

**THE MANAGEMENT  
OF EPILEPSY**  
IN THE PUBLIC  
HEALTH SECTOR,  
2018



Pan American  
Health  
Organization



World Health  
Organization  
REGIONAL OFFICE FOR THE Americas

The Management of Epilepsy in the Public Health Sector, 2018

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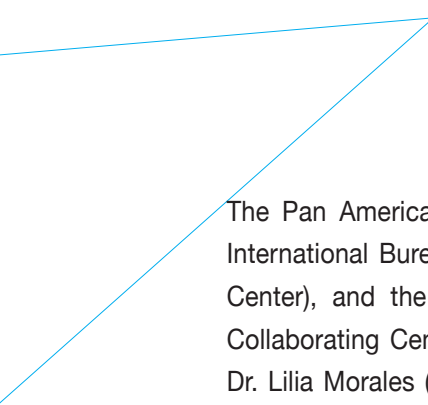
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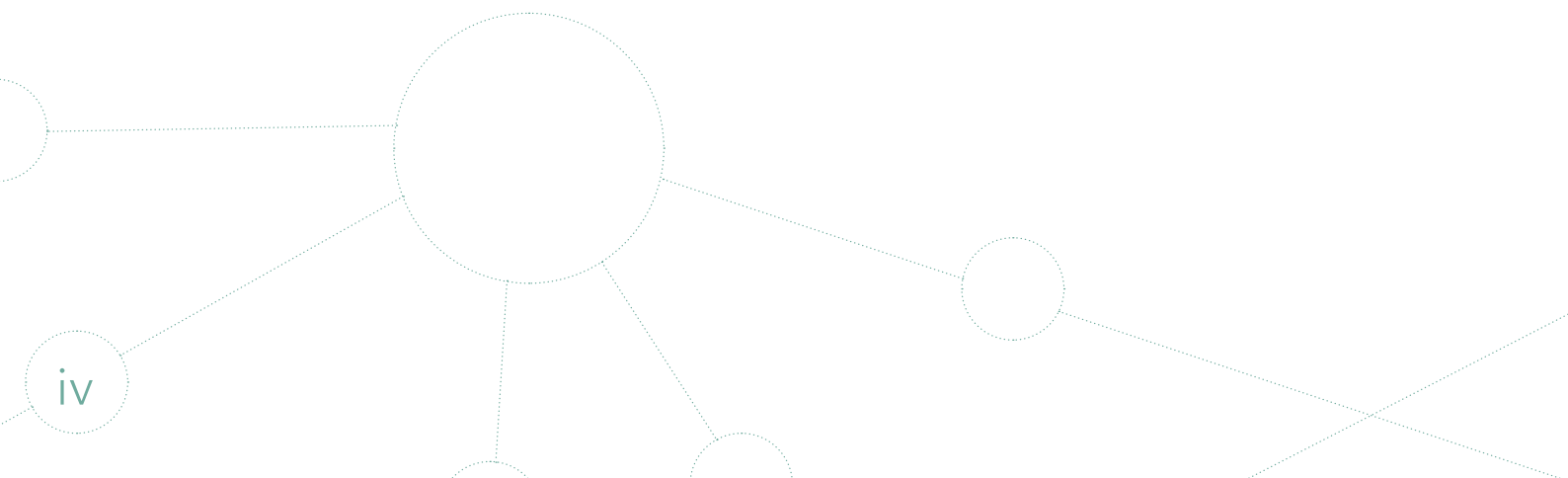
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**Dévorá Kestel**

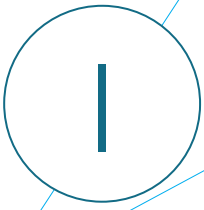
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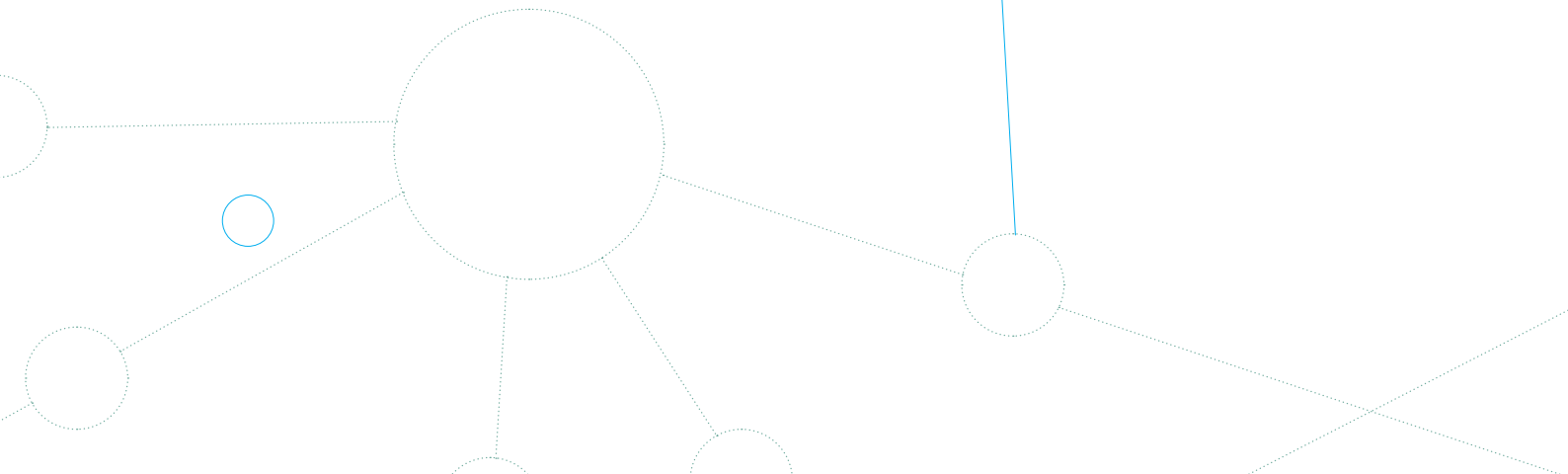
# ACRONYMS



- » AEDs: Anti-epileptic drugs
- » EEG: Electroencephalogram
- » IBE: International Bureau for Epilepsy
- » ILAE: International League against Epilepsy
- » KD: ketogenic diet
- » LAC: Latin America and the Caribbean
- » mhGAP: Mental Health Gap Action Programme (Scaling up care for mental, neurological, and substance use disorders) (WHO)
- » MR: Magnetic resonance
- » NGO: Nongovernmental organization
- » PAHO: Pan American Health Organization
- » PHC: Primary health care
- » WHO: World Health Organization



# INTRODUCTION





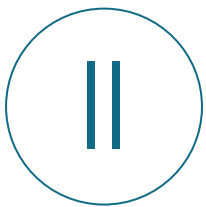
Epilepsy is one of the most common neurological disorders in the world and in our hemisphere, affecting millions of people. However, it is estimated that more than half of people with epilepsy in Latin America and the Caribbean (LAC) do not receive care of any kind from health services. One of the key problems is a limited ability to identify, manage, and monitor epilepsy cases in primary health care (PHC) services. Furthermore, in most LAC countries, the secondary (specialized) care level either has serious limitations or is nearly nonexistent (PAHO, 2011; PAHO/ILAE/IBE, 2013).

In 2011, the 51<sup>st</sup> Directing Council of the Pan American Health Organization (PAHO) adopted its Strategy and Plan of Action on Epilepsy. The corresponding resolution explicitly recognized the burden of epilepsy and the gaps in treatment in the countries and emphasized that this “is an important public health problem” (PAHO, 2011).

In the context of the Directing Council’s mandate, PAHO—with the support of the International League against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE)—published a report compiling the principal data available in LAC countries on resources, programs, and services for the care of people with epilepsy (PAHO/ILAE/IBR, 2013). The report allows the countries to identify their strengths and weaknesses, and to set priorities to improve the health sector’s response.

The 68<sup>th</sup> World Health Assembly (Geneva, May 2015) approved document A68/12, *Global burden of epilepsy and the need for coordinated action at the country level to address its health, social and public knowledge implications*; and the 194 Member States of WHO adopted Resolution WHA68.20, urging the countries, among other things, “to introduce and implement, where necessary and in accordance with international human rights norms and standards, national health care plans of action for epilepsy management, aiming to overcome inequalities and inequities in health, social and other related services, paying special attention to people with epilepsy living in conditions of vulnerability, such as those living in poor and remote areas, including by strengthening public health care services, and by training local human resources with proper techniques” (WHO, 2015).

This document offers guidelines and a frame of reference to help countries design their national epilepsy programs and should be regarded as complementing the Strategy and Plan of Action on Epilepsy (PAHO, 2011) adopted by all the ministers of health of the Americas at the Directing Council of PAHO, and also complementing the resolution and document approved by the World Health Assembly (WHO, 2015).



# EPILEPSY: CONCEPTS AND CLASSIFICATION

Epilepsy is a chronic neurological disease that affects people of all ages around the world. It is characterized by recurrent seizures and is caused by multiple factors. In some cases, there is an underlying genetic cause, but other frequent causes of epilepsy include brain damage caused by prenatal or perinatal injuries (for example, lack of oxygen or injury during childbirth), birth defects or cerebral malformations, head trauma, stroke, neural infections such as meningitis, encephalitis, and neurocysticercosis, and brain tumors. In about half of epilepsy cases, a specific cause cannot be determined (WHO, 2015).

The ILAE regards epilepsy as a disease of the brain, defined operationally by any of the following conditions<sup>1</sup>:

- » At least two unprovoked seizures occurring more than 24 hours apart;
- » One unprovoked seizure and a probability of further seizures similar to general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years;
- » Diagnosis of an epilepsy syndrome.

## CLASSIFICATION OF EPILEPSY

The World Health Organization (WHO) is currently preparing the 11th Revision of the International Classification of Diseases (ICD-11). An advisory group on neurology is working on a version that reflects the main scientific advances in this field since the last classification (ICD-10). ICD codes are used in statistics on mortality and morbidity, and play a vital role in health care planning, training, and allocation of health resources in countries. While used by physicians at all levels, the main users of the ICD codes are primary health care providers.

In 2017, the ILAE updated the classification of epilepsies<sup>2</sup>:

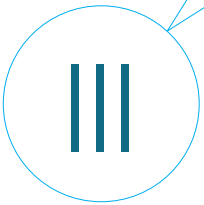
- » Classification by etiology: a) Genetic; b) Structural; c) Metabolic; d) Infectious; e) Immune; and d) Unknown.
- » Classification by seizure type: a) Generalized; b) Focal; and c) Unknown.

The ICD-11 (still in preparation) and the Classification and Terminology of Epilepsy (recently published by the ILAE) are similar and both reflect the current thinking on pathophysiology of epilepsy and convulsions.

<sup>1</sup><https://www.ilae.org/guidelines/definition-and-classification/definition-of-epilepsy-2014>

<sup>2</sup>ILAE (2017). *Operational classification of seizure types by the International League against Epilepsy: Position Paper of the ILAE Commission for Classification and Terminology*. Available at: <http://onlinelibrary.wiley.com/doi/10.1111/epi.13670/full>

ILAE (2017). *ILAE classification of the epilepsies: Position paper of the ILAE Commission for Classification and Terminology*. Available at: <http://onlinelibrary.wiley.com/doi/10.1111/epi.13709/full>



# EPIDEMIOLOGY: MAGNITUDE AND IMPACT

Approximately 50 million people around the world have epilepsy, five million of whom live in the Region of the Americas. Epilepsy represents 0.5% of the global burden of disease, measured in disability-adjusted life years (DALYs), and 80% of that burden corresponds to developing countries (WHO, 2006).

Rates of incidence, prevalence, and mortality due to epilepsy are not uniform worldwide and depend on several factors. In Latin America and the Caribbean, lifetime prevalence affects 17.8 per thousand population, on average (range: 6-43.2). There are no significant differences by sex or age groups (Burneo, J.G. et al., 2005; PAHO, 2011).

Every year there are two million new cases in the world. Studies indicate that the annual incidence in developed countries is approximately 50 per 100,000 population, while in developing countries this figure is nearly double (close to 100 per 100,000).

Mortality is higher in people with epilepsy than in the general population. Worldwide, estimated annual mortality rates range from 1 to 8 per 100,000 population. Mortality from epilepsy in Latin America and the Caribbean is 1.04 per 100,000 population, higher than in the United States and Canada, where it is 0.50 per 100,000 population. In some countries, estimates suggest significant under-reporting. The convulsive or tonic-clonic epileptic state is a complication associated with mortality in 5 to 15% of cases (WHO, 2006; PAHO, 2011; PAHO/ILAE/IBE, 2013).

# IV

## PUBLIC POLICIES AND EPILEPSY

In the last 30 years, most countries in the Americas have reformed their health systems due to the need to increase coverage levels in the population and to improve the quality of response by the health services. At the same time, costs have been rising along with the development of new technologies. Other problems include constraints on public spending, inefficient management, and changes in the role of the State (Roberts, M. et al., 2004).

In recent years, health systems in Latin America and the Caribbean have paid special attention to noncommunicable chronic diseases, including epilepsy. However, care for people with epilepsy remains far from satisfactory, due to, among other reasons: a) a lack of trained physicians; b) unavailability of drugs, especially in PHC; and c) a lack of information and education on epilepsy, both for people with epilepsy and their family members, and for the community.

At the global level, the estimated gap in epilepsy treatment is approximately 75% in low-income countries and about 50% in middle-income countries.

The PAHO report on programs, services, and resources for epilepsy in LAC (PAHO/ILAE/IBE, 2013) emphasizes two important conclusions: 1) two-thirds of countries do not have a program for epilepsy care in the health sector; and 2) 80% of LAC countries do not have appropriate legislation on epilepsy. As a consequence, the human and civil rights of people with epilepsy are frequently violated and discriminatory legislation lacking scientific basis persists. Epilepsy continues to be stigmatized as a disease, largely due to the limited information that the public receives about it.

This presents us directly with some of the challenges faced when designing and implementing public health policies. But it is important to note that the prognosis for epilepsy depends largely on early diagnosis and rapid commencement and continuity of treatment. It is encouraging to know that the vast majority of people with epilepsy can live a normal life if they receive appropriate treatment. The simple provision of four basic anti-epileptic drugs, particularly in PHC, is a crucial, highly effective, and low-cost measure, considering that most patients can control their seizures with monotherapy (PAHO, 2011).

WHO has recommended that certain key measures can be taken at the country level to improve care for people with epilepsy (WHO, 2015):

1. Formulate and implement national policies and legislation to promote and protect the rights of people with epilepsy and prohibit discrimination.
2. Improve health services delivery for people with epilepsy.
3. Integrate epilepsy management into primary health care.
4. Increase access to medicines. It is calculated that if treatment coverage with anti-epileptic drugs was expanded to 50% of cases, the current global burden of epilepsy would be reduced by 13-40%.
5. Implement epilepsy prevention strategies, e.g. promotion of risk-free pregnancies and childbirth, control of cysticercosis, and prevention of head trauma and stroke.
6. Raise public awareness and knowledge about epilepsy.
7. Strengthen health information and surveillance systems.
8. Increase investment in epilepsy research.
9. Collaborate with civil society and other partners.




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# RECOMMENDATIONS FOR THE DESIGN OF A NATIONAL EPILEPSY PROGRAM





## 5.1 RATIONALE FOR A NATIONAL EPILEPSY PROGRAM (PAHO, 2011) (WHO, 2015)

- 
- » Epilepsy is a highly prevalent chronic neurological disease that affects the quality of life of individuals and their entire families.
  - » It is associated with greater morbidity and mortality than in the general population.
  - » It is a disease surrounded by myths and stigma, and people who have it are frequently discriminated against and suffer human rights abuses.
  - » There are cost-effective, evidence-based interventions that can be implemented simply and practically; 70% of affected people can be treated with basic drugs (primarily in monotherapy), and 10% through diet or surgery. Around 20% of cases are complex and do not respond to treatment.
  - » Epilepsy is essentially a clinical diagnosis that can be reached with an appropriate interview and examination.
  - » PHC physicians can be trained to identify and manage most people with epilepsy in their communities (uncomplicated cases).
  - » Although it affects the entire population, epilepsy is most frequent in poor populations with difficult access to health services, and in rural areas.



## 5.2 SITUATION ANALYSIS

As in any planning process, having an appropriate situation analysis is essential for preparing a program, setting priorities, and establishing lines of action. It is also necessary to have country-level epidemiological data on epilepsy, including prevalence, incidence, and mortality, disaggregated at least by age, sex, place of origin, and known causes of the disease. The number of cases evaluated in the health services can give us an initial idea of the magnitude of the problem.

A situation analysis should include an inventory of the programs, services, and resources available to care for people with epilepsy, and explain how the health system is serving the existing needs. This means knowing what human resources are available at the facilities that attend to people with epilepsy at all levels, the existing technology, and the management capacity of different sectors (not only the health sector) in the country.

A good pre-existing health information system (including basic data on epilepsy, as well as research and studies on epilepsy in the country) would be an important source of reference material for the situation analysis.

If a minimum amount of reliable morbidity data is not available, it is advisable to establish an initial database of the people already diagnosed with epilepsy, by region. Patients should be classified according to sex and age groups, and whether their seizures are controlled or refractory to anti-epileptic drugs (AEDs). This patient registry can be updated and enriched on an ongoing and permanent basis.

## 5.3 FORMULATING THE PURPOSE, STRATEGIC AREAS, AND OBJECTIVES

**Purpose:** Strengthen the response of the health sector, providing comprehensive quality care to people with epilepsy, including the necessary resources for health promotion, disease prevention, treatment, and rehabilitation, according to the complexity of their condition, through an integrated network of services, with access at the primary health level.

### Strategic areas and objectives:

STRATEGIC AREA	OBJECTIVES
1. National program, financing, and legislation	<p>1.1 Have the legal and regulatory framework to support the program.</p> <p>1.2 Identify existing gaps in care, financing, and resources, defining what the barriers are and how to address them in order to ensure proper functioning of the health services.</p> <p>1.3 Strengthen cooperation and partnerships between the health sector and other actors for the implementation of the national epilepsy program, including aspects of social protection.</p>
2. Health promotion and epilepsy prevention	<p>2.1 Contribute to health promotion.</p> <p>2.2 Carry out specific activities for epilepsy prevention.</p>

<b>3. Delivery of health services</b>	<p><b>3.1</b> Improve the organization of the services, through an integrated health services network that ensures quality and continuity in the care of people with epilepsy.</p> <p><b>3.2</b> Ensure a diagnosis and early treatment of epilepsy, based in the improvement of the response capacity of the PHC.</p> <p><b>3.3</b> Guarantee access to anti-epileptic drugs and adherence to treatment.</p> <p><b>3.4</b> Develop or improve clinical care guidelines and protocols for people with epilepsy, making them available in the health system and ensuring their implementation.</p>
<b>4. Strengthening of human resources</b>	<p><b>4.1</b> Train health workers in order to improve their competencies in epilepsy management, with special emphasis on PHC workers.</p>
<b>5. Epilepsy information system</b>	<p><b>5.1</b> Improve the epilepsy component of national health information systems, ensuring the collection, processing, and regular analysis of core data on epilepsy.</p> <p><b>5.2</b> Strengthen national research in the field of epilepsy.</p>

## 5.4 RECOMMENDED LINES OF ACTION

### A) EPILEPSY PROGRAM AND LEGAL AND REGULATORY FRAMEWORK

The first strategic recommendation on epilepsy is for a country to have a national program that enables it to comprehensively address problems related to epilepsy. The program should be integrated in public health policies and facilitate the organization of services, based on a community model (PAHO, 2011; WHO, 2013). In countries where it is difficult to establish a national epilepsy program, a possible short-term alternative would be to include epilepsy in the plan for noncommunicable chronic diseases or mental health.

Legislation on epilepsy and other legal mechanisms provide the legal foundation to promote and protect the human rights of people with this disorder<sup>3</sup>, while also providing legal support for a health services program for people with epilepsy. There are two ways to promote this legal framework:

<sup>3</sup> It is recommended to consult the WHO Resource Book on Mental Health, Human Rights and Legislation. Geneva: WHO; 2006.

1. A law on epilepsy. This is the most important recommendation, but few countries have achieved it.
2. Legal provisions on epilepsy, which can be included in different laws and legal instruments. This seems to be most practical and feasible in the short term.

Implementation of national programs for epilepsy care is a challenge that requires intersectoral cooperation, strengthening existing commitments, and finding new partners. Civil society plays an important role and, in particular, organizations of patients and family members. It is essential to allocate resources to implement plans and calculating the financial gap is a first necessary step in planning (PAHO, 2011).

It is advisable to define who is responsible for the subject of neurological diseases and epilepsy at each level of care and each territorial level. It is suggested that at least one neurologist (part- or full-time) in the Ministry of Health should act as the national authority or as advisor to the health authorities on the subject of neurological diseases and epilepsy.

## B) HEALTH PROMOTION AND EPILEPSY PREVENTION

### Strengthen activities for epilepsy prevention

Special attention should be paid to education programs for people with epilepsy, their families, and their communities. These should be implemented at all levels of care, with particular emphasis on the primary health level. It is advisable for a coordinator to be available for this task and for a structured education plan to be prepared.

The most important subjects to consider are: general knowledge about epilepsy; myths, stigma, and discrimination; health promotion, epilepsy prevention, treatments, and recovery; and social protection and guidance on available sources of support. Knowing more about the disease reduces stigma. Education on epilepsy is a key factor for better quality of life and improved prognosis, resulting in the reduction of stigma and associated disability (Eiser, C. et al., 2001; Seiam, A.H., 2011; Taylor, R.S. et al., 2011).

In the field of prevention, it should be kept in mind that the most frequent structural causes of epilepsy in LAC countries are infectious diseases, parasitic diseases (in particular neurocysticercosis), perinatal brain damage, vascular diseases, and head trauma; all of which are preventable with cost-effective, evidence-based interventions (PAHO, 2011).

Neurocysticercosis is an infection of the nervous system caused by the *Taenia solium* larva. Its most common clinical manifestations are acute symptomatic epileptic crises and epilepsy. According to some Latin American studies, community health and education interventions can reduce the incidence of epilepsy caused by neurocysticercosis in hyperendemic populations (PAHO, 2011).

## C) PROVISION OF SERVICES

### Organization by level of care

Levels of care should fit with the structure of the country's health system. It is essential to integrate epilepsy care into the health services network, decentralize specialized services (neurology), and strengthen primary care and community participation.

The functions below are defined by levels of care and by the type of professionals and technical personnel who provide care to people with epilepsy:

LEVEL OF CARE/ FUNCTIONS	TYPE OF PROFESSIONAL OR TECHNICIAN
<p><b>Primary: Family medicine units and PHC centers</b></p> <ul style="list-style-type: none"> <li>- Identification and management of people with epilepsy, or referral to the secondary/specialized level, when appropriate.</li> <li>- Epilepsy training for primary health care teams.</li> <li>- Availability and proper delivery of AEDs.</li> <li>- Education for people with epilepsy, family members, and the community.</li> </ul>	<ul style="list-style-type: none"> <li>- PHC team consists of: general practitioner, nurse, social worker, midwife, and community agents (such as health promoters).</li> </ul>
<p><b>Secondary: Specialized service (neurology service in an ambulatory unit or general hospital)</b></p> <ul style="list-style-type: none"> <li>- Offers territorial coverage based on the established health regions.</li> <li>- Ensures primary care/consultation with a neurologist to confirm diagnosis and recommend action to be taken.</li> <li>- Monitors cases that are complex or hard to manage in PHC.</li> <li>- Treatment of status epilepticus and other emergencies in hospital emergency units.</li> <li>- Has a database or registry of people with refractory and non-refractory epilepsy, classified by sex and age (in each health region).</li> <li>- Maintains links with the primary level and supports it through training, interconsultation, and systematic supervision.</li> <li>- Refers people with refractory epilepsy to tertiary level.</li> </ul>	<ul style="list-style-type: none"> <li>- General neurologist or, if possible, neurologists specialized in children and adults.</li> <li>- Neurology nurse.</li> <li>- Mental health team available for interconsultation (psychiatrist and psychologist).</li> <li>- Emergency teams in general hospitals.</li> <li>- Other professionals and technical personnel (according to availability): neurophysiologist, speech pathologist, social worker, and occupational therapist.</li> </ul>

<p><b>Tertiary: Specialized service of greater complexity (usually an institute, hospital, or another unit at the national level)</b></p> <ul style="list-style-type: none"> <li>- Care for cases that are complex and/or refractory to AEDs.</li> <li>- Neuroimaging of cerebral magnetic resonance.</li> <li>- Prolonged video-electroencephalographic monitoring (minimum 24 hours).</li> <li>- Ketogenic diet for children with refractory epilepsy and, progressively, for others.</li> <li>- Pre-surgical evaluation of people with refractory epilepsy.</li> <li>- Surgical treatment of epilepsy.</li> </ul>	<ul style="list-style-type: none"> <li>- Team of neurologists and epileptologists for children and adults.</li> <li>- Neurology nurses.</li> <li>- Mental health team: psychiatrist, neuropsychologist, and psychologist.</li> <li>- Neurosurgery team trained in epilepsy surgery.</li> <li>- Other professionals and technical personnel: neuropsychologist, kinesiologist, nutriologist and nutritionist specialized in ketogenic diet, speech pathologist, neuro-ophthalmologist, neuroradiologist, and nuclear medicine team.</li> </ul>
<p><b>Central level/Ministry of Health</b></p> <ul style="list-style-type: none"> <li>- Regulatory and technical role: design, approve, and monitor implementation of policies, programs, and technical standards.</li> <li>- Epidemiological situation analysis.</li> <li>- Supervision of services.</li> <li>- Allocation of human and financial resources.</li> <li>- Program evaluation.</li> </ul>	<ul style="list-style-type: none"> <li>- Advisor or coordinator of neurological diseases and epilepsy (full- or part-time).</li> <li>- Technical advisory group, if possible.</li> </ul>

The inverted pyramid, below, summarizes the levels of care in Chile's epilepsy program. This is a good model for Latin America.

**EPILEPSY PROGRAM IN CHILE**

LEVEL	TYPE OF EPILEPSY	HUMAN RESOURCES
1 Primary care	Non-refractory epilepsy	General practitioner, nurse, social worker, midwife, psychologist
2 Ambulatory neurology	Epilepsy with comorbidities	Neurologist, nurse, speech therapist, occupational therapist
3a Integrated medical treatment	Refractory epilepsy	Epileptologist, neurophysiologist, neuropsychologist, neuroradiologist, nuclear medicine specialist, social worker, neuro-ophthalmologist
3b Ketogenic diet		Nutriologist, nutritionist
3c Non-invasive surgery		Neurosurgeon/epileptologist, kinesiologist
3d Invasive surgery		Epileptologist and neurosurgeon

## **Improve the capacity of primary care services to manage people with epilepsy**

PHC is the first line of contact between health systems and the population. Its goal is to bring health care as close as possible to where people live and work. The first level of health care is the first link in the chain of ongoing health care processes. The Declaration of Alma-Ata defines primary health care as “essential health care based on practical, scientifically sound, and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain” (PAHO, 2007, 2011).

Epilepsy is a disorder that should be identified in PHC. Around 70% of cases can be controlled and seizures can be prevented with simple and cost-effective interventions implemented in the primary level. Evidence-based practice, together with the limited number of professionals specialized in most LAC countries, fully justifies the need to strengthen the response capacity in PHC, making this a priority objective. The following are key activities for the achievement of this objective:

- » Meet the training needs of professionals and technical personnel working in PHC.
- » Ensure that specialists at the second level of care provide support and systematic supervision.
- » Provide protocols and clinical care guidelines to PHC physicians.
- » Establish regular mechanisms for interconsultation and for referral and counter-referral.

## **Decentralize specialized neurology care in the health services network, bringing it closer to the first level.**

This means defining the points within the network where referrals are made to neurology services and centers of greater complexity:

- » Develop a decentralized network of neurology services at the secondary level, linked with PHC.
- » Establish the essential requirements for creating a “referral center” and specify the location of these centers.
- » Meet the training needs of professionals and technical personnel working in these services (Levels 2 and 3).
- » Meet human resource and infrastructure needs (in stages).

## Ensure availability of drugs and technology

Pharmacotherapy is the essential element in treatment for people with epilepsy. The general treatment goals are to: prevent seizures, reduce adverse drug effects and drug interactions, improve patients' quality of life, and ensure patients' satisfaction with the treatment received. An important objective of pharmacological treatment of epilepsy is to create a balance between preventing seizures and minimizing adverse effects, to a degree that the patient can tolerate.

AEDs do not offer a permanent cure, but can eliminate or reduce symptoms. The most commonly used drugs, recommended for primary care, are valproic acid, carbamazepine, phenytoin, and phenobarbital (PAHO, 2011). Clobazam, clonazepam, gabapentin, lamotrigine, leviteracetam, oxcarbazepine, tiagabine, topiramate, vigabatrin, and zonisamide, among other drugs, are secondary options. Approximately 25% of patients with epilepsy have seizures that do not respond appropriately to AEDs; of this group, 12-25% are candidates for surgery.

A basic principle of any epilepsy program is to ensure access to anti-epileptic drugs. AEDs should be directly provided at the health center closest to the person's residence, regardless of the frequency of check-ups with a general practitioner or specialist, or the type or severity of the disease.

A sufficient supply of AEDs should be available in PHC for people registered as having epilepsy. At this level, AEDs should be provided with a prescription from a general practitioner, who in turn should be periodically supervised by a neurologist.

With regard to other technology:

- » Cerebral magnetic resonance (MR) should be done according to a protocol for everyone with uncontrolled epilepsy or whose presentation suggests a focal etiology.
- » People with refractory epilepsy should receive prolonged video-electroencephalographic monitoring.
- » A ketogenic diet (KD) and epilepsy surgery are alternative treatments for people with refractory epilepsy, and should be performed only in duly accredited referral centers.

## Adherence to prescribed drug use

Adherence to treatment among people with epilepsy and the health education they receive are essential for successful treatment. Poor adherence to medication is considered the leading cause of failure in pharmacotherapy. Patients who do not regularly follow their treatment experience a larger number of more severe seizures. This leads, among other things, to more visits to emergency services, more hospitalizations, and more use of ambulances. Consequently, non-adherence directly increases health costs and reduces quality of life.

The following conditions or factors affect adherence to epilepsy treatment; the interventions described below can be used to improve adherence:



TYPE OF FACTOR	DESCRIPTION	INTERVENTIONS TO IMPROVE ADHERENCE TO TREATMENT
<b>Socioeconomic factors</b>	<ul style="list-style-type: none"> <li>- Poverty; illiteracy; high cost of medication; local beliefs about the origin of disease.</li> <li>- Risk groups: older adults; children in families with parents who have low educational level; language barriers; immigrants (sometimes undocumented).</li> </ul>	<ul style="list-style-type: none"> <li>- Social needs assessment and coordination with government agencies and humanitarian and community organizations.</li> </ul>
<b>Factors related to the health care system or health team</b>	<ul style="list-style-type: none"> <li>- Distance from treatment unit.</li> <li>- Inadequate reimbursement or lack of health insurance plans.</li> <li>- Irregular or deficient supply of medicines; or medicines not provided free of charge to people with financial hardship.</li> <li>- Limited development of health services; lack of education about AEDs; poor physician-patient relationship.</li> </ul>	<ul style="list-style-type: none"> <li>- Regular and uninterrupted drug supply; good physician-patient relationship; nursing personnel and physicians trained to incorporate administration of medicines into patients' everyday life; health professionals trained to educate about treatment adherence.</li> </ul>
<b>Disease-related factors</b>	<ul style="list-style-type: none"> <li>- Poor memory; duration of previous treatments; treatment failures; high frequency of convulsive seizures.</li> </ul>	<ul style="list-style-type: none"> <li>- Education on drug use; use of memory aids.</li> </ul>
<b>Treatment-related factors</b>	<ul style="list-style-type: none"> <li>- Complex treatments: difficult to understand instructions on how to take the drugs and their adverse effects.</li> </ul>	<ul style="list-style-type: none"> <li>- Self-care of side effects. Motivational intervention; education on adherence; give patients control and opportunity to choose.</li> <li>- Psychological needs assessment; frequent monitoring interviews.</li> <li>- Monotherapy regimens with simple dosage are easy to understand and facilitate adherence.</li> </ul>

## Development of intervention protocols according to level of care

Protocols are essential in to organize and standardize care, deliver best practices, and favor the most cost-effective processes. They are also the basis for surveillance indicators. Examples of important contents for a protocol include:

- » Identification and management of people with epilepsy in PHC.
- » Study and treatment of people with epilepsy, by level of care.
- » Management of epileptic seizures in the emergency service.
- » Referral: a) referral and counter-referral among health system levels; b) referral for treatment with KD; and c) referral to clinic for refractory epilepsy.
- » Informed consent, in accordance with the indicated procedures.
- » Specialized protocols:
  - » Clinical management of AEDs refractory epilepsy
  - » Treatment with ketogenic diet
  - » Indication of brain MRI
  - » Neuropsychological evaluation
  - » Evaluation for epilepsy surgery

WHO has made mhGAP available to the public (Mental Health Gap Action Programme: Scaling up care for mental, neurological, and substance use disorders) (WHO, 2008), as well as an intervention guide that includes a module on epilepsy (WHO, 2016). These tools are especially useful in PHC. These valuable, evidence-based instruments have been validated at the global level and countries can adopt and adapt to their national contexts.

## Persons with epilepsy, levels of care, and types of intervention

CHARACTERISTICS OF THE PERSON WITH EPILEPSY	INTERVENTION
<b>Level 1: PHC center</b>	
Person with suspicion of epilepsy	<ul style="list-style-type: none"> <li>- Medical care and referral to neurology to confirm diagnosis.</li> </ul>
Person with epilepsy	<ul style="list-style-type: none"> <li>- Treatment/ provision and monitoring of AEDs; observe harmful effects of AEDs; monitor evaluations done by other specialists; and monitor adherence to treatment.</li> <li>- Educate patients and family members about epilepsy.</li> <li>- Evaluate overburdening of caregiver, social aspects, and respect for human rights.</li> <li>- Request complementary studies, as needed.</li> <li>- Monitor patient until possible discharge.</li> <li>- Visit homes of people with epilepsy who do not report for scheduled follow-up.</li> <li>- Refer complex and refractory cases or consult with neurologist (second level of care), according to protocols.</li> </ul>
Community groups, as well as people with epilepsy and family members.	<ul style="list-style-type: none"> <li>- Educational activities at health centers, schools, and other community locations.</li> </ul>
<b>Level 2: Neurology service</b>	
Person with suspicion of epilepsy	<ul style="list-style-type: none"> <li>- Study the case and confirm epilepsy diagnosis.</li> <li>- Priority care where epilepsy is suspected.</li> </ul>
Person with epilepsy, in treatment	<ul style="list-style-type: none"> <li>- Neurologist begins treatment, according to protocol, with monotherapy and first-generation drugs.</li> <li>- In hard-to-control cases, evaluate treatments with second-line AEDs, according to protocol and correcting dose.</li> <li>- Improve the etiologic study.</li> <li>- Referral to other specialists, as needed.</li> <li>- Measures to prevent status epilepticus.</li> <li>- Cross-referral of cases that can be handled at PHC level.</li> <li>- Refer to third level of care for complicated and refractory cases, according to protocols.</li> </ul>
Person with seizure or status epilepticus	<ul style="list-style-type: none"> <li>- Intensive care, pharmacological treatment, examinations; decide whether or not hospitalization is required. Establish monitoring.</li> </ul>

### Level 3: Specialized services of greater complexity

Person with epilepsy with uncontrolled seizures or refractory case

- Evaluation of treatment with different AEDs, according to protocol and correcting dose.
- Improve the etiologic study.
- Refer to other professionals on the team, or specialists, according to need.
- Take steps to prevent status epilepticus.
- Analyze relevance of other nonpharmacological treatments.

Person with epilepsy with uncontrolled seizures, and candidate for ketogenic diet

- Implement KD with periodic monitoring to correct the diet and evaluate side effects and impact on seizures.

Person with epilepsy with uncontrolled seizures or refractory case and candidate for epilepsy surgery

- Study with prolonged EEG monitoring, brain MRI with epilepsy protocol, neuropsychological and psychometric study and evaluation; evaluation by speech pathologist; clinical assessment by epileptologist, evaluation by neuro-ophthalmologist, neuro-radiologist, neurosurgeon, and neurophysiologist.
- Epilepsy surgery in specific cases that meet requirements established in protocols.

## D) STRENGTHENING HUMAN RESOURCES

In order to improve care of people with epilepsy, a key objective is to define and implement continuing education programs/content for health professionals and technical personnel. The following comments and suggestions are presented according to levels of health care.

### Level 1: Primary care:

- » Training for PHC professionals and technical personnel, developed by neurologists in the corresponding second-level health services. Epilepsy training should be systematic, with contents adjusted to functions at the PHC level. In-person, virtual, or mixed media can be used.
- » Virtual courses or online workshops/video conferences sponsored by the MoH or other institutions (universities, nongovernmental organizations (NGOs), or scientific societies).
- » Mechanisms for support and regular contact between neurologists and PHC physicians. Different alternatives can be used, including telephone, email, and mobile apps. A neurologist can be assigned the periodic task of answering questions on epilepsy from PHC professionals, based on a territorial division.
- » Periodic visits by neurologists to the corresponding PHC centers for interconsultation and discussion/analysis of epilepsy cases.

## Level 2: Neurology services:

- » The neurology specialization program should include epilepsy as a priority issue.
- » Continuing education for neurologists should include epilepsy.
- » Periodic training of neurologists who work in hospitals and who attend to people with seizures or status epilepticus in emergency services.

## Level 3: Specialized services of greater complexity:

- » Training for neurologists specializing in epilepsy (epileptologists).
- » Training in epilepsy surgery for neurosurgeons and epileptologists.
- » Training in KD for nutriologists and nutritionists.
- » Education in neuropsychology for psychologists and/or neurologists.
- » Training in epilepsy for neuroradiologists.

## E) EPILEPSY INFORMATION SYSTEM

Information systems are key to bridging existing gaps in knowledge, and to support decision-makers. They should not be simply a data collection mechanism; they should become a management tool. Epidemiological surveillance can include rapid evaluation procedures, sentinel sites, etc. (PAHO, 2011)

A national program should focus its efforts on (PAHO, 2011):

- » Evaluating health services that offer care to people with epilepsy, establishing a baseline and following up.
- » Improving the epilepsy component of national information systems, ensuring regular collection and analysis of basic data on epilepsy.
- » Strengthen epilepsy research, based on the needs and priorities of each country.

## 5.5 DEVELOPING AN EVALUATION AND MONITORING MECHANISM

Experience shows that the observatory model can be an efficient mechanism for program evaluation when adapted to each country's criteria. An observatory serves as a working platform that makes resources and computer technology available, and is made up of a network of people and institutions that produce and share analyses and information on epilepsy in the country. An observatory helps to:

- » Strengthen surveillance and monitoring of the epilepsy program, which means periodically evaluating: a) coverage; b) relevance of activities; c) availability of trained resources; and d) cost-effectiveness of interventions.
- » Disseminate processes and positive experiences that can be reproduced in other parts of the country.
- » Evaluate the dynamics of processes and trends.
- » Promote epilepsy research.

For better results, greater efficiency at lower costs, and higher user satisfaction, the program should set clear objectives in each strategic area, together with the corresponding activities, and indicators aligned with the objectives and priorities. Targets should be defined for each country according to historical trends, the frame of reference of global and regional targets, the resources available to achieve these targets, and the national context.

With regard to targets, the following should be kept in mind:

- » Training of health professionals and technical personnel should be associated with increased response capacity in the health services. For example, a key indicator is the percentage of PHC physicians who have completed epilepsy training.
- » The target for availability of pharmacological treatment should be based on basic drugs at the PHC level that offer better control of seizures at a lower cost.
- » Measurement of the integration of epilepsy management into the health services network is essential in order to improve access and opportunities for care.
- » Indicators of financial and human resources evaluate the response capacity of the health system.
- » Indicators of production of services (e.g., number of cases treated per 100,000 population) make it possible to evaluate population coverage to some degree.
- » Case registries facilitate the collection of data on the prevalence of epilepsy (satisfied demand).

The Annex to this document presents a list of suggested indicators that could be adapted to the national context. It is important to define at what level each indicator will be used; for example, some could be process indicators used only at the local level. In countries with more developed health systems, more complex indicators could also be used.

## 5.6 FINANCING

The great challenge facing LAC countries is to ensure that their national epilepsy programs are not merely theoretical frameworks of “what we should do,” but are platforms for action, with regular allocated financing that supports the execution of planned interventions.

Resources should be provided within the framework of an evidence-based planning process to implement more cost-effective interventions, followed by evaluations of the results.

The financing system should focus on covering interventions aimed at improving diagnosis and treatment, especially in PHC. For the development of specialized services, investments should be made in facilities that are best prepared to function in a network, are located strategic places, and have the most appropriate physical and human resources.

In order to ensure program financing, it is recommended to:

- » Determine, as precisely as possible, the number of people with epilepsy in the population.
- » Define the types of services required at each level of health care.
- » Estimate the cost of training human resources.
- » Formulate investment and maintenance projects for technological equipment, based on needs at referral facilities at the second and third levels of care.

Direct costs attributable to epilepsy involve: medical consultations, laboratory tests, visits to emergency services, anti-epileptic drugs, and hospitalization. Indirect costs include: lost working days, lost income, lower quality of life, costs of failed treatment, and adverse drug effects. Direct costs are significantly lower for patients with controlled epilepsy, compared to those with uncontrolled epilepsy.

## 5.7 DEVELOPMENT OF A LOCAL MODEL FOR THE CARE OF PEOPLE WITH EPILEPSY

For countries that propose progressive implementation of an epilepsy program, starting with a pilot or demonstration project, the following is recommended:

### Site selection:

- » Select a region, department, province, or district that is representative of the country in terms of the health situation, considering geographical location, available epidemiological data, sociocultural characteristics, and the management capacity of the health sector.
- » The selected area should correspond to a territorial unit of the health system, in order to reflect the network of existing services (public, private, and others), and should include different levels of care (at least primary and secondary).
- » Consider the country's priorities. For example, if vulnerable groups are a key objective, a rural district will be required, most likely one with high poverty levels.

### Planning and organization:

- » Planning ahead of time guarantees the success of the program.
- » Stratify the levels of epilepsy care according to the complexity of care, and define the local health care network.
- » Establish the entry and exit points of people with epilepsy in the services network, and locate the points in the network where care is provided for more complex cases, as well as referral facilities.
- » Design a mechanism for continuous information and monitoring.



Implement a model aligned with the national health system, defining key feasible interventions. The following elements are important:

- a.** Workforce: have a census of people with epilepsy who receive care in the public health system. Classify this population as refractory/non-refractory, and by age and sex groups.
- b.** In primary health care, investigate people suspected of a first epileptic seizure, and manage and monitor cases at the secondary and tertiary levels.
- c.** Educate people with epilepsy and their family members.
- d.** Available human and technical resources: neurologists, basic drugs, and technology (electroencephalography, video-electroencephalographic monitoring, neuroimaging, and resources for KD). Identify the existing gap in needs in order to arrange for the necessary resources.
- e.** Training is a priority process that should begin with the professionals at PHC facilities. Insofar as possible, this training should be delivered by neurologists in the same care network, ideally in person and supported by interconsultation. Training should be continuous and supervised within the services. It should also include continuing medical education for neurologists and specialists at the secondary level.
- f.** Establish the priority problems that should be addressed, determining their causes and associated risk factors; for example: limited human resources training, inadequate interventions at certain levels of care, inefficient health care network, limited education for people with epilepsy and their families, or lack of technological, financial, or human resources.
- g.** Intra- and intersectoral coordination (include mainstreaming of children in schools and adults in workplaces).

Financial aspects: calculate immediate, medium-term, and long-term costs of the activities to be implemented, as well as human resources, drug, technology, and/or infrastructure needs. Training costs should come first, since human resources education is required before other activities can begin.



VI

TOOLBOX FOR DESIGNING  
A NATIONAL EPILEPSY  
PROGRAM: RECOMMENDED  
DOCUMENTS AND WEBSITES

## 6.1 DOCUMENTS

- PAHO (2011). Strategy and Plan of Action on Epilepsy. 51st Directing Council of PAHO, 2011. Washington, DC: PAHO; 2011, document CD51/10, Rev. 1 and Resolution CD51.R8. Available at:  
[http://www.paho.org/hq/index.php?option=com\\_docman&task=doc\\_download&gid=14463&Itemid=270&lang=en](http://www.paho.org/hq/index.php?option=com_docman&task=doc_download&gid=14463&Itemid=270&lang=en)  
[http://www.paho.org/hq/index.php?option=com\\_docman&task=doc\\_download&gid=15042&Itemid=270&lang=en](http://www.paho.org/hq/index.php?option=com_docman&task=doc_download&gid=15042&Itemid=270&lang=en)
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[http://apps.who.int/gb/ebwha/pdf\\_files/WHA68/A68\\_12-en.pdf](http://apps.who.int/gb/ebwha/pdf_files/WHA68/A68_12-en.pdf)  
[http://apps.who.int/gb/ebwha/pdf\\_files/WHA68/A68\\_R20-en.pdf](http://apps.who.int/gb/ebwha/pdf_files/WHA68/A68_R20-en.pdf)
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<http://apps.who.int/iris/bitstream/10665/250239/1/9789241549790-eng.pdf?ua=1>

### Chilean documents:

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<https://www.ligaepilepsia.cl/central/documentos/e76ea1a375db7850efb89c352bb8c9de.pdf>
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[http://revistachilenadeepilepsia.cl/wp-content/uploads/2014/08/201102\\_completa.pdf](http://revistachilenadeepilepsia.cl/wp-content/uploads/2014/08/201102_completa.pdf)

## 6.2 WEBSITES

- Pan American Health Organization (PAHO) / see publications and mandates:  
[http://www.paho.org/hq/index.php?option=com\\_content&view=article&id=281&Itemid=353&lang=en](http://www.paho.org/hq/index.php?option=com_content&view=article&id=281&Itemid=353&lang=en)
- World Health Organization (WHO) / Neurology and Public Health:  
[http://www.who.int/mental\\_health/neurology/en/#](http://www.who.int/mental_health/neurology/en/#)
- International League against Epilepsy (ILAE): <http://www.ilae.org/>
- International Bureau for Epilepsy: <https://www.ibe-epilepsy.org/>
- Ministerio de Salud de Chile / Enfermedades No Transmisibles / Epilepsia:  
<http://www.redcronicas.cl/temas-de-salud/epilepsia/>
- Liga Chilena contra la Epilepsia. <https://www.ligaepilepsia.cl/>

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  - b. Resolution: [http://apps.who.int/gb/ebwha/pdf\\_files/WHA68/A68\\_R20-en.pdf](http://apps.who.int/gb/ebwha/pdf_files/WHA68/A68_R20-en.pdf)
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[http://www.paho.org/hq/index.php?option=com\\_docman&task=doc\\_download&gid=15042&Itemid=270&lang=en](http://www.paho.org/hq/index.php?option=com_docman&task=doc_download&gid=15042&Itemid=270&lang=en).
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# ANNEX: INDICATORS

N°	DESCRIPTION	MEASUREMENT/ ESTIMATE	DATA SOURCE	FREQUENCY
1	Existence of laws and legal instruments related to people with epilepsy, consonant with technical and international human rights standards	<ul style="list-style-type: none"> <li>– Absolute measurement</li> <li>– Result: Yes/No</li> </ul>	Official documentation from legislative and executive branches	Annual, at national level
2	Percentage of health services (PHC and neurology) with epilepsy case registries	<p>Percentage:</p> <ul style="list-style-type: none"> <li>– Numerator (A): number of health services (PHC and neurology) with epilepsy case registries</li> <li>– Denominator (B): total number of health services (PHC and neurology)</li> <li>– Rate (%) = <math>A/B \times 100</math></li> </ul>	Reports from territorial health offices	Annual
3	Number of cases of epilepsy recorded in the health services (PHC and neurology), disaggregated by sex, age group, and origin <sup>i</sup>	<p>Absolute numbers:</p> <ul style="list-style-type: none"> <li>– number of epilepsy cases recorded in the health services (PHC and neurology), disaggregated by sex, age group, and origin</li> </ul>	Records from health services (PHC and neurology) that have implemented a census of epilepsy cases	Monthly/Annual
4	Ratio of epilepsy consultations in ambulatory neurological services, per 100,000 population <sup>ii</sup> (by sex, age, and origin)	<p>Ratio per 100,000 population:</p> <ul style="list-style-type: none"> <li>– Numerator (A): number of epilepsy consultations recorded in ambulatory neurological services</li> <li>– Denominator (B): general population</li> <li>– Ratio = <math>A/B \times 100,000</math></li> </ul>	Outpatient consultation records	Annual
5	Rate of epilepsy consultations in PHC services, per 100,000 population <sup>iii</sup> (by sex, age, and origin)	<p>Ratio per 100,000 population:</p> <ul style="list-style-type: none"> <li>– Numerator (A): number of epilepsy consultations recorded in PHC services (as primary diagnosis)</li> <li>– Denominator (B): general population</li> <li>– Rate = <math>A/B \times 100,000</math></li> </ul>	Outpatient consultation records	Annual
6	Number/ percentage of epilepsy cases referred from PHC to specialists (neurology service)	<p>Percentage:</p> <ul style="list-style-type: none"> <li>– Numerator (A): number of cases with epilepsy referred from PHC to neurology services</li> <li>– Denominator (B): total number of epilepsy cases seen in PHC</li> <li>– Rate (%) = <math>A/B \times 100</math></li> </ul>	<p>Outpatient consultation records</p> <p>Local referral records</p>	Monthly/Annual

<sup>i</sup> If the country has a reliable case registry, it can be used to estimate the prevalence of cases, based on satisfied demand and other criteria.

<sup>ii</sup> Most countries record care given and contacts, but not cases (a case can have several contacts during a year). It is not realistic to assume that a case registry can be established in the short term; for this reason the indicator can be estimated on the basis of recorded contacts. Nevertheless, switching to “cases” in the medium term is something that should be discussed, and the viability of doing so in the country needs to be studied.

<sup>iii</sup> As with the previous indicator, many countries record care given and contacts, but not cases (a case can have several contacts during a year). A major limitation is that records of PHC consultations often fail to indicate the diagnosis, which makes it difficult to identify care given to people with epilepsy.

7	Percentage of people with epilepsy attended in PHC	<p>Percentage:</p> <ul style="list-style-type: none"> <li>- Numerator (A): number of epilepsy cases attended in PHC</li> <li>- Denominator (B): total number of cases attended in PHC</li> <li>- Rate (%) = <math>A/B \times 100</math></li> </ul>	Outpatient consultation records	Annual
8	Percentage of people with epilepsy who receive the required AEDs (in PHC or neurology service)	<p>Percentage:</p> <ul style="list-style-type: none"> <li>- Numerator (A): number of epilepsy cases that receive the required AEDs</li> <li>- Denominator (B): total number of recorded epilepsy cases</li> <li>- Rate (%) = <math>A/B \times 100</math></li> </ul>	Outpatient consultation records Clinical files	Monthly/Annual
9	Percentage of people with epilepsy attended by a neurologist within 15 days of the date of referral	<p>Percentage:</p> <ul style="list-style-type: none"> <li>- Numerator (A): number of people with epilepsy attended by a neurologist within 15 days of the date of referral</li> <li>- Denominator (B): total number people with epilepsy referred to a neurologist</li> <li>- Rate (%) = <math>A/B \times 100</math></li> </ul>	Consultation records from neurology services Clinical files	Monthly, in neurology services
10	Percentage of people with epilepsy whose seizures are controlled in emergency services in less than 30 minutes	<p>Percentage:</p> <ul style="list-style-type: none"> <li>- Numerator (A): number of people with epilepsy whose seizures are controlled in emergency services in less than 30 minutes</li> <li>- Denominator (B): total number of people with epileptic seizures attended in emergency services</li> <li>- Rate (%) = <math>A/B \times 100</math></li> </ul>	Records from emergency services Clinical files	Monthly, in general and pediatric hospitals
11	Percentage of people with epilepsy who receive a brain MRI and a report within 30 days of making a request	<p>Percentage:</p> <ul style="list-style-type: none"> <li>- Numerator (A): number of epilepsy cases with MRI completed and reported within 30 days of the user requesting the service</li> <li>- Denominator (B): total number of epilepsy cases with a completed MRI</li> <li>- Rate (%) = <math>A/B \times 100</math></li> </ul>	Records from neuro-radiology services	Monthly, in neuro-radiology services



12	Percentage of minors with epilepsy for whom KD is indicated and implemented	<p>Percentage:</p> <ul style="list-style-type: none"> <li>– Numerator (A): number of minors with epilepsy for whom KD is indicated and who are under a nutritionist's supervision</li> <li>– Denominator (B): total number of minors with epilepsy for whom KD is indicated</li> <li>– Rate (%) = <math>A/B \times 100</math></li> </ul>	Records from nutrition and neurology services	Monthly, in nutrition and neurology services
13	Percentage of epilepsy cases with pre-surgical evaluation requested and completed within 6 months	<p>Percentage:</p> <ul style="list-style-type: none"> <li>– Numerator (A): number of epilepsy cases with pre-surgical evaluation requested and completed within 6 months</li> <li>– Denominator (B): total number of epilepsy cases with pre-surgical evaluation completed</li> <li>– Rate (%) = <math>A/B \times 100</math></li> </ul>	Hospital records	Monthly, in hospitals with epilepsy surgery service
14	Number of cases that received epilepsy surgery, disaggregated by sex, age group, origin, and service that carried out the intervention	<p>Absolute numbers:</p> <ul style="list-style-type: none"> <li>– Number of cases that received epilepsy surgery, disaggregated by sex, age group, and origin and service that carried out the intervention</li> </ul>	Hospital surgery records	Monthly, in hospitals with epilepsy surgery service
15	Neurologists per 100,000 population	<p>Ratio per 100,000 population:</p> <ul style="list-style-type: none"> <li>– Numerator (A): number of neurologists</li> <li>– Denominator (B): general population</li> <li>– Ratio = <math>A/B \times 100,000</math></li> </ul>	Human resources records	Annual
16	Percentage of PHC physicians trained in epilepsy, who meet the established requirements <sup>iv</sup>	<p>Percentage:</p> <ul style="list-style-type: none"> <li>– Numerator (A): number of PHC physicians with certified epilepsy training</li> <li>– Denominator (B): total number of physicians who work in PHC</li> <li>– Rate (%) = <math>A/B \times 100</math></li> </ul>	Continuing education records Human resources records	Annual
17	Mortality from epilepsy, per 100,000 population	<p>Ratio per 100,000 population</p> <ul style="list-style-type: none"> <li>– Numerator (A): number of deaths from epilepsy</li> <li>– Denominator (B): general population</li> <li>– Index = <math>A/B \times 100,000</math></li> </ul>	Death records	Annual

<sup>iv</sup> It is necessary to define, in each country, what constitutes basic training in epilepsy at the PHC level (e.g. based on mhGAP, with a support and monitoring program). PHC physicians should meet basic training standards for certification. The ministry of health should regularly monitor and report data on the number of PHC physicians who have been trained.



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