



Strategy and plan of action



on
epilepsy



**Pan American
Health
Organization**



Regional Office of the
World Health Organization

Strategy and Plan of Action on Epilepsy



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Strategy and Plan of Action on Epilepsy

Introduction

1. Epilepsy is one of the world's most common chronic neurological disorders. Roughly 50 million people suffer from it, 5 million of them in the Region of the Americas (1-5). Nevertheless, it is estimated that over 50% of these people in Latin America and the Caribbean have no access to services (2, 6-9). Furthermore, the stigma attached to people with epilepsy is a barrier to the exercise of their human rights and social integration (1-2, 10-11).
2. It is important to note that scientific advances have improved the understanding and management of epilepsy. This fact, combined with political will, makes this the right time for the Pan American Health Organization (PAHO) and its Member States to make this important public health problem a priority.
3. This document includes the input received from a consultative process in which the International League against Epilepsy (ILAE), the International Bureau for Epilepsy (IBE), the ministries of health, and other national organizations, the Department of Mental Health and Substance Abuse of the World Health Organization (WHO), PAHO technical programs, and as a group of experts participated.

Background

4. Various PAHO and WHO program documents and resolutions serve as the background and underpinnings for this strategy and plan of action.
5. The Global Campaign against Epilepsy: Out of the Shadows (10) was officially launched in 1997 in Geneva, Switzerland, through an agreement among WHO, the ILAE, and the IBE. In 2000, the Declaration of Santiago on Epilepsy in Latin America was adopted in Chile (12). In 2005, a declaration on this subject was also issued in the United States. In 2008, with support from the ILAE and the IBE, PAHO published the report *Informe sobre la Epilepsia en Latinoamérica* [Report on Epilepsy in Latin America] (2).
6. The countries of the Region adopted the Health Agenda for the Americas 2008-2017 (13). The 48th Directing Council of PAHO (2008) approved the Strategic Plan 2008-2012 (14), in which Strategic Objective 3 focuses on chronic noncommunicable diseases.

7. The Directing Council of PAHO has approved technical documents and adopted resolutions in different years on issues related to epilepsy. These include: (a) Disability: Prevention and Rehabilitation in the Context of the Right to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health and Other Related Rights (2006) (15); (b) Strategy and Plan of Action on Mental Health (2009) (16); and (c) Health and Human Rights (2010) (17).
8. In 2008, WHO officially launched the Mental Health Gap Action Program (mhGAP) (18), which recognized epilepsy as one of the eight priority conditions. In 2010 it published the mhGAP Intervention Guide for Mental, Neurological and Substance Use Disorders in Non-specialized Health Settings (mhGAP-IG), disorders that include epilepsy (19).

Situation Analysis

9. Diagnosing epilepsy is essentially a clinical process that can be performed in nonspecialized health settings by taking a good clinical history and performing an examination; an international classification is available that facilitates diagnosis (20, 21). Epilepsy may be caused by genetic, structural, metabolic, or unknown factors (21). Among the structural factors, the most common causes in Latin America and the Caribbean are infectious and parasitic diseases (especially, neurocysticercosis), perinatal brain damage, vascular diseases, and head trauma, all of which are preventable (1-3).
10. 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 (22, 23).
11. The prognosis in cases of epilepsy depends on the etiology of the illness, as well as early and sustained treatment. It is estimated that up to 70% of people with epilepsy can live normal lives if they receive proper care (1).

Burden, Prevalence, and Mortality

12. Epilepsy accounts for 0.5% of the global burden of disease, measured in disability-adjusted life years (DALYs), with 80% of that burden corresponding to the developing countries (1). This disorder accounts for 0.7% of the regional burden of disease; the distribution by sex does not yield significant differences, and the highest burden, 2.8%, is found in the 5-14 age group. At 0.4%, the United States and Canada have a lower burden than Latin America and the Caribbean, where the figure is 0.9%.
13. The global epilepsy incidence, prevalence, and mortality indexes are not uniform and are dependent on several factors (1). According to a series of 32 community-based studies, the lifelong prevalence in Latin America and the Caribbean stands at an average of 17.8 per 1,000 population (range: 6-43.2). There were no significant differences by sex or age group (24).
14. Mortality rates among people with epilepsy are higher than for the general population. The estimated annual global mortality rate ranges from 1 to 8 per 100,000 population (1, 2). A regional mortality study that ran from 1999 to 2007 found an annual average of 7,179 deaths from epilepsy (as the primary cause), a rate of 0.8 per 100,000 population, with a higher index in men (1.0) than women (0.60). In the groups aged 20-59 and over 60, the highest rates of 1.0 and 1.2, respectively, are reported. The mortality index in Latin America and the Caribbean is 1.1, higher than that of the United States and Canada, which is 0.4 (25). It is believed that there is significant underreporting in some countries.

15. A recent study of the treatment gap yielded a figure of 75% in low-income countries and over 50% in the majority of middle-income countries (6-8).

Role of Auxiliary Diagnostic Tools

16. The electroencephalogram (EEG) is a useful tool for the diagnosis and classification of epileptic syndromes. Access to the EEG is limited in many countries, and electroencephalographic video monitoring is available at only a few specialized centers (2).
17. Computerized axial tomography (CAT) remains a useful tool, owing given its low cost and ability to detect obvious lesions such as the calcifications from neurocysticercosis (26). Magnetic resonance imaging (MRI) of the brain is recommended as the technique of choice for identifying the most common etiologies in epilepsy (27). However, neuroimaging equipment in Latin America and the Caribbean is rare and is usually concentrated in the private sector, in addition to being unaffordable to the majority of the population (2).

Treatment and Rehabilitation

18. The majority of countries in Latin America and the Caribbean have the four basic drugs in their arsenal (phenobarbital, phenytoin, carbamazepine, and valproic acid), but only at the secondary and tertiary levels of care. Ensuring the supply of these four antiepileptics is essential, when we consider that seizures can be controlled with monotherapy regimens in up to 70% of cases. In 1990, WHO determined that the average cost of medication (with phenobarbital) could be as low as US\$ 5 per patient per year (1).
19. Public services in most Latin American and Caribbean countries do not have new generation antiepileptics, which are useful in intractable cases but are more expensive. Measurement of drug-plasma concentrations is not performed on a regular basis, even though it is a useful procedure (2, 28).
20. Surgical intervention for epilepsy is an effective treatment and is recommended in some cases that cannot be controlled with drugs; surgical interventions may reach some 10% of the total (1, 29).
21. In the integrated management of people with epilepsy, consideration of psychosocial factors is essential and includes education for self-management; that is, the measures and behaviors that people with epilepsy should adopt and maintain to control their illness (30). In some cases, complementary measures can also be helpful; these include, for example, the use of natural products, vitamins, relaxation techniques, a healthy diet, religious or cultural activities, and social support; such measures are acceptable as long as the patient continues the basic drug therapy (31).
22. The objective of rehabilitation is to improve the quality of life of people with epilepsy and integrate them into society and the work environment. The interventions that are selected will depend on the complexity of the cases; most people with epilepsy enjoy a substantial degree of autonomy and only a minority suffers from serious forms. This group includes persons with disabilities and people who are institutionalized or highly dependent on their families; here, it is essential to develop patients' social and occupational skills (2).

Programs and Services

23. The available data show that only 34% of countries in Latin America and the Caribbean reported having national epilepsy programs. (2). Some of the key problems in delivering services to people with this disorder are the limitations on diagnosis, management, and monitoring in primary health care. Many countries lack intervention protocols, or those that they do have are not up-to-date (2).

24. In the majority countries in Latin America and the Caribbean, the secondary--or specialized--level of care has serious limitations and is sometimes nonexistent. There is little or no linkage between primary health care and the neurology services (2).
25. The average number of neurologists per 100,000 population in the Region of the Americas is 0.3 (higher than the global average of 0.18) (3). The number varies from country to country, with a very high concentration in the capitals and major cities (2). Some 76% of countries in the Hemisphere report the existence of associations of neurologists and other professionals working in the field of epilepsy (3).
26. Some 92% of countries report having EEG and electroencephalographic video monitoring equipment. However, this does not necessarily mean that they can offer full coverage to the population (2, 3).
27. There is a high proportion of psychiatric comorbidity with epilepsy that often goes unrecognized and is therefore not treated properly; mental disorders are seen in some 25% 50% of people with epilepsy, with a higher prevalence in patients with poor control of epileptic crises (32-33). These disorders include depression, anxiety, and psychosis, as well as cognitive and personality changes. Epilepsy cases associated with psychosis or dementia are often confined to psychiatric hospitals or social welfare institutions.
28. Relations with traditional health care systems, especially in rural areas and indigenous communities, are weak. In certain populations, for cultural and other reasons people with epilepsy are still taken primarily to traditional healers.

Human Rights of People with Epilepsy¹

29. The exercise of human rights is fundamental for people with epilepsy, especially those with some degree of disability. The barriers can be related to access to health services, restrictions on personal freedom, lack of job opportunities, exclusion from educational systems, legal constraints to exercising particular rights, and inadequate living conditions in some psychiatric institutions (17).
30. The human rights violations range from the most obvious to the most subtle--for example, not being able to obtain a driver's license or restrictions on the ability to choose where they work. Sometimes it is not a matter of having the legal instruments but of enforcing them.

1 We suggest consulting:

Pan American Health Organization. Strategy and Plan of Action on Mental Health. 49th Directing Council of PAHO, 61st Session of the WHO Regional Committee for the Americas, 28 September 2 October 2009, Washington, D.C., USA. Washington, D.C.: PAHO 2009 (Document CD49/11 and Resolution CD49.R17) [cited 2011 Feb. 23]. Available at:

<http://new.paho.org/hq/dmdocuments/2009/CD49-11-e.pdf>.

[http://new.paho.org/hq/dmdocuments/2009/CD49.R17%20\(Eng\).pdf](http://new.paho.org/hq/dmdocuments/2009/CD49.R17%20(Eng).pdf).

Pan American Health Organization. Health and Human Rights. 50th Directing Council of PAHO, 62nd Session of the WHO Regional Committee for the Americas; 27 September-1 October 2010; Washington, D.C., USA. Washington, D.C.: PAHO; 2010 (Document CD50/12, Concept Paper, and Resolution CD50.R8) [cited 2011 Feb. 23]. Both available at:

http://new.paho.org/hq/index.php?option=com_docman&task=doc_download&gid=7979&Itemid=.

http://new.paho.org/hq/index.php?option=com_docman&task=doc_download&gid=8954&Itemid=.

Proposal

31. The Strategy and Plan of Action 2012-2021 are based on a general vision of the Americas with respect to epilepsy; however, there are major differences among countries and even within a single country. This document describes the experiences in our Hemisphere, expresses the commitment of the governments, and is compatible with the Global Action Program (mhGAP).
32. A gender, ethnicity, and cultural diversity approach, as well as a primary health care, health promotion, human rights, and social protection approach are cross-cutting lines of all the strategic areas. Priority will be given to care for vulnerable groups or those with special needs.
33. In order to support this Strategy and Plan of Action, PAHO will collaborate with the ILAE, the IBE, and other partners; set priorities; mobilize resources; and encourage cooperation among countries.
34. Principles and values: (a) universal access; (b) equity; (c) Pan American solidarity; (d) respect for the human rights of people with epilepsy; (e) social participation; (f) use of the best available scientific evidence; (g) protection of vulnerable groups; (h) respect for the historical and cultural frameworks of communities; (i) comprehensive health care; and (j) responsibility and accountability.
35. Vision: PAHO is at the forefront of cooperation efforts to assist the Member States in ensuring optimal health for the entire population of the Americas and promote the well-being of families and communities.
36. Purpose: Strengthen the integrated response of the health sector through appropriate lifelong treatment programs for people with epilepsy that include prevention, treatment, and rehabilitation activities.

Strategic Areas, Indicators, Objectives, and Activities

Strategic Area 1: Programs and legislation for the care of people with epilepsy and protection of their human rights.

Indicators

- Number of countries with a national epilepsy plan in place. (Baseline in 2010: 10. Target: 20 by 2015 and 30 by 2020.)
- Number of countries that have modified/amended and updated the legislative framework for epilepsy to bring it into line with international human rights standards. (Baseline in 2012²: Target: 10 by 2015 and 25 by 2020.)
- Instrument and Methodology for comprehensive evaluation of national epilepsy programs and services developed and published.³ (Baseline in 2010: 0. Target: 1 by 2012 and 1 revised by 2020.)

² Baseline under construction.

³ The instrument/methodology for evaluating national epilepsy programs will include the following components, inter alia: (a) intersectoral coordination mechanisms; (b) organization and development of epilepsy treatment services, from PHC up to the specialized level; (c) package of essential interventions for persons with epilepsy in PHC; (d) availability of epilepsy drugs in PHC; (e) psychosocial rehabilitation; (f) promotion and prevention component as part of epilepsy treatment plans; (g) actions to fight stigma; (h) regular collection and analysis of basic data on epilepsy (with a breakdown by at least sex and age) in the health information system; (i) human resources development; and (j) financing.

- Number of countries that have evaluated their national epilepsy program and/or services.⁴ (Baseline in 2010: 0. Target: 25 by 2013-2014 and 30 reevaluated/evaluated by 2019-2020.)

Objective 1.1: Have national epilepsy programs in place.

Regional activities

- 1.1.1 Provide technical cooperation to the countries to design, reformulate, strengthen, and implement national epilepsy programs.

National activities

- 1.1.2 Formulate or review the national epilepsy program and implement it, giving particular attention to the most vulnerable groups with special needs.

Objective 1.2: Bring national legislation on epilepsy into line with international human rights norms and standards.

Regional activities

- 1.2.1 Provide technical cooperation to the countries to review and update the legislative framework and current legal regulations pertaining to epilepsy.

National activities

- 1.2.2 Promote—with government agencies, legislative bodies, and civil society—the review and enforcement of the current legislative framework pertaining to epilepsy.
- 1.2.3 Review and institute the pertinent measures governing the procedures applicable to people with epilepsy, especially those with psychosis, dementia, or disability, who are subjected to long-term confinement in psychiatric hospitals, social welfare institutions, and penitentiaries, situations that could constitute human rights violations (such as involuntary commitment, physical restraint, isolation, and substandard institutional conditions).
- 1.2.4 Systematically forge ties with the courts and human right agencies to enforce the law.

Objective 1.3: Have the financial and human resources necessary for the execution of national epilepsy programs.

Regional activities

- 1.3.1 Cooperate with the countries to assess program financing and the cost of epilepsy treatment services.

⁴ This will make it possible to improve and increase the baseline, as well as the indicators to be measured.

National activities

- 1.3.2 Review the cost and financing of the epilepsy program and respective services, as well as the structure of the expenditure, defining short-, medium-, and long term goals for funding service delivery, with emphasis on primary care.
- 1.3.3 Identify potential sources of financing and donors and request funding.

Objective 1.4: Create and strengthen health sector partnerships with other key sectors and actors, including the private sector.

Regional activities

- 1.4.1 Cooperate with the countries to strengthen the formation of national networks.
- 1.4.2 Support associations of people with epilepsy and their families, facilitating information-sharing among countries and dissemination of the lessons learned.
- 1.4.3 Strengthen partnerships with international institutions and other regional partners.

National activities

- 1.4.4 Create an intersectoral coordinating body.
- 1.4.5 Promote social participation as part of the formulation, execution, and evaluation of the epilepsy program.
- 1.4.6 Provide public sector support for organizations of users and families and actively involve them in epilepsy programs.

Strategic Area 2: Health services network for the treatment of people with epilepsy, with emphasis on primary health care and the provision of drugs.

Indicators

- Regional epilepsy mortality rate (per 100,000 population). (Baseline in 2010: 0.8. Target:< 0.8.)
- Percentage of people with epilepsy who are not treated. (Baseline in 2009: an estimated 60%. Target: 30% by 2020.)
- Preparation and publication of a regional epilepsy training module (guides), based on the competencies required to meet the needs, targeting primary care workers.⁵ (Baseline in 2010: 1 (mhGAP-IG). Target: 1 adapted to the regional level by 2013 and 1 revised by 2020.)

Objective 2.1: Provide a package of essential interventions for people with epilepsy in primary health care, ensuring access to basic medications and education for self management.

Regional activities

- 2.1.1 Collaborate with the countries in organizing the delivery of service to people with epilepsy, with emphasis on boosting the response capacity in primary health care.

⁵ The mhGAP Intervention Guide for mental, neurological, and substance use disorders in non-specialized health settings (mhGAP-IG) is a global tool that is currently available but will need to be adapted to the regional level.

- 2.1.2 Collaborate with the countries to guarantee the supply and availability of antiepileptics in primary health care, studying alternatives such as the Strategic Fund.

National activities

- 2.1.3 Organize health service delivery to people with epilepsy, with emphasis on: (a) decentralizing neurology services; (b) improving effectiveness in primary health care; (c) examining coverage and equity in access to services; (d) integrating services with local and community support networks; and e) evaluating and surmounting administrative barriers to interventions.
- 2.1.4 Prepare and apply guides or protocols for essential epilepsy interventions in primary health care. The WHO package of interventions (mhGAP) (19) can be adapted to local conditions and will take life cycle, sex, and sociocultural and ethnic characteristics of the populations into consideration. It should also include education for self-management as a key component; this will improve adherence to medication regimes and the adoption of healthy behaviors to ensure positive outcomes.
- 2.1.5 Add antiepileptics to the national list of essential drugs and guarantee their availability in primary health care.
- 2.1.6 Improve the mechanisms for monitoring people with epilepsy, as well as the referral and counter-referral systems.
- 2.1.7 Promote community participation, increasing the population's acceptance and use of the services.
- 2.1.8 Develop relations with traditional or community care systems.
- 2.1.9 Promote intersectoral efforts in the execution of interventions.

Objective 2.2: Organize the network of neurology and mental health services for people with epilepsy at the secondary and tertiary levels.

Regional activities

- 2.2.1 Form a regional group of experts to advise countries on the organization of secondary and tertiary care.

National activities

- 2.2.2 Create or reorganize neurology services in the country to decentralize them and their human resources.
- 2.2.3 Take steps to ensure that mental health services are prepared to treat people with epilepsy, in terms of comorbidity and facilitating diagnosis and basic treatment (16).
- 2.2.4 Promote the creation of crisis intervention units in general hospitals and the development of partial hospitalization modalities, to strengthen the link between these types of services and primary health care.
- 2.2.5 Establish agreements between the health authorities and universities to elicit the support of neurology residents for public health services.
- 2.2.6 Create at least one basic epilepsy surgery center, in keeping with the available resources and population of the country.

- 2.2.7 Develop plans for the education of specialized human resources and their placement in the health system over the next 10 years.
- 2.2.8 Determine the availability of auxiliary diagnostic tools for epilepsy (EEG, CAT, and MRI) and program their better distribution in the health system, along with new acquisitions over a 10-year period.

Objective 2.3: Establish a rehabilitation program for people with epilepsy.

Regional activities

- 2.3.1 Cooperate with the countries in the implementation of rehabilitation activities for people with epilepsy, adopting a multisectoral human rights approach.

National activities

- 2.3.2 Formulate and execute a community-based rehabilitation program with a human rights approach and the support of other sectors (for example, housing, labor, social protection, finance, justice, among others), shifting the focus of rehabilitation from an institutional setting to a real life context.
- 2.3.3 Assess the population of people with epilepsy who have been confined for lengthy periods in hospitals and social welfare institutions in order to develop individualized rehabilitation plans suited to their clinical status and social situation.
- 2.3.4 Guarantee psychopedagogical and family care for children with epilepsy and learning disabilities.

Objective 2.4: Provide training for primary health care workers to improve their epilepsy diagnosis and management skills.

Regional activities

- 2.4.1 Cooperate with the countries in the development and execution of epilepsy training processes, especially for primary care personnel.
- 2.4.2 Create a regional working group for the design of a regional training model on epilepsy with support from the ILAE, IBE, and academic institutions.
- 2.4.3 Provide support for meeting regional and subregional educational needs through virtual courses or distance learning.
- 2.4.4 Review and reach a consensus on the basic principles that should govern current neurology graduate programs in the countries of the Region.

National activities

- 2.4.5 Develop training programs that support and consider integration and appropriate coordination between services and local support systems.
- 2.4.6 Create an up-to-date database of human resources in the field of neurology.

- 2.4.7 Execute training plans for primary health care workers both before they join the neurology service and while they are working there.
- 2.4.8 Develop expanded training plans that include informal service providers, community health workers, and workers from other sectors.
- 2.4.9 Collaborate with universities and teaching institutions specializing in health to foster the inclusion and improvement of epilepsy curriculum contents.

Strategic Area 3: Education and sensitization of the population, including the people with epilepsy and their families.

Indicator

- Preparation and publication of regional guides for the design and implementation of epilepsy prevention activities in the countries. (Baseline in 2010: 0. Target: 1 by 2013 and revised in 2020.)

Objective 3.1: Improve knowledge about epilepsy among the population and people with the disorder and their families, and heighten community support.

Regional activities

- 3.1.1 Cooperate with the countries in the implementation of epilepsy education and awareness programs for the population.
- 3.1.2 Prepare a work model and educational materials that can be used/adapted by the countries.

National activities

- 3.1.3 Develop and implement an epilepsy education program for communities and families, with special emphasis on the instructors.
- 3.1.4 Work systematically with the media.
- 3.1.5 Promote the formation and development of psychoeducational groups, supported by health personnel or using the self-help and mutual support modality.
- 3.1.6 Seek intersectoral, interinstitutional cooperation from the health sector, including associations of users and family members.

Objective 3.2: Include a health promotion and epilepsy prevention component in national epilepsy programs.

Regional activities

- 3.2.1 Cooperate with the countries to include concrete health promotion and disease prevention measures in national epilepsy programs.

National activities

- 3.2.2 Include a section on health promotion in the epilepsy program that is linked with the national health promotion plan.
- 3.2.3 Adopt measures to prevent the most common causes of epilepsy; these measures should be implemented jointly or primarily by other programs or entities.

Objective 3.3: Reduce the stigma, discrimination, and social isolation surrounding people with epilepsy.

Regional activities

- 3.3.1 Prepare a work model and educational materials that can be used or adapted by the countries to wage campaigns against the stigma, discrimination, and social isolation of people with epilepsy.

National activities

- 3.3.2 Formulate and execute a regular, systematic campaign to combat the stigmatization of people with epilepsy and discrimination against them.

Strategic Area 4: Strengthening of the ability to produce, assess, and use information on epilepsy.

Indicators

- Publication of a regional methodological document for the development of epilepsy indicators, prepared through a consultative process with the participation of a group of experts. (Baseline in 2010: 0. Target: 1 by 2014.)
- Regional report on epilepsy concluded and published (includes data on morbidity and mortality, burden, programs, services, and resources). (Baseline in 2010: 1 from 2008. Target: 1 by 2015 and 1 by 2020.)
- Publication of a collection of epidemiological research on epilepsy in Latin America and the Caribbean. (Baseline in 2010: 0. Target: 1 by 2015 and 1 by 2020.)

Objective 4.1: Improve National Information Systems, ensuring the regular collection and analysis of basic data on epilepsy.

Regional activities

- 4.1.1 Provide technical cooperation to the countries to introduce and improve epilepsy data in national health information systems.
- 4.1.2 Create a group of experts and carry out a regional consultation to prepare and recommend indicators for practical use in countries.
- 4.1.3 Prepare and disseminate subregional and regional reports.

National activities

- 4.1.4 Strengthen systems for the recording, monitoring, and processing of epilepsy data (including mortality); ensuring that records consider at least sex and age.
- 4.1.5 Create local case registries.
- 4.1.6 Identify epilepsy indicators, providing for periodic analysis of the available information.
- 4.1.7 Monitor the quality of care.
- 4.1.8 Prepare and disseminate annual epilepsy reports.

Objective 4.2: Improve epilepsy research based on each country's needs and the available resources.

Regional activities

- 4.2.1 Set priorities for epilepsy research.
- 4.2.2 Support multicenter epilepsy studies in collaboration with the ILAE, the IBE, and other institutions working in this field.
- 4.2.3 Prepare and disseminate subregional and regional reports on the most important studies and research in the field of epilepsy.

National activities

- 4.2.4 Compile, analyze, and disseminate the results of epidemiologic studies and other existing epilepsy research in the country.
- 4.2.5 Improve research and cooperation among institutions and decide what new national research will be given priority to ensure that such studies address the needs of the population.
- 4.2.6 Encourage and support community-based studies that not only indicate the incidence and prevalence of the disease, but also assess comorbidity and other demographic and socioeconomic conditions, as well as risk factors, costs, the impact of the interventions, among others.

Common regional activities for all strategic areas

- (a) Compile, evaluate, and disseminate information on innovative experiences and lessons learned.
- (b) Prepare and disseminate the best available scientific information that supports the design and execution of the national epilepsy programs.
- (c) Promote projects for technical cooperation among countries.
- (d) Design and execute regional pilot or demonstration projects, when advisable.
- (e) Support countries in the mobilization of resources.

Monitoring, Assessment, and Evaluation

37. This plan of action contributes to the achievement of Strategic Objectives 3⁶ of the PAHO Strategic Plan. The region-wide expected results to which this Plan contributes are detailed in Annex B. The monitoring and evaluation of this Plan are in alignment with the Organization's results-based management framework, as well as its performance monitoring and evaluation processes. In this regard, progress reports will be issued based on the information available at the end of each biennium.o.
38. The sources of the necessary information are: (a) PAHO/WHO mortality database; (b) country reports requested from the ministries of health; (c) reports of the Regional Mental Health Project; and (d) compilations of research.
39. During the last year of the Plan, an evaluation will be conducted for the purpose of identifying the strengths and weaknesses in its overall execution, as well as the causative factors in its successes and failures, along with future actions. As part of the evaluation processes, it is suggested that the standardized epidemiologic surveillance and study methods recommended by the ILAE be introduced (34).

Action by the Directing Council

40. The Directing Council is requested to consider epilepsy a priority and support the strengthening of the health sector response to this problem, with special emphasis on primary health care; to review the information provided in this document; and to explore the possibility of adopting the proposed resolution presented in Annex A.

6 SO 3: To prevent and reduce disease, disability and premature death from chronic non-communicable conditions, mental disorders, violence and injuries.

References

1. World Health Organization. Neurological Disorders: Public Health Challenges [Internet]. Geneva, Switzerland: WHO; 2006 [accessed 16 Feb. 2011]. Available at: http://www.who.int/mental_health/neurology/neurodiso/en/index.html.
2. Pan American Health Organization/World Health Organization–Liga Internacional Contra la Epilepsia–Buró Internacional para la Epilepsia. Informe sobre la Epilepsia en Latinoamérica [Internet]. Washington (DC), US. Washington (DC): OPS; 2008 [accessed 16 Feb. 2011]. Available at: <http://www.infocom-ca.org.pa/files/Informe%20epilepsia.pdf>.
3. World Health Organization–International League against Epilepsy–International Bureau for Epilepsy. Atlas: Epilepsy Care in the World 2005 [Internet]. Geneva, (Switzerland). WHO; 2005 [accessed 16 Feb. 2011]. Available at: http://www.who.int/mental_health/neurology/Epilepsy_atlas_r1.pdf.
4. Theodore W H, Spencer S S, Wiebe S, et al. Epilepsy in North America: A report prepared under the auspices of the Global Campaign against Epilepsy, the International Bureau for Epilepsy, and the World health Organization [Internet]. ILAE. *Epilepsia* 2006 Oct;47(10):1700-1772 [accessed 16 Feb. 2011]. Available at: <http://www.ilae-epilepsy.org/Visitors/Chapters/documents/usa.pdf>.
5. Epilepsy Foundation. About Epilepsy and Seizures [Internet]. Landover (MD) US: Epilepsy Foundation [accessed 16 Feb. 2011]. Available at: www.epilepsyfoundation.org/about/statistics.cfm.
6. Meyer A-C, Dua T, Ma J, Saxena S, Birbeck G. Global Disparities in the epilepsy treatment gap: a systematic review [Internet]. *Bull World Health Organ.* 2010; 88:260-266 [accessed 16 Feb. 2011]. Available at: <http://www.scielosp.org/pdf/bwho/v88n4/a11v88n4.pdf>.
7. Andrade-Noronha A L., Marques L H., Borges M A, Cendes F, Mantovani-Guerreiro C., Li L.M. Assessment of the Epilepsy treatment Gap in two cities of South-East of Brazil [Internet]. *Arq Neuropsiquiatr* 2004;62(3-B):761-763 [accessed 23 Feb. 2011]. Available at: <http://www.scielo.br/pdf/anp/v62n3b/a03v623b.pdf>
<http://www.ncbi.nlm.nih.gov/pubmed/15476064>.
8. Medina M T, Duron R M, Martinez L, Osorio J R, Estrada A L, Zúniga C, Cartagena D, Collins J S, Holden K R. Prevalence, Incidence, and Etiology of Epilepsies in Rural Honduras: The Salama Study [Internet]. *Epilepsia* 2005;46(1):124-131 [accessed 16 Feb. 2011]. Available at: <http://onlinelibrary.wiley.com/doi/10.1111/j.0013-9580.2005.11704.x/abstract?systemMessage=Wiley+Online+Library+will+be+disrupted+2nd+Apr+from+10-12+BST+for+monthly+maintenance>
<http://www.ncbi.nlm.nih.gov/pubmed/15660778>.
9. Mbuba CK, Ngugi AK, Newton CR, Carter JA. The epilepsy treatment gap in developing countries: a systematic review of the magnitude, causes, and intervention strategies [Internet]. *Epilepsia.* 2008 Sep;49(9):1491-503. Epub 2008 Jun 13 [accessed 23 Feb. 2011]. Available at: <http://onlinelibrary.wiley.com/doi/10.1111/j.1528-1167.2008.01693.x/pdf>
<http://www.ncbi.nlm.nih.gov/pubmed/18557778>.
10. World Health Organization–International League against Epilepsy–International Bureau for Epilepsy. Epilepsy: Out of the Shadows [Internet]. The Netherlands: ILAE/IBE/WHO; 2003 [accessed 16 Feb. 2011]. Available at: http://www.who.int/mental_health/management/en/GcaeBroEn.pdf.
11. De Boer HM. Seizure. Epilepsy stigma: moving from a global problem to global solutions [Internet]. 2010 Dec;19 (10):630-6. Epub 2010 Nov 13 [accessed 23 Feb. 2011]. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/21075013>.

12. Liga Internacional Contra la Epilepsia/Buró Internacional para la Epilepsia. Declaración Latinoamericana sobre Epilepsia [Internet]. Santiago, Chile: ILAE/IBE; 2000 [accessed 25 Feb. 2011]. Available at: http://www.globalcampaignagainstepilepsy.org/files/latin_american_declaration_epilepsy_spanish.pdf.
13. Pan American Health Organization. Health Agenda for the Americas 2008 2017 [Internet]. Washington (DC): US. PAHO; 2007(presented by the ministers of health of the Americas in Panama City) [accessed 16 Feb. 2011]. Available at: http://www.paho.org/English/DD/PIN/Health_Agenda.pdf.
14. Pan American Health Organization. Strategic Plan 2008-2012 [Internet]. Washington (DC) US. Washington (DC): PAHO; 2008 (Official Document No. 328). [accessed 16 Feb. 2011]. Available at: <http://new.paho.org/hq/dmdocuments/2009/OD-328%20complete%20document.pdf>.
15. Pan American Health Organization. Disability: Prevention and Rehabilitation in the Context of the Right to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health and Other Related Rights [Internet]. 47th Directing Council of PAHO, 58th Session of the WHO Regional Committee for the Americas; 25-29 September 2006; Washington (DC), US. Washington (DC): PAHO; 2006 (Document CD47/15 and Resolution CD47.R1) [accessed 16 Feb. 2011]. Available at: <http://www.paho.org/english/gov/cd/CD47-15-e.pdf> ;
<http://www.paho.org/english/gov/cd/CD47.r1-e.pdf>.
16. Pan American Health Organization. Strategy and Plan of Action on Mental Health [Internet]. 49th Directing Council of PAHO, 61st Session of the WHO Regional Committee for the Americas; 28 September-2 October 2009; Washington (DC), US. Washington (DC): PAHO; 2009 (Document CD49/11 and Resolution CD49.R17) [accessed 25 Feb. 2011]. Available at: <http://new.paho.org/hq/dmdocuments/2009/CD49-11-e.pdf>
[http://new.paho.org/hq/dmdocuments/2009/CD49.R17%20\(Eng.\).pdf](http://new.paho.org/hq/dmdocuments/2009/CD49.R17%20(Eng.).pdf).
17. Pan American Health Organization. Health and Human Rights. [Internet]. 50th Directing Council of PAHO, 62nd Session of the WHO Regional Committee for the Americas; 27 September-1 October 2010; Washington (DC), US. Washington (DC): PAHO; 2010 (document CD50/12 and resolution CD50.R8) [accessed 16 Feb. 2011]. Available at: http://www.update.un.org/disabilities/documents/paho_mh_concept_paper.pdf
http://new.paho.org/hq/index.php?option=com_content&task=view&id=3149&Itemid=2401&lang=en.
18. World Health Organization. mhGAP: Mental Health Gap Action Programme: Scaling up care for mental, neurological, and substance use disorders [Internet]. Geneva, Switzerland. WHO; 2008 [accessed 16 Feb. 2011]. Available at: http://www.who.int/mental_health/evidence/mhGAP/en/index.html.
19. World Health Organization. mhGAP Intervention Guide for mental, neurological and substance use disorders in non-specialized health settings: Mental Health Gap Action Programme (mhGAP) [Internet]. Geneva, Switzerland. WHO; 2010 [accessed 16 Feb. 2011]. Available at: http://whqlibdoc.who.int/publications/2010/9789241548069_eng.pdf.
20. Pan American Health Organization/World Health Organization. International Statistical Classification of Diseases and Related Health Problems, 10th Revision [Internet]. Washington (DC), US. PAHO/WHO; 1995 (Scientific Publication No. 554) [accessed 25 Feb. 2011]. Available at: http://www.sld.cu/galerias/pdf/sitios/dne/vol1_contenido.pdf.
21. Berg AT, Berkovic SF, Brodie MJ, Buchhalter J, Cross JH, van Emde Boas W, Engel J, French J, Glauser TA, Mathern GW, Moshé SL, Nordli D, Plouin P, Scheffer IE. Revised terminology and concepts for organization of seizures and epilepsies: report of the ILAE Commission on Classification and Terminology, 2005–2009 [Internet]. *Epilepsia*. 2010 Apr;51(4):676-685. Epub 2010 Feb 26 [accessed 16 Feb. 2011]. Available at: <http://www.ilae-epilepsy.org/Visitors/Documents/BergClassificationEpilepsia2010.pdf>

22. Garcia HH, Pretell EJ, Gilman RH, Martinez SM, Moulton LH, Del Brutto OH, Herrera G, Evans CA, Gonzalez AE; Cysticercosis Working Group in Peru. A trial of antiparasitic treatment to reduce the rate of seizures due to cerebral cysticercosis [Internet]. *N Engl J Med*. 2004 Jan 15;350(3):249-58 [accessed 23 Feb. 2011]. Available at: <http://www.sonny2.com/articles/neurocystocercosis01.pdf>
<http://www.nejm.org/doi/full/10.1056/NEJMoa031294>.
23. Medina MT, Aguilar-Estrada RL, Alvarez A , Durón RM, Martínez L, Dubón S, Estrada AL, Zúniga Cartagena D, Thompson A , Ramírez E, Banegas L, Osorio JR, Delgado-Escueta AV , Collins JC, Holden KR. Reduction in rate of epilepsy from neurocysticercosis by community interventions: The Salamá, Honduras study [Internet]. *Epilepsia*, no. doi: 10.1111/j.1528-1167.2010.02945.x [accessed 16 Feb. 2011]. Available at: <http://onlinelibrary.wiley.com/doi/10.1111/j.1528-1167.2010.02945.x/abstract>.
24. Burneo JG, Tellez-Zenteno J, Wiebe S. Understanding the burden of epilepsy in Latin America: a systematic review of its prevalence and incidence [Internet]. *Epilepsy Res*. 2005 Aug-Sep;66(1-3):63-74 [accessed 23 Feb. 2011]. Available at: [http://www.epires-journal.com/article/S0920-1211\(05\)00138-5/](http://www.epires-journal.com/article/S0920-1211(05)00138-5/)
<http://www.ncbi.nlm.nih.gov/pubmed/16125900>.
25. Pan American Health Organization/World Health Organization. Mortality database browser – total deaths by country, year, sex, age group and causes of deaths [Internet]. Washington (DC), US. PAHO; 2010 [accessed 16 Feb. 2011]. Available at: http://ais.paho.org/phis/viz/mort_totaldeaths.asp.
26. Nash TE, Del Brutto OH, Butman JA, Corona T, Delgado-Escueta A, Duron RM, EvansCA, Gilman RH, Gonzalez AE, Loeb JA, Medina MT, Pietsch-Escueta S, Pretell EJ, Takayanagui OM, Theodore W, Tsang VC, García HH. Calcific neurocysticercosis and epileptogenesis [Internet]. *Neurology*. 2004 Jun 8;62(11):1934-1938 [accessed 16 Feb. 2011]. Available at: <http://www.neurology.org/content/62/11/1934.abstract>.
27. International League Against Epilepsy. Recommendations for neuroimaging of patients with epilepsy. Commission on Neuroimaging of the International League Against Epilepsy [Internet]. *Epilepsia* 38 (11): 1255-1256, 1997 [accessed 16 Feb. 2011]. Available at: <http://onlinelibrary.wiley.com/doi/10.1111/j.1528-1157.1997.tb01226.x/pdf>.
28. Marson AG, Kadir ZA, Hutton JL, Chadwick DW. The new antiepileptic drugs: a systematic review of their efficacy and tolerability [Internet]. *Epilepsia* Vo. 38 (8),859-880 Aug 1997. [accessed 16 Feb. 2011]. Available at: <http://onlinelibrary.wiley.com/doi/10.1111/j.1528-1157.1997.tb01251.x/abstract>.
29. Campos, Manuel G. et al. Essentials for the establishment of an epilepsy surgery program. In: *Textbook of Epilepsy Surgery*. Hans Lüders (Ed.). Informa, UK, 2008 (Chapter 163) [accessed 2011 Feb. 23]. Available at: <http://informahealthcare.com/doi/abs/10.3109/9780203091708.172>.
30. Di Iorio, C. Epilepsy self-management. In: *Handbook of Health Behavior Research II: Provider Determinants*. David S. Gochman (Ed.). New York, Plenum Press 1997: p. 213-230.
31. Pearl PL, Robbins EL, Bennet HD, Conry JA. Use of complementary and alternative therapies in epilepsy: cause for concern.[Internet]. *Arch Neurol*. 2005;62:1472-1475. [accessed 16 Feb. 2011]. Available at: <http://archneur.ama-assn.org/cgi/content/extract/62/9/1472>.
32. LaFrance, WC, Jr, Kanner, AM, and Hermann, B. Psychiatric comorbidities in epilepsy. In: *International Review of Neurobiology* [Internet]. 2008;83(347-383) DOI: 10.1016/S0074-7742(08)00020-2. [accessed 8 July 2011]. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/18929092>.

33. Barry, JJ. The Recognition and Management of Mood Disorders as a Comorbidity of Epilepsy. In *Epilepsia*, 44(Suppl. 4):30–40, 2003 [Internet]. Blackwell Publishing, Inc. International League Against Epilepsy [accessed 8 July 2011]. Available at: <http://onlinelibrary.wiley.com/doi/10.1046/j.1528-1157.44.s4.4.x/pdf>.
34. Thurman, D. J., Beghi, E., Begley, C. E., Berg, A. T., Buchhalter, J. R., Ding, D., Hesdorffer, D. C., Hauser, W. A., Kazis, L., Kobau, R., Kroner, B., Labiner, D., Liow, K., Logroscino, G., Medina, M. T., Newton, C. R., Parko, K., Paschal, A., Preux, P.-M., Sander, J. W., Selassie, A., Theodore, W., Tomson, T., Wiebe, S., for the ILAE Commission on Epidemiology (2011), Standards for Epidemiologic Studies and Surveillance of Epilepsy. *Epilepsia*, 52: 2–26. Article first published on line: 7 Sept 2011. DOI: 10.1111/j.1528-1167.2011.03121.x [Consultado el 2 Octubre del 2011]. Disponible en: <http://onlinelibrary.wiley.com/doi/10.1111/j.1528-1167.2011.03121.x/abstract>



**Pan American
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Regional Office of the
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51st DIRECTING COUNCIL 63rd SESSION OF THE REGIONAL COMMITTEE

CD51/10, Rev. 1 (Eng.)

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CD51/10, Rev. 1 (Eng.) / ORIGINAL: SPANISH

Strategy and Plan of Action on Epilepsy

THE 51st DIRECTING COUNCIL,

Having reviewed the Bureau report *Strategy and Plan of Action on Epilepsy* (Document CD51/10);

Recognizing the burden that epilepsy represents globally and particularly in the Region of the Americas in terms of morbidity, mortality, and disability, as well as the gap between the number of people with this disorder and those who receive no treatment;

Understanding that this is an important public health problem whose prevention, treatment, and rehabilitation are feasible through specific evidence-based measures;

Considering the context and justification for action offered by the Health Agenda for the Americas, the PAHO Strategic Plan 2008-2012, the WHO Program of Action (mhGAP), and the Global Campaign against Epilepsy: Out of the Shadows;

Observing that the *Strategy and Plan of Action on Epilepsy* addresses the principal work areas and defines technical cooperation lines to meet the different needs of the countries,

RESOLVES:

1. To endorse the provisions of the Strategy and Approve the Plan of Action on Epilepsy and their implementation under the particular conditions of each country to provide an appropriate response to current and future needs.
2. To urge the Member States to:
 - a) make epilepsy a priority in national health policy by executing specific national programs suited to the conditions of each country to sustain achievements and make progress toward meeting new goals, especially in relation to reducing the existing treatment gaps;

- b) strengthen legal frameworks as appropriate in order to protect the human rights of people with epilepsy and ensure effective enforcement of the laws;
 - c) promote universal equitable access to medical care for all people with epilepsy by strengthening health services in systems based on primary health care and integrated service networks;
 - d) ensure the availability of the four antiepileptic drugs considered essential for treating people with epilepsy, especially at the primary care level;
 - e) strengthen neurology services as support for case detection and management at the primary care level, ensuring adequate distribution of the necessary auxiliary diagnostic media;
 - f) support effective participation by the community and associations of users and family members in activities designed to secure better care for people with epilepsy;
 - g) consider strengthening human resources as key to improving national epilepsy programs, through systematic training geared especially to the personnel in primary health care;
 - h) promote intersectoral and educational initiatives directed to the population to combat the stigma and discrimination suffered by people with epilepsy;
 - i) close the information gap in the field on epilepsy by improving the production, analysis, and use of information, including research;
 - j) strengthen partnerships between the health sector, other sectors, and nongovernmental organizations, academic institutions, and key social actors.
3. To request the Director to:
- a) assist the Member States in the preparation and execution of national epilepsy programs within the framework of their health policies, taking this strategy and plan of action into account, with a view to correcting inequities and giving priority to the care of vulnerable and special needs groups, including indigenous populations;
 - b) collaborate in the evaluation and restructuring of the countries' neurology and mental health services;
 - c) facilitate the dissemination of information and the sharing of positive innovative experiences, and promote technical cooperation among the Member States;
 - d) promote partnerships with the International League against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE), as well as with international agencies, governmental and nongovernmental organizations, and other regional actors in support of the broad multisectoral response needed for the execution of this strategy and plan of action;
 - e) evaluate the implementation of this strategy and plan of action and report to the Directing Council in five years.