on them, denying them life opportunities and causing suffering.



Epilepsy ranks fifth among all neurological causes for disability-adjusted life years, disproportionately affecting low- and middle-income countries





Up to 70% of people with epilepsy could become seizure-free after appropriate diagnosis and antiseizure medicines

Up to 70% of people with epilepsy could become seizure-free after appropriate diagnosis and antiseizure medicines, which can cost as little as US\$ 5 per year, and could lead full, productive lives (11). Treatment of epilepsy can be very cost-effective, contributing to reducing the economic burden of the disorder (12). Despite this evidence, there is a treatment gap for epilepsy which means that more than 50% of people with epilepsy in most LMIC do not receive the treatment they need.

In determining the measures necessary to reduce the global burden of epilepsy, consideration should also be given to the potentially preventable causes of certain types of epilepsy, which account for roughly one fourth of all epilepsy cases. They include perinatal risk factors, traumatic brain injuries, stroke and central nervous system infections (13). These causes disproportionately affect people in LMIC.

Tackling epilepsy requires a multi-stakeholder approach at national and local levels, which considers epilepsy from a life-course perspective. Governments, policy-makers, academia, health-care professionals, private sector establishments, people with epilepsy and the public at large must come together to decrease the burden of this condition.

This document provides strategic actions for the development and implementation of epilepsy-related policies and programmes. Through the systems approach defined by the *Operational framework for primary health care* issued jointly by WHO and the United Nations Children's Fund (14), 11 levers for change are outlined that would have the greatest impact in reducing the epilepsy burden at country and community levels. A WHO steering group was convened to ensure a multisectoral approach and guide the development of the brief. Expert consultations were held with epilepsy researchers, health professionals, representatives of civil society organizations and people with lived experience from all over the world. Input from the expert consultations was incorporated into the draft of the brief, which was then further reviewed by external experts and WHO steering group members to refine its contents.

The technical brief is intended for a broad range of stakeholders. Governments, policy-makers and programme managers in ministries of health, social protection, education, human rights and other sectors at national and local levels can implement the proposed actions to restructure and strengthen their approach and services. The levers and corresponding actions will also be useful in planning and programming by civil society groups, professional associations, academic institutions, organizations of people with epilepsy and their families and carers, development partners, and global and national funding initiatives.



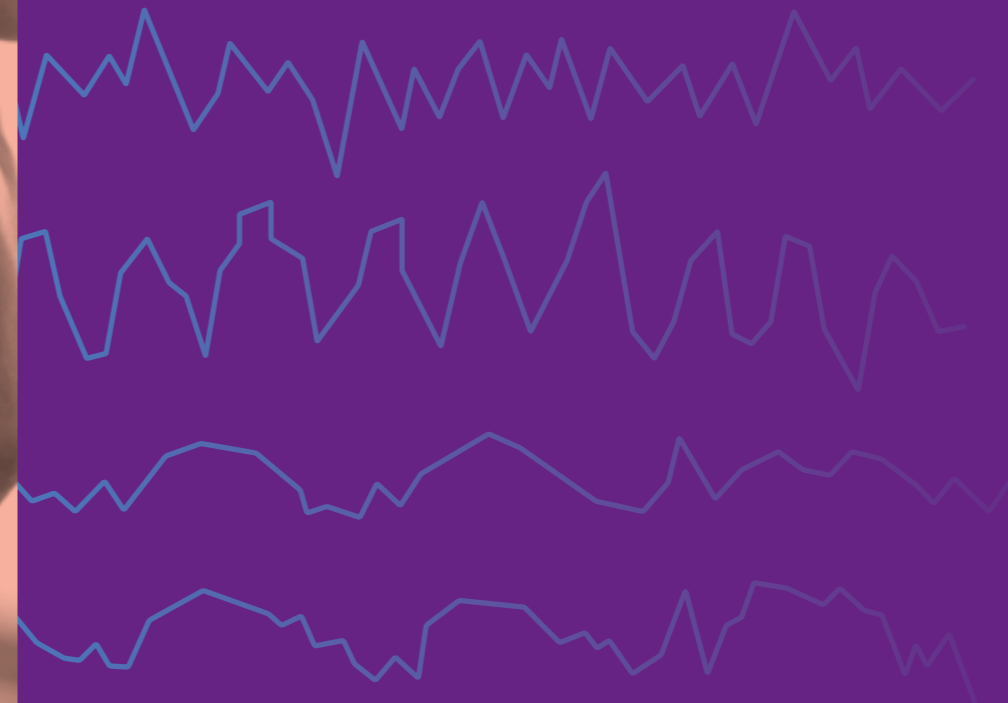


The treatment gap for epilepsy

Many people with epilepsy do not receive the necessary treatment to control their seizures, and the gap varies drastically globally, exceeding 75% in most low-income countries and 50% in most middle-income countries (15, 16). This gap results from a combination of lack of capacity in health-care systems, inequitable distribution of resources, a low priority accorded to epilepsy care and insufficient care-seeking behaviour due to lack of awareness and/or stigmatization. Lack of appropriate treatment further complicates the social and economic burden of epilepsy.



The treatment gap for epilepsy exceeds 75% in most low-income countries and 50% in most middle-income countries



Barriers to diagnosis and treatment of epilepsy

A number of structural factors limit diagnosis of epilepsy and lead to the treatment gap (15, 17). These factors may vary by setting; however, uneven provision of health services due to lack of resources, poor access to knowledgeable health workers and to medicines and complicating comorbid conditions are global concerns.

- There is a shortage of neurologists globally, but particularly in LMIC. Within countries, the shortage is more pronounced in rural and remote areas. The WHO Neurology Atlas 2017 provides estimates of 0.03 neurologists per 100 000 population in LMIC and 4.74 per 100 000 population in high-income countries (HIC), and only 23% of countries worldwide had neurologists in rural areas (18). In these areas, people with epilepsy are commonly treated by primary health-care providers and community health workers, who may not have the necessary knowledge and skills about epilepsy to provide immediate and long-term care (19). Misconceptions about the possibility of treating epilepsy successfully at primary health-care level compound the problem.
- Geographical barriers, particularly distance from health facilities, prevent many people from seeking treatment for epilepsy (20). Additionally, the misconception that epilepsy is transmissible by contact affects the provision of first aid for seizures (21). Such barriers can be reduced by raising awareness of epilepsy and its management in communities and among local health-care providers, strengthening clinical networks and access to telehealth and ensuring a reliable supply of antiseizure medication.
- Traditional and faith healers are frequently the first contact for affected people in many LMIC; however, their knowledge and beliefs regarding the origins and treatment of epilepsy vary widely, which often results in incorrect or very delayed diagnosis and treatment (22).
- Lack of diagnostic technologies such as electroencephalography (EEG) in many LMIC creates a perceived barrier to establishing a diagnosis of epilepsy. Most cases of epilepsy can, however, be diagnosed and managed without resort to sophisticated investigations, and the lack of such means should not limit scaling up of care by primary care providers in rural settings.

- Poor access to antiseizure medicines severely constrains the provision of good-quality, uninterrupted care for epilepsy, which may result in breakthrough seizures and poor seizure control, reducing the quality of life of those affected (23). According to a report by WHO/Health Action International of a survey of 46 countries, less than half of all pharmacy outlets had stocks of a single antiseizure medication of those on the WHO list of essential medicines (24). Regulatory issues, supply chain interruptions, lack of storage facilities and variation in the prescribing patterns of physicians constrain continuous availability of affordable, quality antiseizure medications. In some countries, erratic supplies and circulation of substandard or counterfeit products also limit care.
- Roughly half of all people with epilepsy also have other physical or mental health conditions (25), which are associated with poorer health outcomes, increased health-care needs, decreased quality of life and greater social exclusion (26). The most prevalent comorbid mental health conditions are depression (23%) and anxiety (20%), which exacerbate seizures, reduce quality of life and increase social and economic exclusion. Children with epilepsy experience high rates of behavioural and cognitive comorbidity (27,28).

Misconceptions and discrimination

People living with epilepsy face devastating social consequences, including stigmatization, discrimination and violations of their human rights. Negative attitudes, myths and false beliefs prevent many from seeking treatment. Misconceptions about the cause, the genetics and characteristics of epilepsy have historically influenced public attitudes and led to practices such as sterilization, interdiction of marriage and social isolation of people with epilepsy (29). These forms of discrimination may be institutionalized in legislation. In addition, people with epilepsy are at increased risk of sexual violence and unplanned pregnancy.

- People with epilepsy frequently face barriers to education and employment and are ostracized due to inaccurate beliefs about how epilepsy is acquired (30, 31). They are also less likely to marry and face discrimination due to unfounded beliefs about heritable transmission to offspring and the perception that they will not be able to fulfil their family roles (30,32-35). They are at increased risk of sexual violence and abuse (36).



Roughly half of all people with epilepsy also have other physical or mental health conditions. The most prevalent comorbid mental health conditions are depression and anxiety



Stigmatization of people with epilepsy contributes significantly to poorer mental health and quality of life, factors that are often felt more acutely than the effects of the seizures themselves

- Institutional stigmatization, such as discriminatory legislation pertaining to driving, education, employment and marriage, may prevent people with epilepsy from fully participating in social and community life (37). Family members of people with epilepsy may also experience stigmatization and discrimination, reducing their quality of life (38).
- Stigmatizing experiences strongly affect the psychological well-being and the quality of life of people with epilepsy and their families, as seen in many settings worldwide (39-41). Stigmatization of people with epilepsy contributes significantly to poorer mental health and quality of life, factors that are often felt more acutely than the effects of the seizures themselves (42,43). In many settings, no consideration is given of the psychosocial aspects of epilepsy care or empowerment for self-care to support the person and family. Psychological treatment such as family counselling, cognitive behavioural therapy and relaxation techniques can be provided as adjunctive treatment to people with epilepsy (44,45).
 - People with epilepsy and their families and carers should also be informed how to render first aid, which activities are possible and recommended for a healthy lifestyle and which ones should be avoided, and how to identify safety risks and manage seizure triggers as part of the self-management of epilepsy. Such approaches must be adapted for different age groups over the life course to reflect their needs.
 - A comprehensive approach to addressing stigmatization and discrimination includes not only programmes for stigma reduction and raising awareness in society and communities, but also a review of legislation, policies and institutional practices, health promotion for delivery of first aid and advocacy for social inclusion.

Consequences of the treatment gap for epilepsy

Epilepsy is associated with other health consequences (**see Box 1**), which are exacerbated if the disorder is not treated.

BOX 1. The consequences of epilepsy



People with epilepsy are at increased risk of:

- Injury, drowning or suffering from burns as a result of seizures (46)
- road traffic accidents
- hospitalization for seizures or status epilepticus
- sudden unexpected death (known as SUDEP) (47, 48)
- depression, suicide and other mental health conditions (49-51)
- neurological, cardiovascular and respiratory disorders (52)
- socio-economic marginalization, which affects professional status and personal relationships
- being victims of sexual violence and abuse
- malnutrition, particularly during food insecurity and other humanitarian crises.



They also face reduced prospects of:

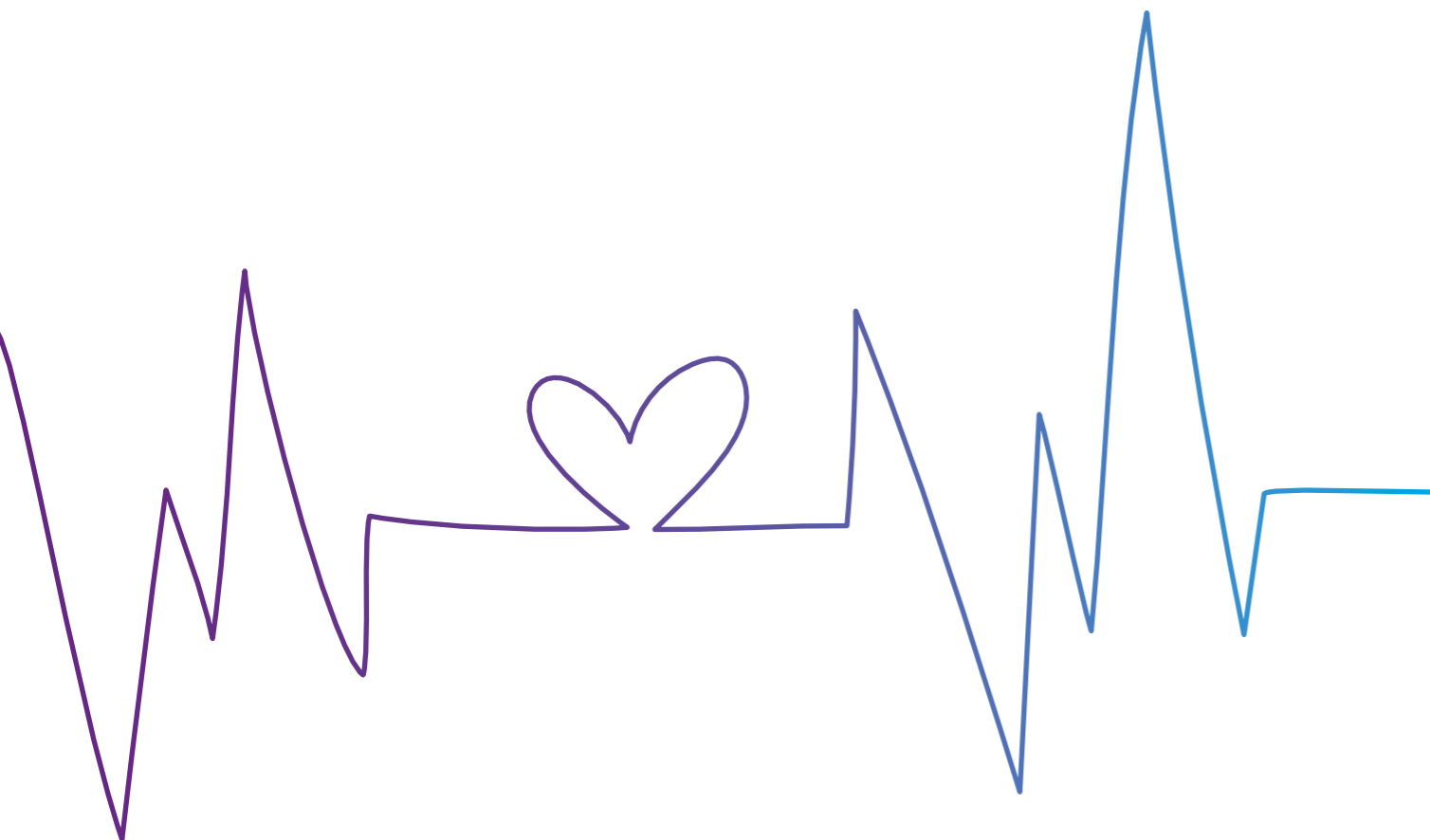
- completing schooling and accessing higher education (30)
- marrying or sustaining relationships (30, 53)
- securing employment (30)
- obtaining a driving licence (11).



Studies indicate that the incidence of epilepsy is up to four times higher in the most socioeconomically deprived sections of the population

Existing inequities in socioeconomic status, place of residence and other characteristics make some groups more affected by epilepsy than others. Studies in HIC indicate that the incidence of epilepsy is up to four times higher in the most socioeconomically deprived sections of the population, and this is likely to be exacerbated by gender, ethnicity, rural residence, and other indicators of vulnerability (31). Lower socioeconomic status is related to poor access to health services, inadequate awareness of medical care and infrequent outpatient clinic visits (54). The incidence and prevalence of epilepsy are higher and the treatment gap twice as high in rural than in urban communities (14,55).

The association between epilepsy and socioeconomic deprivation is bidirectional: health-care spending by people with epilepsy and their families, often out of pocket in many LMIC, can result in financial hardship and poverty. People with epilepsy tend to have lower income and poorer education and health outcomes than the general population, factors which affect them throughout their whole lives (56, 57). Inequities undermine good health and well-being, the quality of education and opportunities for work for many people with epilepsy and their families. Legislation protecting the rights of people with epilepsy is essential.





Integrated prevention and care for epilepsy

Epilepsy is a complex chronic condition that typically requires long-term management, and people with epilepsy and their families have various, dynamically changing needs that extend beyond health. Therefore, a number of sectors – most importantly, health, social and educational services – must coordinate to meet their needs for an optimal quality of life. Holistic care for epilepsy requires integrated, people-centered care to address the disorder and any comorbid conditions. A multisectoral response, based on the perspectives of people with epilepsy and their families, will provide the structural conditions necessary for successful care. These include strategic planning, human and financial resources, a regulatory framework, a functioning health system, legislation that ensures respect for human rights and constant feedback from people with epilepsy and their families. In addition, prevention through public health interventions is key to reducing the burden of new cases of epilepsy.

Reduction of the epilepsy treatment gap and of inequities will contribute to alleviating the economic and social consequences of epilepsy (58). Existing tools and campaigns have been mobilizing resources at the global level. The Global Campaign Against Epilepsy, spearheaded by WHO, the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE), has been working since 1997 to raise public and professional awareness of epilepsy and to encourage governments to address the needs of people with epilepsy, including awareness, education, diagnosis, care and prevention (59).



Health, social and educational services must coordinate to meet the needs of people with epilepsy and their families

The first global report on epilepsy produced by WHO and partners in 2019 summarized available evidence and provided guidance to governments, policy-makers and stakeholders on how to reduce the burden of epilepsy under the universal health coverage agenda (11).

About one fourth of all epilepsy cases can be prevented by public health measures. Perinatal risk factors, traumatic brain injury, stroke and central nervous system infections are the four risk factors amenable to primary prevention (see Box 2). Thus, addressing these factors will reduce the burden and economic impact of epilepsy, prevent morbidity and save health system resources.

BOX 2. Opportunities for prevention of epilepsy

- About 15% of cases of epilepsy in children in HIC and 17% in LMIC can be attributed to perinatal causes. The risk factors are low gestational age at delivery, low birth weight, poor maternal nutritional status or pre-eclampsia, lack of skilled birth attendants, inadequate method of delivery, perinatal infection (e.g., HIV), and other adverse events and conditions (11). Adequate pre- and perinatal care and obstetrical services can reduce the number of new cases of epilepsy.
- Traumatic brain injury is the cause of epilepsy in 4% of cases in LMIC and 5% of cases in HIC (11). Common causes of such injury are road accidents, falls and violence, including intimate partner violence (60). Increasing public awareness and improving social and infrastructural conditions can mitigate this risk factor for epilepsy.
- Population-based studies have identified stroke as a common cause of epilepsy (12–40% in HIC, 5–15% in LMIC) (11). Epilepsy associated with stroke can be prevented by health promotion in primary health care for reducing cardiovascular risk factors such as high blood pressure, diabetes and obesity and avoidance of tobacco and excessive alcohol use.
- Although many central nervous system infections are preventable, 2–3% of all epilepsies in HIC and about 5% of epilepsies in LMIC are caused by such infections, which include bacterial meningitis and viral encephalitis, neurocysticercosis (caused by *Taenia solium* [pork tapeworm]) and cerebral malaria (61). Programmes for the control of communicable disease should target these conditions in areas in which they are endemic.



Use of the mhGAP intervention guide facilitates diagnosis and improves the knowledge and confidence of health-care workers

The WHO Mental health gap action program (mhGAP) facilitates diagnosis and integrated management of a range of mental, neurological and substance use conditions in non-specialized care, and epilepsy is identified as a priority (62). Use of the mhGAP intervention guide facilitates diagnosis and treatment by non-specialist health-care professionals and improves the knowledge, attitudes and confidence of health-care workers (63) and the quality of life of people with lived experience by alleviating their symptoms. Initiatives to reduce the treatment gap have demonstrated potential in improving the lives of people with epilepsy by shifting care to the primary health workers and equipping them with the necessary skills to diagnose and treat epilepsy, improving access and raising awareness within communities (see Box 3).

BOX 3. Successful task-shifting programmes for epilepsy

Country-level initiatives for responding to the epilepsy treatment gap show that significant gains can be achieved. In the “Fight against epilepsy” initiative of the Ministry of Health of Ghana, in collaboration with WHO, management and care for epilepsy in the community increased from 15% to 38% after training primary health-care workers and community volunteers, raising awareness and strengthening monitoring and evaluation (64). In the Myanmar Epilepsy Initiative, these activities increased community coverage from 2% at baseline to 47% (65). The Mozambique Epilepsy Initiative benefited a population of over 2 million, improved monitoring and evaluation of epilepsy indicators in the health information system and resulted in the launching of a national epilepsy plan to train all psychiatry technicians in the country by 2022. In a pilot project in Viet Nam, training of village health workers to identify people with epilepsy, primary care providers to diagnose and treat people with epilepsy and specialists to supervise them reduced the gap in treatment of epilepsy by 39% over 4 years.



The *Intersectoral global action plan on epilepsy and other neurological disorders (2022-2031)*, adopted by the World Health Assembly in May 2022, is based on the principles of universal health coverage. It charts a comprehensive pathway to prioritizing epilepsy care by governments, increasing access to high-quality care and medicines, investment in epilepsy research and social programmes for people with epilepsy (66). The plan identifies actions to be taken by policy-makers, professionals, researchers, advocates and communities to tackle the global burden of neurological disorders. The plan also highlights the priority of epilepsy care in the public health agenda and creates entry points for other neurological disorders.

The comprehensive response proposed by the *Intersectoral global action plan on epilepsy and other neurological disorders* reflects a “whole-of-society”, multi-stakeholder approach throughout the life-course. With concrete actions, clear, measurable indicators and the commitment of national and international stakeholders, great advances can be made in preventing epilepsy, delivering appropriate treatment and care and reducing the burden of the condition for individuals and their families and communities. The approaches should be adapted to country-specific needs. Inequities should be fully addressed, particularly in relation to gender, rural–urban residence and economic levels. Policies should ensure that systems are orientated towards person-centred care and meeting the priorities of people with epilepsy by promoting partnerships, investment and innovation. Other relevant international commitments that have been undertaken through adoption of World Health Assembly and United Nations General Assembly resolutions are listed in **Annex 1**.

The *Intersectoral global action plan* emphasizes primary health care and community approaches to increase access to treatment throughout settings and make the most of available resources. WHO differentiates **primary health care**, an approach to health systems that maximizes equity, efficiency and effectiveness through integrated health services (centred on primary care and public health functions), multisectoral policy and action and empowered people and communities, from **primary care**, which is first-contact health services that are people-centred, continuous, comprehensive and coordinated (14). While primary care is a core component of integrated health services and, therefore, the primary health care approach, strengthening primary care is insufficient to drive health system transformation toward universal health coverage and the other health-related Sustainable Development Goals, leaving no one behind.



Levers for change



The levers and related actions are not independent but are interconnected. All are essential to an integrated national response to epilepsy

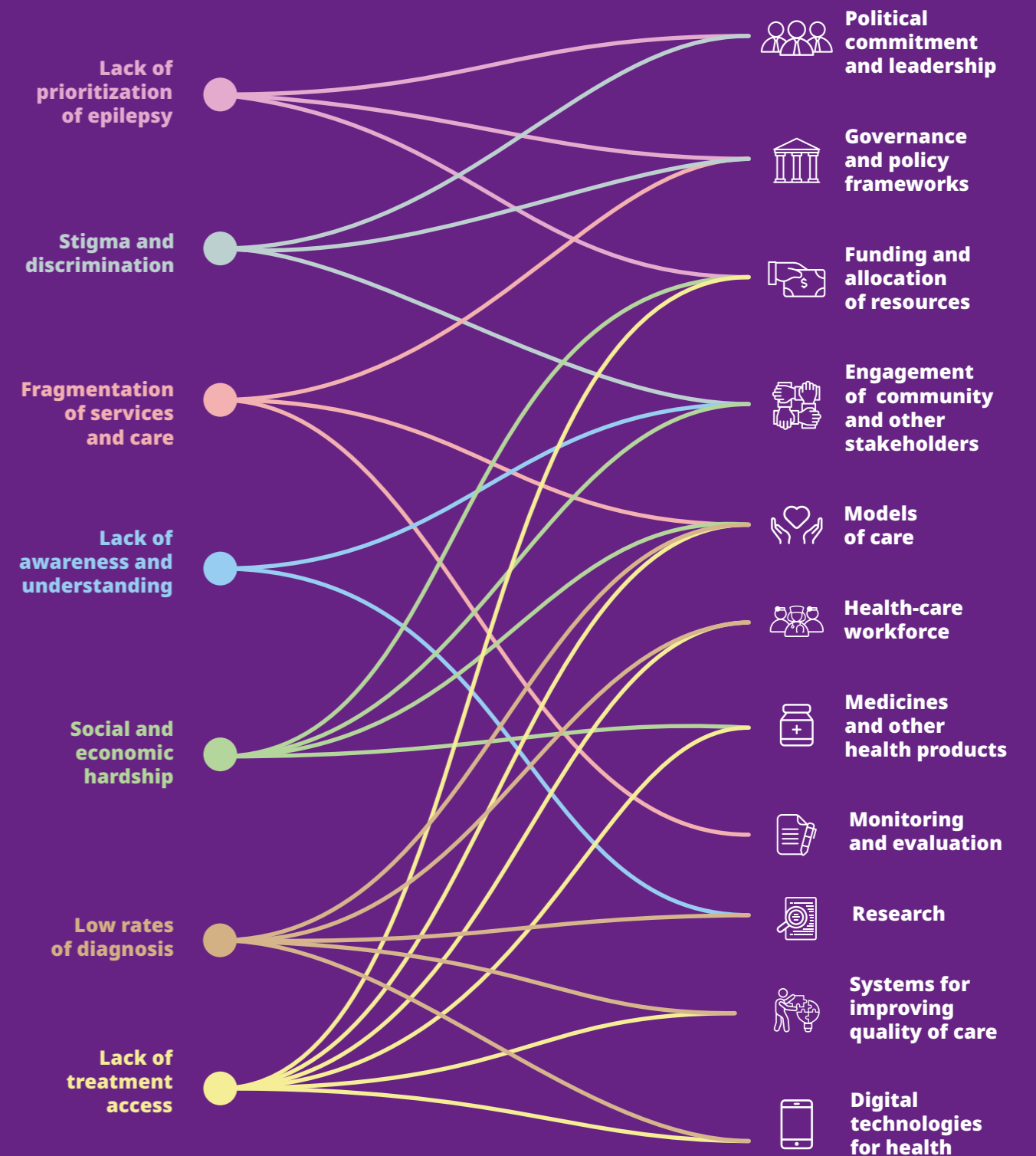
This section uses the expertise of the *Operational framework for primary health care (14)*, which proposes ways to strengthen health systems and demonstrably improve health for all. Specific actions for tackling epilepsy are listed below. The actions and interventions are grouped into “levers”, as defined in the framework. The levers address the challenges to the epilepsy response that have been identified in the section above (**Figure 1**). They extend beyond primary health care setting in recognition of the multisectoral and life-course approach required for a disorder that has repercussions in many areas of life.

Countries vary in the level of provision of epilepsy services. Political, cultural and social contexts also vary and have significant effect on the availability and access to epilepsy services for different populations. Therefore it is necessary to prioritize the actions listed below, taking into consideration local needs. When possible, they should be planned and executed with broad engagement of all sectors of society, including the government, nongovernmental organizations and the private sector. Importantly, the perspectives and rights of people with epilepsy and their families and carers should be included in all activities.

The levers and related actions are not independent but are interconnected. All are essential to an integrated national response to epilepsy to achieve the objectives of the *Intersectoral global action plan on epilepsy and other neurological disorders (66)*.

The actions in each lever are described at policy and operational levels. Policy actions lay the groundwork for regulation, strategies and long-term decisions, while the operational actions are central to planning fieldwork and delivering care and support. Each lever has a consistent structure comprised of a narrative description, actions that can be applied at policy and operational levels, and tools and resources that facilitate actions for the lever. A brief case study for each lever showcases how interventions at this lever can enhance national approaches to epilepsy.

FIGURE 1.
Levers for change





Political commitment and leadership

This lever addresses the political engagement of decision-makers and other stakeholders to raise the profile of epilepsy prevention, treatment and care, in recognition of the importance of commitment and leadership for tackling epilepsy and the need for champions, training in advocacy and creating the right conditions for continuity of political effort.

Implementers

Political leaders, government, civil society including advocacy organizations and organizations of people with epilepsy.

Policy level

- Generate commitment of policy-makers to work with wide representation of people with epilepsy and their families and carers, health-care providers and community members such as traditional healers.
- Establish national and regional collaboration for professional and policy-making bodies and civil society and create links between government, nongovernmental organizations and organizations representing people with epilepsy.
- Strengthen political commitment to enact and implement laws to protect people with epilepsy and eliminate stigmatization and discrimination.
- Advocate for use of an integrated life-course approach to generate political commitment by ministries and other institutions.

Operational level

- Proactively include people with epilepsy in advocacy for political commitment and change.
- Train advocates and champions for epilepsy in health diplomacy so that they can communicate with government and train community leaders, religious leaders and opinion leaders.
- Build a network of leaders in academia, communities and local institutions to ensure continuity in working with the government on sustainable initiatives for epilepsy.
- Establish dialogue outside health system structures, particularly with the education and labour sectors, to increase their sensitivity and ensure a comprehensive approach to epilepsy.
- Build platforms to foster dialogue, exchange of knowledge, coordinated action and sharing of best practices among advocates for epilepsy care.

Resources

- *Epilepsy: a public health imperative* (11)
- *Intersectoral global action plan on epilepsy and other neurological disorders (2022-2031)* (66)
- *Towards a dementia plan: a WHO guide* (67)





Political commitment and leadership: case study

Domesticating the Intersectoral global action plan on epilepsy and other neurological disorders in Eswatini

In Eswatini, the objectives of the Intersectoral global action plan on epilepsy and other neurological disorders are being integrated into the national policy framework and strategies. Within the IGAP Trendsetter project, the Eswatini Epilepsy Organization is reviewing institutional capacity, creating strategic partnerships and advocating for better policy and legislative environments for people with epilepsy. The Organization conducted a stakeholder analysis, developed a management plan to adopt the Intersectoral global action plan, together with advocates, and convened a technical working group to develop a national plan of action. Workshops have been held with partner organizations and government agencies to increase awareness of epilepsy and to present evidence in schools, communities and clinics. The Organization engages with legislators to gain their support for filling the gaps in policy and legislation for epilepsy care (68).





Governance and policy frameworks

Under this lever, governance structure, legislation, regulations and policy frameworks are considered for all systems and sectors for a holistic approach to addressing epilepsy. The approach emphasizes coordinated action, respect for human rights, policies specifically for epilepsy and mechanisms for their implementation and monitoring.

Implementers

Government representatives in health, social support, education, labour, disability and human rights, and organizations of people with epilepsy.

Policy level

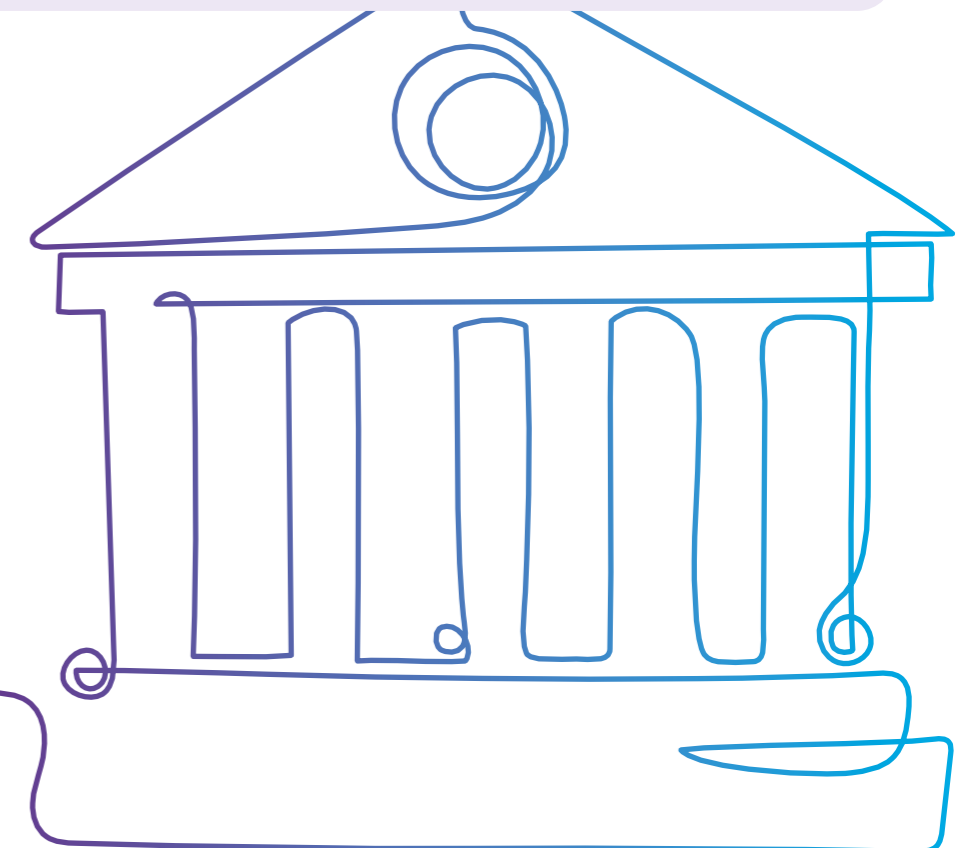
- Engage broad group of government stakeholders beyond health, especially in civil affairs, education, labour, organizations of people with disabilities, societies for epilepsy and similar entities.
- Provide a road map for addressing epilepsy that contains mechanisms for effective oversight, actions for change and building coalitions of people and organizations working on epilepsy.
- Mainstream policies to support people with epilepsy, their families and carers in the health, social, economic, educational, labour, recreational and legal systems.
- Establish a mechanism to ensure consistent, accessible recourse against acts of exclusion and violations of human rights at all levels.

Operational level

- Revise policies on health and particularly mental health and noncommunicable diseases to include care for people with epilepsy, and address cross-cutting issues, such as gender equity, human rights, minority status and socioeconomic status.
- Review and update regulation and policies to support people with disabilities, in particular epilepsy, including integrative schooling, employment regulations and social benefits.
- Remove restrictions on full participation of people with epilepsy in society, such as marrying, obtaining a driving license, attending educational institutions.
- Embed activities on prevention of epilepsy and promotion of brain health in sectors such as the health system, education, employment and labour, sports and law enforcement.

Resources

- *Intersectoral global action plan on epilepsy and other neurological disorders (2022-2031) (66)*
- *Nothing for us, without us: opportunities for meaningful engagement of people living with NCDs (69)*





Governance and policy frameworks: case study

Policy response in El Salvador: development of national guidelines for epilepsy care



The aim of the team working on the guidelines is to improve the government supply of antiseizure medicines

El Salvador is developing national guidelines for epilepsy care in order to address what neurologists estimate to be a treatment gap of 60% to 70%. A collaboration was established by the National Epilepsy Commission of the Ministry of Health and the local chapter of the International League Against Epilepsy to produce the guidelines, whose goal was to create a robust referral framework. This includes referral of complex cases – such as women who are pregnant and people with mental health conditions – to appropriate levels of care.

Validation and integration of the guidelines improved the knowledge of physicians. Further work will be conducted to teach them what epilepsy is, how to differentiate people at high risk and how to refer them to specialist care. Few statistics are available on the incidence and prevalence of epilepsy in El Salvador. The next goal is therefore to establish standardized diagnostic criteria for better care protocols and medication protocols. The aim of the team working on the guidelines is to improve the government supply of antiseizure medicines to ensure regular stocks, wider choice and more information for physicians on how to use them (70).





Funding and allocation of resources

Actions in this lever are intended to ensure sustainable, efficient funding for diagnosis, treatment, research and advocacy for epilepsy in universal health coverage packages, increase social protection for people with epilepsy, provide a platform and incentives for high-quality care and prevent financial hardship. The actions required to increase financing for epilepsy will vary considerably depending on both a country's starting point and local, political and economic considerations.

Implementers

Ministers of Finance, finance managers and planners, health-care funding managers.

Policy level

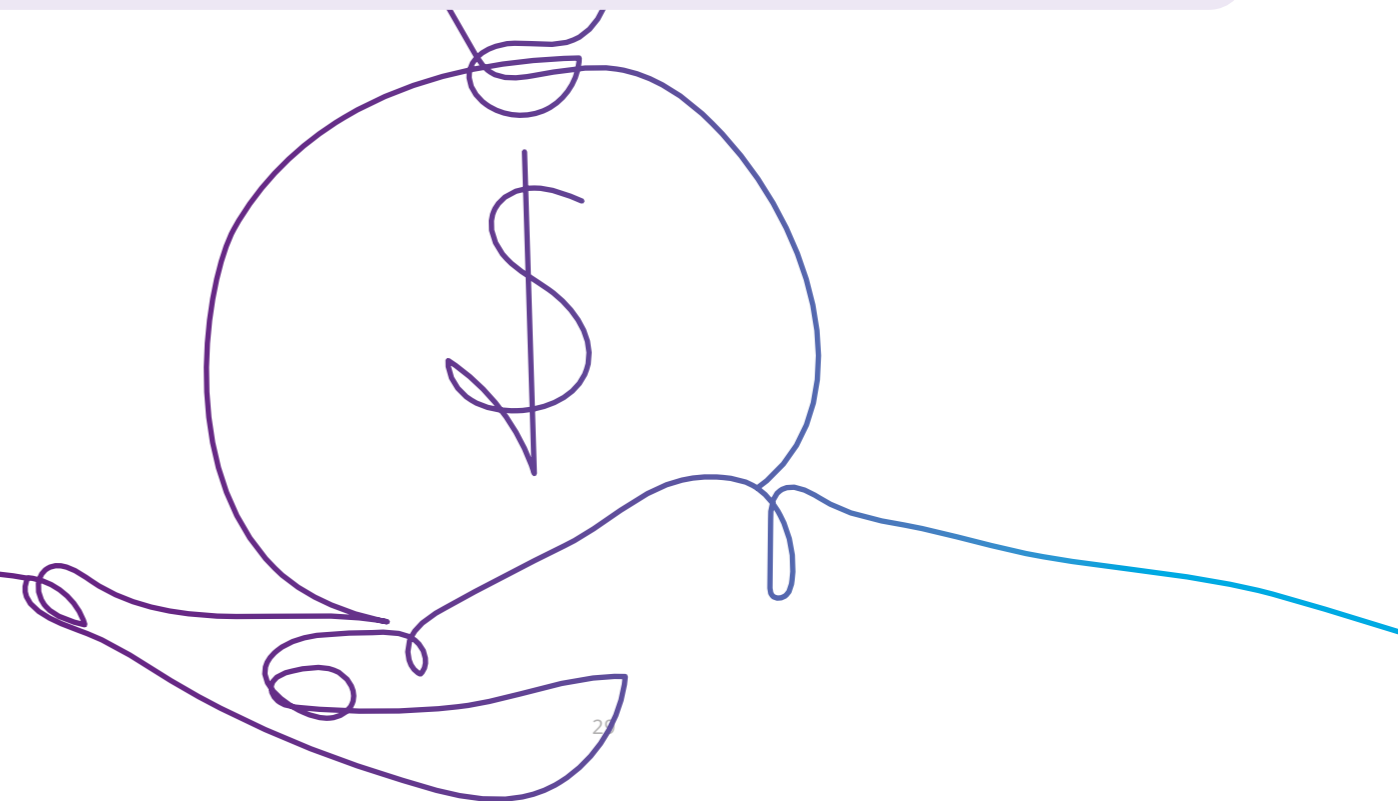
- Create a dedicated governmental budgetary allocation for epilepsy and provide consistent funding for epilepsy care for hard-to-reach populations.
- Explore other funding mechanisms for epilepsy, such as frameworks for funding noncommunicable diseases, and encourage development of other sustainable models.
- Fully include epilepsy diagnosis and treatment in benefits package for universal health coverage.
- Ensure disability allowances are commensurate with the cost of living in social protection mechanisms for people with epilepsy, their carers and family members.

Operational level

- Assess the national need on tackling epilepsy, allocate sustainable resources, and review spending regularly to increase efficiency of funds spent and avoid loss of monies.
- Identify or generate evidence for investment in epilepsy prevention, promotion and treatment to drive change and justify resource allocation to improve care.
- Include financial considerations of emergency care and medical supplies for people with epilepsy in humanitarian response plans.
- Prioritize and allocate efficiently funding to support organizations and advocacy groups for epilepsy.
- Ensure that people with epilepsy are aware of the available support and receive all the financial and substantive assistance, benefits and institutional support to which they are entitled.

Resources

- One Health Tool (71)
- A system-wide approach to analysing efficiency across health programmes (71)
- Universal Health Coverage Compendium (73)
- WHO-CHOICE (74)
- Mental health investment case: a guidance note (75)





Funding and allocation of resources: case study

Epilepsy prevention can reduce public health expenses: birth interventions in India

The aim of the PREVENT study in South India is to determine whether improved care during labour can reduce perinatal brain injury and prevent the incidence of epilepsy, thus reducing the high economic burden of epilepsy in India, where 12 million people have the condition. About 20% of infants with birth-related brain injury will develop epilepsy during early childhood. The interventions proposed include birth companions for women in labour, fetal surveillance during active labour, and brain-oriented early newborn care. This optimized care bundle is planned to be delivered to 80 000 women in participating hospitals over 2 years. If the results show that it is effective, it can be included into the national “Labour room quality improvement” programme. It could avert about 50,000 cases of epilepsy in India every year, reducing public health expenses and ensuring future contributions to the economy. The study is led by an international team of experts in neonatal brain injury, neuroimaging, midwifery, epilepsy, and qualitative research, with representatives of parents and community leaders (76).





Engagement of community and other stakeholders

The intention of this lever is to ensure engagement of a wide range of stakeholders, mobilize society and organizations to understand the problems, define solutions, change attitudes, create networks, provide support, raise awareness and reduce stigmatization of people with epilepsy. The main mechanisms to be used are advocacy in the community, raising awareness about epilepsy, dispelling prejudice, building capacity for community support of people with epilepsy and providing information about the available services and mechanisms of support.

Implementers

Policy-makers, health promotion managers and planners, organizations of people with epilepsy and their families, community organizations, private sector, academics and researchers.

Policy level

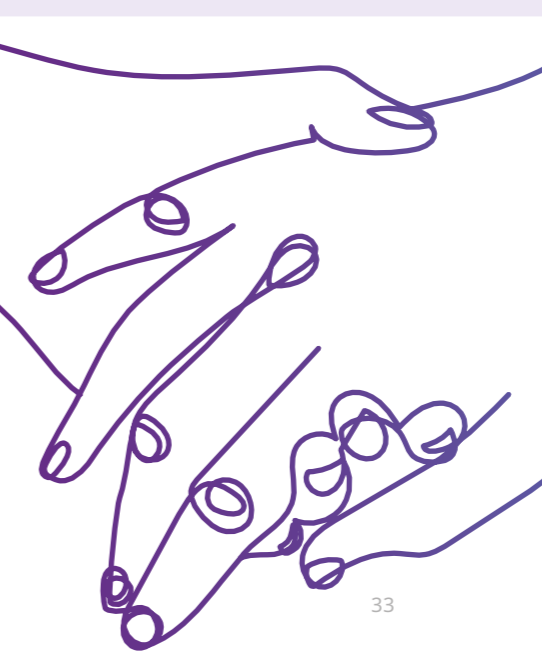
- Ensure the participation of organizations of persons with epilepsy in government decision-making as early as possible so that they can be involved in designing policies and services in a transparent and inclusive manner.
- Establish mechanisms for the inclusion of persons with epilepsy and their organizations in planning and managing services.
- Create sustained partnerships between civil society organizations, governmental bodies, scientific organizations and organizations of people with lived experience working on epilepsy, and increase international collaborations.
- Draft regulations on transparent engagement with the private sector and create consultative processes to maximize their strategic impact and constructive partnership.

Operational level

- Carry out stakeholder and relationship mapping of key stakeholders in epilepsy advocacy, diagnosis, treatment, research and support in order to understand their needs and preferences and plan activities for engagement and empowerment.
- Strengthen the capacity of organizations of people with epilepsy to tackle stigmatization and discrimination and to understand, promote and protect the human rights of people with lived experience, in line with the United Nations Convention on the Rights of Persons with Disabilities.
- Construct a road map for reducing stigmatization in epilepsy, plan campaigns for employers, educators, social workers and the general community to de-stigmatize epilepsy, and integrate tools and practices for reducing stigmatization into policies and plans.
- Survey attitudes and knowledge about epilepsy, nationally and locally, in order to prepare messages to fill knowledge gaps, and develop relevant communication materials for each intended audience.
- Use social media to disseminate information, maximize reach and foster inclusion and engagement, particularly of young people.

Resources

- WHO Information Kit on Epilepsy (77)
- mhGAP Community Toolkit (78)
- Nothing for us, without us: opportunities for meaningful engagement of people living with NCDs (69)





Engagement of community and other stakeholder: case study

Training teachers on epilepsy in India



An important part of improving diagnosis was improving the knowledge of teachers and health workers about epilepsy

In India, a 3-year programme to determine the gap in treatment of epilepsy in children was funded by the Indian Council of Medical Research, Delhi. Records of the National Child Health Programme, in which mobile units screen for about 30 diseases and conditions in government-run schools, showed that the rate of diagnosis of epilepsy was below the statistical average. Because of strong stigmatization by communities, symptoms of epilepsy in children may be underreported by parents and teachers, and children with symptoms may not be allowed to attend school. An important part of improving diagnosis was therefore improving the knowledge of teachers and health workers about epilepsy.

A 1-day workshop with interactive lectures and role play was developed to provide information about the disorder, the educational needs of children with epilepsy, communication with parents, addressing stigmatization and giving first aid, including use of medicines. An overwhelming positive response from 250 teachers and health workers indicated a strong interest in learning about epilepsy. Furthermore, some of the trainees subsequently educated other teachers and students (79).





Models of care

This lever concerns models of quality, person-centered care for epilepsy in all sectors. A model of care is a conceptualization of how services should be delivered, including the processes of care, organization of providers, management of services and identified roles and responsibilities of different platforms and providers. Models of care should be attentive to the different needs of subgroups of people with epilepsy and their conceptualization should include the perspectives of people with epilepsy. Models of care should be defined in different sectors and across different services and should include management of co-morbid conditions, self-care and telehealth services.

Implementers

Service planners and managers in health, social, educational sectors, educators and trainers of professionals in these sectors, academics and researchers, employers, organizations of people with epilepsy and their families.

Policy level

- Review existing models of care and the connections between them both vertically (e.g., at different levels of the health system) and horizontally (e.g., between sectors), with the goal of updating them according to the best evidence available.
- Ensure that diagnosis, treatment and care for people with convulsive and non-convulsive epilepsy both for acute and chronic care are fully included in the universal health coverage package.
- Collaborate with people with epilepsy and create mechanisms to address their needs during different phases of the life-course.
- Introduce policies which support telemedicine and other technologies to expand access, reduce out-of-pocket and hidden costs, improve diagnosis and treatment and effectively manage comorbidity.
- Integrate prevention of epilepsy into all sectors, e.g., health, education, social support, law enforcement, sports, employment health and safety.

Operational level

- Develop and implement integrated models of care, from diagnosis to end-of-life in health and social sectors, use multidisciplinary team approach and emphasize communication among all levels of providers.
- Develop evidence-based models of care which include referral and back-referral and clear routes to access to services beyond primary care.
- Develop protocols for the integration of epilepsy care in the care for chronic non-communicable diseases (e.g., hypertension and diabetes) as well as in emergency preparedness planning.
- Design and introduce training programs to address stigmatization and discrimination at all levels of the health and social sectors.
- Analyze the cost-effectiveness of models of care and ensure regional sharing of best practices and innovative approaches.
- Establish national helplines and websites with accessible information for self-care and for planning, accessing and organizing epilepsy care and services.
- Ensure unpaid carers, such as family, have adequate support, financial or in-kind, including training to strengthen their knowledge and skills in epilepsy management and thus increase efficacy of care.

Resources

- mhGAP operations manual (80)
- Mental health in primary care: illusion or inclusion? (81)
- “Fight against epilepsy” initiative in Ghana (64)
- Myanmar Epilepsy Initiative (65)
- Implementation of mhGAP in Mozambique: integrating epilepsy care into the primary health care system (82)



Models of care: case study

Epilepsy care in a health emergency: Ukraine

The war in Ukraine, which began in February 2022, has severely disrupted healthcare in many parts of the country, with infrastructural damage to facilities, logistical difficulties and a reduced supply of medicines. The ILAE Emergency Response (Ukraine) Task Force has attempted to maintain health services for people with epilepsy. A key consideration was to establish a foundation for accepting and distributing financial contributions. One of the first steps was a rapid survey to establish the requirements, types and proportions of antiseizure medicines used in the country in order to re-establish regular supplies with the help of donations. A logistics chain was put in place from a distribution hub in the western part of the country, with various channels of delivery, such as the Ukrainian Army and humanitarian convoys. Detailed information was gathered on where people with epilepsy could receive help abroad. Online consultations were organized with adult and pediatric epileptologists to fill the gaps in care, coordinated by the Task Force, which also helped to find sources of humanitarian aid and provide services to physicians and people with epilepsy remaining in Ukraine. Although a crisis response cannot replace a well-functioning health-care system, rapid action in a health emergency can preserve the health and lives of people (83).





Health-care workforce

This lever addresses the needs, competence, resourcing and distribution of health personnel, both those specialized in neurology and non-specialized health workers, for diagnosis, treatment, management and care of people with epilepsy. Structural, regulatory and operational actions are proposed that could be taken by policy-makers, managers, educators and planners to ensure staff availability, motivation and capacity-building. There is strong emphasis on training health workers to deliver care in the community and thus extend epilepsy services. Where resources are stretched, task-sharing models can be used to optimize the use of available workforce.

Implementers

Ministries of Health, educators of all cadres of health workers, public and private health-care institutions, national and subnational level healthcare managers and service planners, health-care workers, development partners, civil society organizations.

Policy level

- Improve training of medical and allied health professionals in the diagnosis, treatment and management of convulsive and non-convulsive epilepsy, with appropriate job aids, and include people with epilepsy, their perspectives, views and preferences in developing training curricula.
- Clearly define the roles and responsibilities of general and specialized health- and social-care workers in epilepsy care to ensure optimal, efficient allocation of epilepsy-related tasks.
- Extend the role of primary health-care practitioners, providers and allied health professionals in diagnosing and managing epilepsy, especially in low-resource settings.
- Incentivize all health cadres to undertake education and training in neurology by creating accessible in-service qualification training and specialization, and incentivize work in underserved areas.
- Regulate and fund supervision and mentoring in epilepsy diagnosis and treatment for health providers in under-resourced settings.

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- Include the mhGAP-IG module on epilepsy in the pre-service training curricula for health-care providers, including nurses, doctors, pharmacists and other health workers.

Operational level

- Identify the relevant competences required for epilepsy diagnosis and management, and ensure its integration into pre-service education and in-service training curricula.
- Survey and identify gaps in the knowledge and attitudes of specialist and non-specialist health workers.
- Prepare and use training packages on epilepsy for various health-worker cadres with their participation; include validation of training, cascade models, refresher training and continuing education; and involve people with epilepsy and carers in training.
- Train community health workers, nurses, midwives, social workers and teachers to recognize and manage epilepsy, especially in LMIC.
- Involve practitioners of traditional and complementary medicine and faith healers in the diagnosis and treatment of epilepsy.
- Identify professionals who can detect and refer possible cases of epilepsy in all sectors, including psychologists, psychiatrists, educators and employment health medicine services, and train them in best practices.
- Support early-career professional and mentoring programmes in epilepsy for health workers.
- Build regional and international clinical networks to exchange expertise and provide support, particularly for cases of rare types of epilepsy.

Resources

- mhGAP-IG 2.0 (63)
- mhGAP training manuals (84)
- mhGAP-IG 2.0 App (e-mhGAP)
- Global strategy on human resources for health: Workforce 2030 (85)
- WHO guideline on health policy and system support to optimize community health worker programmes (86)



Health-care workforce: case study

Changing pediatric care for epilepsy through cascade training



In post-training surveys, 99% of attendees rated the course highly, while 85% report improved diagnosis skills

Since 2005, the British Paediatric Neurology Association has been working to raise the quality of care for children with epilepsy by providing training on diagnosis and treatment. The Paediatric Epilepsy Training course is designed for all health professionals and covers treatment, referral and holistic care which includes the family. The 1-day courses are run by volunteer paediatric neurologists, paediatricians and epilepsy nurses. By 2014, more than 4500 people had attended a course, and the Association now organizes courses abroad on request.

In a cascade model, members of the British Paediatric Neurology Association visit the country, teach the course to local health professionals and mentor their training efforts. Currently, 13 countries on the five continents offer the course, and it has been translated into Portuguese and Spanish. In post-training surveys, 99% of attendees rated the course highly, while 85% report improved diagnosis skills. The curriculum for the course is reviewed internationally every 3 years and is found to work well, with only minor adaptations necessary according to setting (87).





Medicines and other health products

The focus of this lever is the availability and affordability of appropriate, safe, effective, quality medicines and other health products and therapies for the diagnosis and management of epilepsy. Actions emphasize use of evidence-based selection methods, including WHO's essential and priority lists, to guide procurement and reimbursement decisions for medicines and other health products.

Implementers

Ministries of Health, national regulatory authorities for medicines and other health products, supply chain planners and managers, economics and procurement specialists in healthcare, medicine manufacturers and distributors, facility managers and healthcare workers who can prescribe.

Policy level

- Develop and regularly update national essential medicines lists based on the local context and needs and aligned with WHO's model list of essential medicines.
- Ensure the availability of essential medicines at the three levels of health care.
- Develop reliable procurement, supply, storage and distribution systems for antiseizure medicine that minimize waste and stockouts, ban counterfeit and substandard products, and provide equitable access to the necessary medicines for all, including in emergencies and crises.
- Allocate budgets and resources to ensure procurement and supply of antiseizure medicines and subsidize medicines in universal health coverage benefits packages to ensure their affordability for people with epilepsy and their families.
- Develop national treatment guidelines based on the best available evidence on the efficacy, safety, quality and cost-effectiveness of antiseizure medicines and other health products.

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- Strengthen health information systems to improve the traceability of medicines and collect data to better understand the demand of medicines within countries and regions.
- Continually renew, upgrade and maintain diagnostic and assistive infrastructure, particularly in low-resource settings.

Operational level

- Ensure the availability, access to and use of antiseizure medicines and appropriate diagnostic technology, train health care workers and technicians in their use, and improve infrastructure.
- Provide clear guidance on use of antiseizure medicines as well as on treatment of mental and physical comorbid conditions.
- Provide easy-to-understand information on the use of antiseizure medicines for people with epilepsy, including labelling in local languages, to encourage updating of and adherence to treatment.
- Ensure alert mechanisms and back-up procedures for supply to prevent stocks from being exhausted and undesirable changes in prescribed antiseizure medications.
- Include essential diagnostic technology for epilepsy in the range of neurology tools, such as electroencephalography and magnetic resonance imaging.
- Ensure access to a range of health interventions, including non-medicinal interventions (e.g., psychosocial treatment) to accompany medication-based treatment.

Resources

- WHO model list of essential medicines (88)
- Selection of essential medicines at country level. Using the WHO model list of essential medicines to update a national essential medicines list (89)
- WHO global model regulatory framework for medical devices including in vitro diagnostic medical devices (90)
- Improving access to and appropriate use of medicines for mental disorders (91)



Medicines and other health products: case study

Concerns over quality of antiseizure medicines in global survey

A global survey in 2019-2020 by the International League Against Epilepsy collected information on the barriers to use of generic antiseizure medication. Responses on questions about prescriptions, drug availability and regulation were received from 800 physicians. Responses to questions about regulatory control of drug quality differed substantially between those in high-income countries, where 79% confirmed extensive regulatory control, and those from low- and middle-income countries, where the same statement was made by 35% and 38% respectively. Thus, perception pointed to fewer regulations over generic medicines in lower-income countries and reduced the confidence of physicians in the quality of medication. The responders considered that more and unbiased training was necessary on generic antiseizure medicines, their production and their approval.

Over half of responders reported that their country's policies and laws did not allow a switch between brand and generic medications. The survey highlighted that substitution of medicines may be made when the prescription is fulfilled, so that physicians are unaware of the antiseizure medicines their patients are taking (92).





Monitoring and evaluation

This lever addresses monitoring and evaluation of epilepsy services and care in robust health information systems for collecting, generating and analysing reliable data to improve decisions and for local and national actors.

Implementers

Government agencies for public health and health-care data, health service planners and managers, academics and researchers.

Policy level

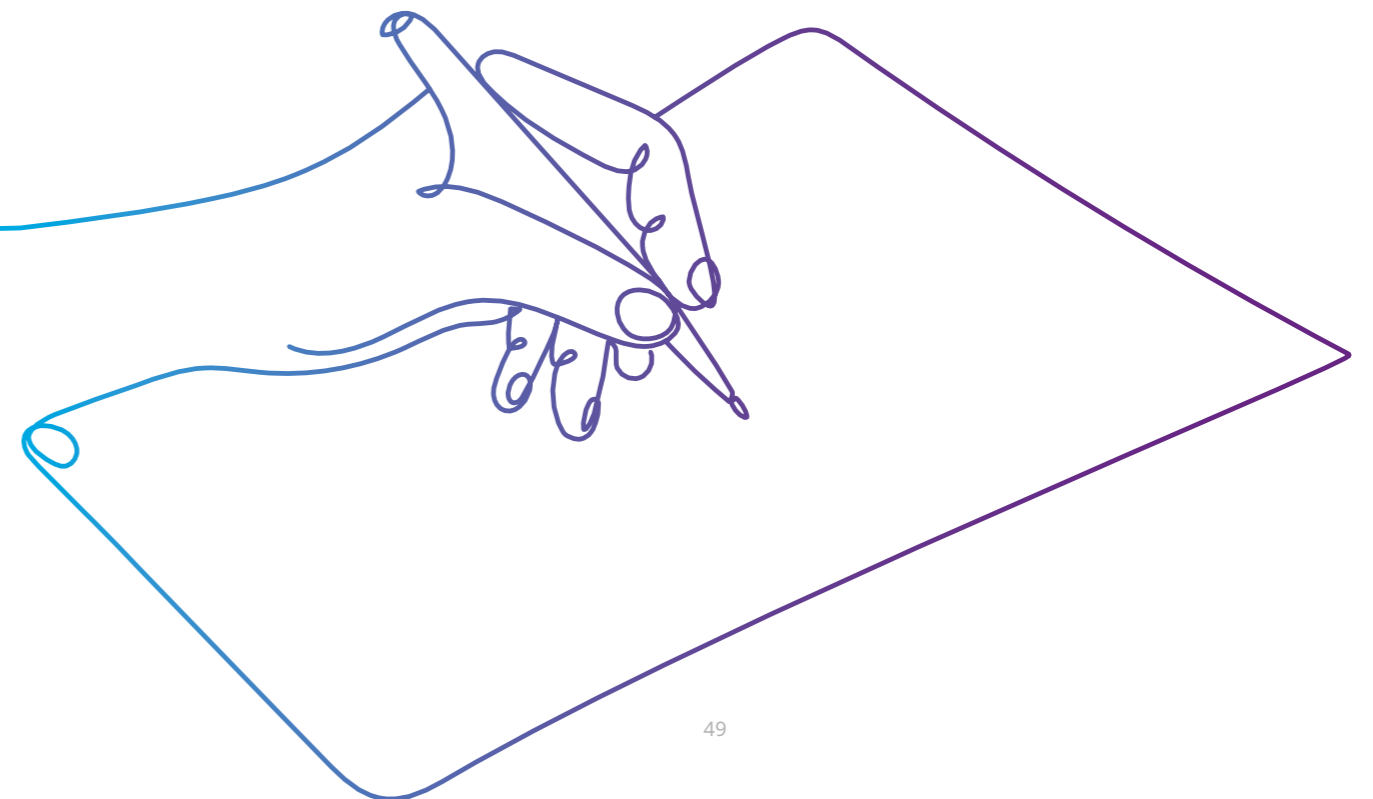
- Develop and strengthen health information systems to cover all health care, and collect data on indicators relevant to the diagnosis, treatment, management and care of people with epilepsy.
- Ensure clear understanding of the role of monitoring and evaluation in iterative improvement of epilepsy care and measurement of indicators.
- Use the results of monitoring and evaluation of epilepsy practices to revise policies.
- Plan for monitoring and evaluation cycles at minimum every 2 years and allocate appropriate human and financial resources.
- Facilitate multisectoral engagement and participation (for example communities, private sector, civil society groups and people with epilepsy and their families) when developing and implementing monitoring and evaluation systems.

Operational level

- Provide continuous training and support to the health-care workforce in monitoring and evaluation, with reliable protocols for data verification and analysis.
- Establish and measure meaningful indicators of the quality of health services and care for epilepsy.
- Include the perspectives of people with epilepsy and their families in all aspects of monitoring and evaluation.
- Routinely collect information on the diagnosis and management of epilepsy.
- Incorporate results of monitoring and evaluation into improving services for people with epilepsy.

Resources

- mhGAP operations manual (80)
- Primary health care measurement framework and indicators: monitoring health systems through a primary health care lens (93)
- Monitoring, evaluation and review of national health strategies: a country-led platform for information and accountability (94)
- Atlas: country resources for neurological disorders (18)





Monitoring and evaluation: case study

Reporting for the WHO Neurology Atlas

The 2017 edition of the WHO Neurology Atlas summarized information on 94% of the world population, representing 132 countries, one Associate Member of WHO and one territory. Data were collected from a questionnaire on resources and services for neurological disorders, and a list of specific disorders, including dementia, epilepsy, stroke, traumatic brain injury and multiple sclerosis. Ministries of Health were requested to assign focal points to complete the questionnaire; a guide and a glossary were provided to ensure standardization. Members of national neurological associations were also asked to complement the data. Data were collected in 2014 and 2015, aggregated and analyzed.

The WHO Neurology Atlas is a helpful resource when planning to improve deficits in neurological care nationally and globally. The data can be used to demonstrate levels of service and medication availability, as well as structural aspects such as financing and policy. The Atlas can be used for advocacy, monitoring, evaluation and measuring progress in improving care for people with neurological disorders (18).





Research

This lever refers to research and knowledge management on epilepsy, including dissemination of lessons learnt and use of the knowledge to scale up successful strategies for diagnosis, treatment and care. Optimal use of research funds and careful prioritization in a research agenda of the most urgent questions should be combined with capacity-building for researchers and expanding the scope and rigour of research methods to provide usable evidence.

Implementers

Government scientific and research authorities, research institutions and networks, academics and researchers, national service planners and managers, research funders.

Policy level

- Identify national research priorities and gaps in research on epilepsy.
- Raise the profile of epilepsy in research funding initiatives, fostering collaborations among governmental institutions, nongovernmental organizations and industry.
- Build paths for career development in epilepsy research for young professionals, particularly in LMIC.
- Create regulations and networks for private sector investment in research on epilepsy.
- Ensure all research is people-centred and that people with lived experience are involved at all stages.
- Create an enabling environment for research with a transparent and appropriate regulatory environment, sustainable funding, and ensure equity, diversity, and inclusiveness across all research activities.
- Ensure appropriate stringent ethics review and equity in all research on epilepsy.
- Use research evidence to inform the development and updating of epilepsy policy.

Operational level

- Assess levels of awareness of epilepsy, identify unmet needs, and understand the priorities of people with epilepsy.
- Involve and support people with epilepsy, their families and carers to participate actively in setting priorities and designing, planning, executing and evaluating research to ensure the greatest impact.
- Foster research on the epidemiology, causes, co-morbidity, diagnosis, management and prevention of epilepsy throughout the life course.
- Support implementation research to inform the scaling-up of effective interventions and models in epilepsy care.
- Encourage interdisciplinary research on the social aspects of epilepsy, such as social inclusion, respect for human rights and relationships, and on the links between poverty and other social determinants of health and the health outcomes of people with epilepsy.
- Support research on innovation (e.g., digital tools and telemedicine) in epilepsy care in low-resource settings.
- Ensure communication of research results to relevant audiences and their application in management of epilepsy.

Resources

- Epilepsy: a public health imperative (11)
- A blueprint for dementia research (95)



Research: case study

Epilepsy Pathway Innovation in Africa (EPIInA)

The aim of the 5-year EPIInA project, led by University of Oxford in collaboration with WHO, is to better understand and change management of epilepsy in Ghana, Kenya and the United Republic of Tanzania. The work includes prevention of epilepsy due to onchocerciasis and perinatal injury, improving the rate of accurate diagnosis of epilepsy by use of app-based technologies, increasing adherence to antiseizure medicines through text messaging and raising public awareness to reduce the stigmatization experienced by people with epilepsy. The project includes studies of care pathways and training health workers to apply the WHO mhGAP guidelines to diagnose and treat epilepsy in primary health care.

The field work in each country is performed by national teams of epileptologists and neurologists. EPIInA provides valuable opportunities to doctoral candidates to advance research in their countries, including evaluation of the cost of care, drug metabolism, parasitology of epilepsy, ethnography, oral histories of people with epilepsy and prevalence rates in densely populated urban settlements. The results will be used to inform policy and practice on epilepsy in the three countries (96).





Systems for improving quality of care

This lever addresses continuous assessment and feedback at local, subnational and national levels to improve the quality of integrated services for epilepsy. Quality improvement is a shared responsibility of all those who deliver services, support and care and should be integral to planning.

Implementers

National, district and facility service planners and managers of health and social care, civil society organizations, organizations of people with epilepsy and their families.

Policy level

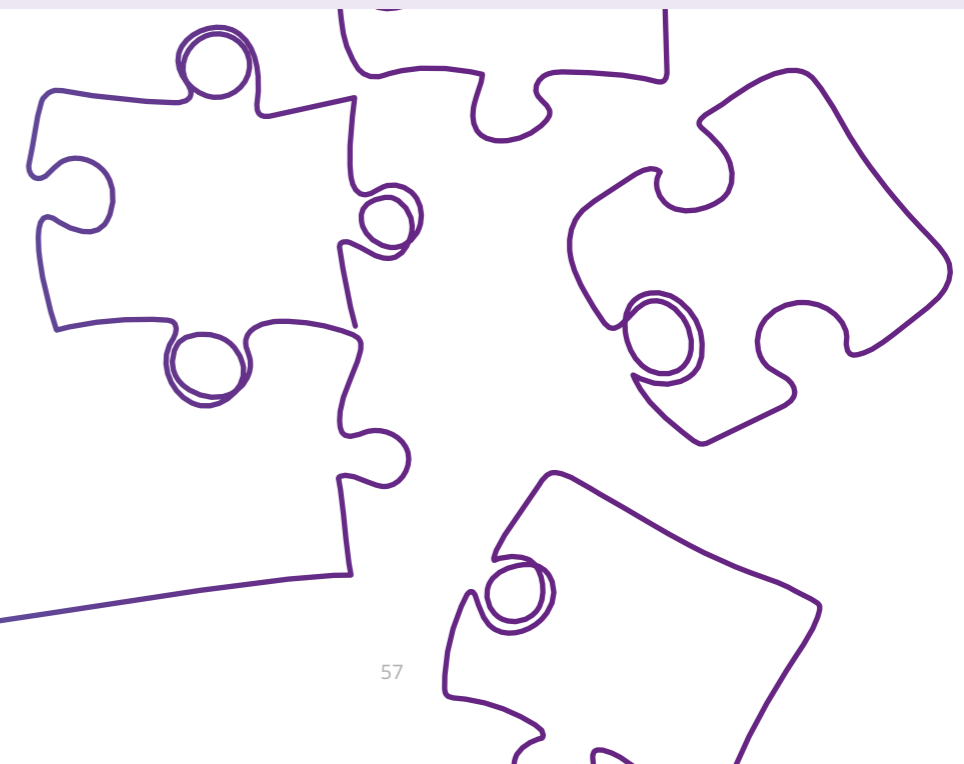
- Ensure review at a minimum of every 2 years of all policies on epilepsy (e.g., frameworks and packages of care and others), and incorporate global and local lessons learnt.
- Include cyclical evaluation of the knowledge and competencies of health-care personnel in order to improve the quality of epilepsy care.
- Improve regulations and the obligations and training of health-care providers to respect the choices of people with epilepsy.
- Ensure that a quality improvement cycle is person-centred and people with epilepsy are involved at all stages.
- Design effective systems for monitoring compliance with human rights standards from multiple sources of information, in consultation with people living with epilepsy.

Operational level

- Develop measures of the quality of care in epilepsy that are based on global standards and the local context; include qualitative assessment and support for better measurement techniques, instruments and methods.
- Evaluate epilepsy management and care, disease burden, comorbidity and the economic impact of epilepsy in the country to establish baselines for comparison.
- Ensure feedback from health workers to improve the health data management system by including their perspectives on ease of use.
- Assess the availability of care including multidisciplinary care at all levels of the health system, to ensure inclusion of people in all age groups, vulnerable populations and people with severe disability.
- Build capacity through online platforms, webinars and training to give skills to informal carers and families, disseminate best practices, and provide platforms for sharing stories and providing carer relief.
- Institute mechanisms to enable people with epilepsy and their families to provide feedback on quality health services (e.g., through feedback forms) and incorporate the feedback in improvement efforts.

Resources:

- WHO Quality Toolkit (97)
- mhGAP operations manual (80)



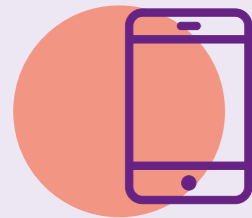


Systems for improving quality of care: case study

Improving education on electroencephalography in Asia and Oceania

Electroencephalography (EEG) is important in diagnosis of epilepsy, but many countries do not have enough experienced technologists. Neurologists require additional training to interpret the results of an EEG to ensure they do not read it incorrectly and miss cases. In Asia, EEG technology is often available only in large cities and private facilities, incurring additional costs for people with epilepsy. To increase the knowledge of neurologists, the educational organization for ILAE-Asia and Oceania, ASEPA, is offering an EEG course throughout Asia for neurologists, psychiatrists, and EEG technologists, including trainees in these areas. A certification examination is offered at epilepsy conferences and ASEPA workshops, and those who pass both parts of the examination become certified encephalographers – that number was 311 as of June 2018. Although there are still gaps in the number of skilled EEG readers, the course is increasing the number of EEG technicians and interpreters in Asia and Oceania (98).





Digital technologies for health

This lever addresses regulation and use of digital technologies to improve the diagnosis, management and care of epilepsy by facilitating access to care and service delivery, improve effectiveness and efficiency and promote accountability while protecting privacy and empowering people with epilepsy, their families and carers.

Implementers

Policy-makers, health service planners and managers, technology developers for health services, civil society organizations providing support to people with epilepsy and their families, organizations of people with epilepsy and their families.

Policy level

- Establish policies to support integration of digital health services into diagnosis, treatment, care and self-care of epilepsy by identifying gaps in existing efforts that could be filled through new technologies.
- Create and facilitate platforms for collection of essential clinical and diagnostic data on epilepsy, including data obtained remotely.
- Create policies and mechanisms to ensure secure transfer and sharing of sensitive medical information for identification and diagnosis of epilepsy.
- Embed education, training, certification and continuing education for the use and accuracy of digital technologies for professionals working in epilepsy management, treatment and care, and involve people with epilepsy to ensure person-centred perspectives.
- Regulate the use of artificial intelligence in health care, particularly for epilepsy, to facilitate decision-making by non-specialists while protecting the privacy of individuals.

Operational level

- Enable access to evidence-based digital technologies for self-management of seizures and other needs in epilepsy, with medication regimens.
- Pilot-test and use where appropriate multi-channel telehealth platforms for accessible diagnostics and epilepsy management and care at all levels of health care, including digital tools for hard-to-reach populations.
- Establish a user-friendly digital system to manage digital and phone appointments for people with epilepsy.
- Maximize the use of digital tools for training and self-directed learning of health-care workers in diagnosis and treatment of epilepsy.
- Increase digital health literacy in people with epilepsy, their families and carers, and provide accessible information about epilepsy in local languages on digital platforms in diverse settings, including education, employment, sports and law enforcement.

Resources

- mhGAP-IG 2.0 App (e-mhGAP)
- WHO guideline: recommendations on digital interventions for health system strengthening (99)
- Global strategy on digital health 2020-2025 (100)



Digital technologies for health: case study

WHO Academy to offer mhGAP online courses



The courses will be designed for online access and the Academy platform will be available on desktop and mobile devices

The WHO Academy, the learning centre of the World Health Organization, is planning to offer online and in-person training to millions of health workers around the world. Currently under development, the goals of the Academy are to ensure that health workers, policy makers and public health practitioners can access up-to-date personalized training when and where they need it. This will help countries to achieve the health targets of the Sustainable Development Goals.

mhGAP is the WHO programme for integrating mental, neurological and substance use conditions into primary care around the world, and training in this programme will also be offered at the WHO Academy. The courses will be designed for online access and the Academy platform will be available on desktop and mobile devices, in low-bandwidth settings and with downloadable, offline options. This will allow health workers anywhere in the world to learn, practice and maintain new competence for diagnosing and treating epilepsy, one of the conditions included in mhGAP (101).

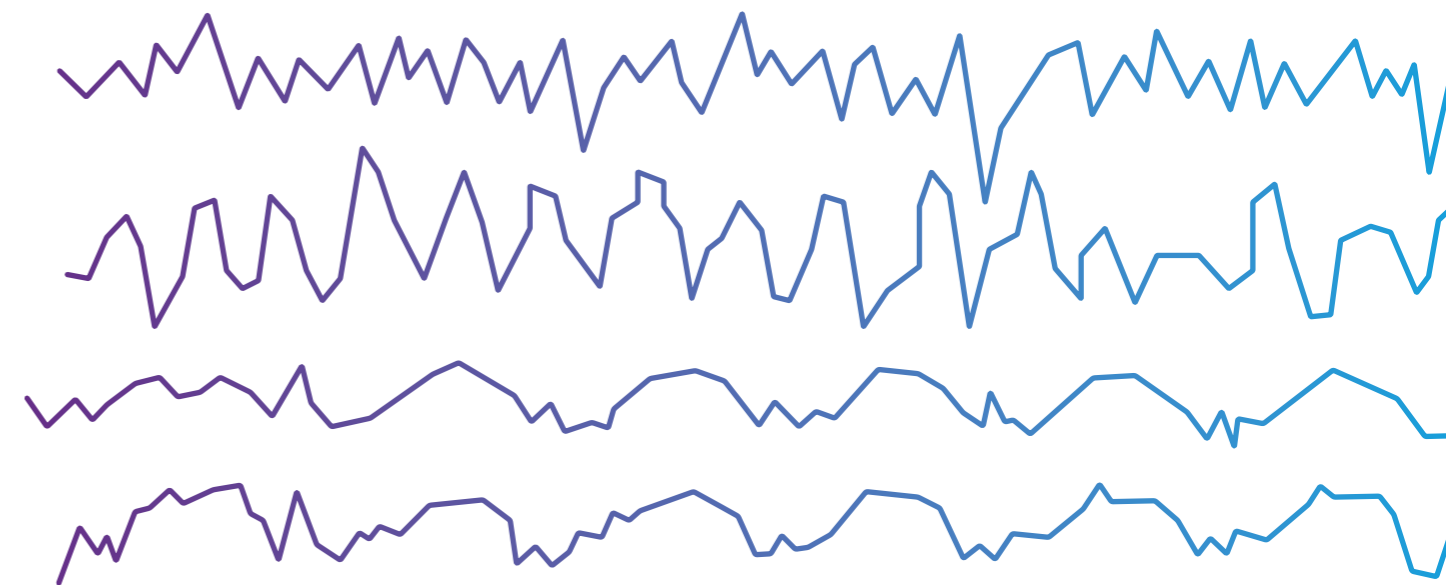


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Annex

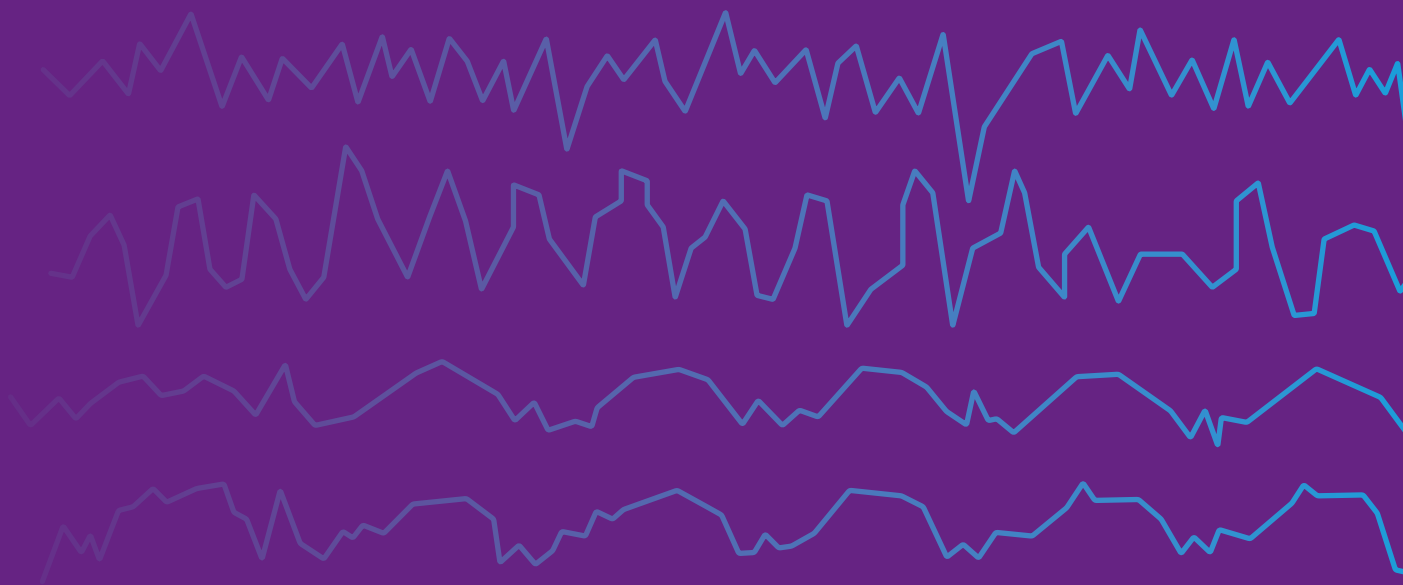
ANNEX 1.

Relevant international commitments made by adoption of World Health Assembly and United Nations General Assembly resolutions

- Global actions on epilepsy and other neurological disorders (2020) (1)
- Resolution to address the global burden of epilepsy (2015) (2)
- Strategy and plan of action on epilepsy for 2012–2021 (3)
- Comprehensive mental health action plan 2013–2030 (4)
- Global strategy to reduce the harmful use of alcohol (2010) (5)
- Global action plan for the prevention and control of noncommunicable diseases 2013–2030 (6)
- UN political declaration on the prevention and control of noncommunicable diseases (2018) (7)
- Follow-up to the political declaration of the high-level meeting of the General Assembly on the prevention and control of non-communicable diseases (8)
- A road map for neglected tropical diseases 2021–2030 (9)
- Defeating meningitis by 2030: a global road map (10)
- Newborn health action plan (11)
- Decade of action for road safety 2021–2030 (12)
- Access to essential medicines (2014) (13)
- Strengthening the role of the health system in addressing violence, in particular against women and girls, and against children (14)
- Global strategy on human resources for health: Workforce 2030 (2016) (15)
- Improving access to assistive technology (2018) (16)
- Rehabilitation 2030: a call for action initiative (17)
- Strengthening of palliative care as a component of comprehensive care throughout the life course (2014) (18)
- Global technical strategy for malaria 2016–2030 (19)
- World Health Assembly document A56/10 also addressed the control of neurocysticercosis, which is an important cause of epilepsy (20)

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