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STRATEGY AND PLAN OF ACTION ON EPILEPSY: FINAL REPORT

Background

1. This final report presents progress achieved in implementing the Strategy and Plan of Action on Epilepsy (Document CD51/10, Rev. 1) (1), adopted by the 51st Directing Council of the Pan American Health Organization (PAHO) in 2011 through Resolution CD51.R8 (2). The strategy and plan of action aimed to “strengthen the integrated response of the health sector through appropriate lifelong treatment programs for people with epilepsy that include prevention, treatment, and rehabilitation activities,” with the shared commitment of PAHO Member States. It complemented other epilepsy-related resolutions, technical documents, and plans approved by PAHO and the World Health Organization (WHO) (3-4). The strategy and plan of action includes four strategic areas, with 13 specific objectives and 11 indicators.

Analysis of Progress Achieved

2. Member States overall have made significant progress in implementing the strategy and plan of action, although advances have been uneven across countries. The majority of the targets have either been achieved (four) or partially achieved (five). One target was not achieved, and one had insufficient data to allow evaluation. The assessment of the indicators follows the criteria for rating outcome and output indicators at regional level as presented in Annex B of Addendum I to the Report of the End of Biennium Assessment of the PAHO Program and Budget 2018 2019/Final Report on the Implementation of the PAHO Strategic Plan 2014 2019 (Document CD58/5, Add. I) (5). As noted in the midterm review (6), “the action plan does not present a precise logical framework, and not all strategic areas have targets and corresponding indicators.” This final report assesses the strategy and plan of action’s indicators by strategic area.

3. The Pan American Sanitary Bureau (PASB or the Bureau) supported countries with implementation of the strategy and plan of action through the publication of key technical documents on epilepsy. This included the development, adaptation, and revision of tools for training, program implementation, and evaluation. PASB also supported the expansion of interventions to address the needs of people with epilepsy within primary health care using tools such as the WHO Mental Health Gap Action Programme (mhGAP-IG), which

has a module on management and assessment of epilepsy (7). The module on epilepsy was prioritized in almost 30 countries that implemented this program (5). Additionally, virtual courses on mhGAP were developed in both English and Spanish and delivered through the PAHO Virtual Campus for Public Health.

4. PASB's collaboration extends to professional and advocacy groups at the country, regional, and global levels. The Bureau has collaborated with the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE), both of whom actively participated in the design and implementation of the strategy and plan of action. In addition, collaborative partnerships have been established with the Epilepsy Society of the Caribbean and the Canadian League Against Epilepsy. Of note, two institutions in the field of epilepsy became PAHO/WHO Collaborating Centers, one in Chile in 2014 and the other in Honduras in 2016. Both played important roles in implementation of the strategy and plan of action.

5. Over the past two years, the COVID-19 pandemic has led to severe disruptions in mental, neurological, and substance use services across the Region of the Americas. There have been significant interruptions to the management of emergencies arising from neurological disorders (including status epilepticus), as well to diagnostic and laboratory services. This has delayed the diagnosis and treatment of persons with epilepsy and increased the risk of relapse (8).

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

6. Significant progress was made in this area. The number of countries with a programmatic and legal framework on epilepsy increased, although the targets for 2020 were only partially achieved. Barriers to implementation included the following: *a)* some Member States did not develop a specific plan for epilepsy, contending that epilepsy should instead be included in a broader programmatic context; *b)* the COVID-19 pandemic interrupted efforts to develop epilepsy plans and laws over in the past two years; *c)* WHO submitted a proposed global action plan for epilepsy and other neurological disorders, which was positively received, and several Member States preferred to design national programs aligned with that global plan due to the synergies in addressing the burden of epilepsy and other neurological disorders; and *d)* the approval of laws on epilepsy is a slow process that occurs in the legislative branch and does not depend directly on the ministry responsible for health.

Indicator, baseline, and target	Status
<p>1.1. Number of countries with a national epilepsy plan in place</p> <p>Baseline (2010): 10 Target (2020): 25</p>	<p><i>Partially achieved.</i> In 2020, 18 countries had a national epilepsy plan in place.</p>

Indicator, baseline, and target	Status
<p>1.2. Number of countries that have modified/amended and updated the legislative framework for epilepsy to bring it into line with international human rights standards</p> <p>Baseline (2012): not defined Target (2020): 15</p>	<p><i>Partially achieved.</i> By 2020, 10 countries had reviewed, modified, and updated their legislative frameworks related to epilepsy.</p>
<p>1.3. Instrument and methodology for comprehensive evaluation of national epilepsy programs and services developed and published</p> <p>Baseline (2010): 0 Target (2020): 1 revised by 2020</p>	<p><i>Achieved.</i> A questionnaire about basic information on programs, services, and resources was prepared and implemented in 2013 (9). It was subsequently revised and expanded for the preparation of the WHO Neurology Atlas (2017) (10).</p>
<p>1.4. Number of countries that have evaluated their national epilepsy care program and/or services</p> <p>Baseline (2010): 0 Target (2020): 20</p>	<p><i>Partially achieved.</i> By 2020, 18 countries had evaluated their national epilepsy care programs and/or services.</p>

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

7. The epilepsy mortality rate for the Region has increased slightly, with rates varying widely by subregion and country. The regional median mortality rate is higher in men (1.96 per 100,000 population) than in women (1.18). The highest rate is observed in the age group 65 years and over (above 2.0) (11). A continuing barrier to reducing the regional mortality rate is the insufficient number of neurologists: the regional median is 0.7 per 100,000 population, with a large majority of these specialists located in capital cities and other urban areas. Another barrier is the inconsistent availability of essential medications for epilepsy, especially at the primary care level (10).

8. Based on available data, it was not possible to determine the expected increase in treatment coverage. However, many countries have reported progress toward this objective, especially the expansion of services at the community level and in primary care. Notably, an important effort was made by the two Collaborating Centers to obtain this indicator in Chile and Honduras. There is a continuing need to collect data on epilepsy treatment coverage in all countries of the Region.

9. Important advances were observed in the training of primary health care (PHC) workers in epilepsy assessment and management. The adaptation and implementation of mhGAP in local contexts was prioritized by several countries and in PAHO's technical cooperation. In 2020, the mhGAP Epilepsy Module was used to train PHC workers and implement interventions at the primary care level in over 29 countries within the Region. This was an important advance compared to 2013, when only eight countries had training programs on epilepsy management in PHC (5).

Indicator, baseline, and target	Status
<p>2.1. Regional epilepsy mortality rate (per 100,000 population)</p> <p>Baseline (2010): 0.8 Target (2020): <0.8</p>	<p><i>Not Achieved.</i> The regional median epilepsy mortality rate in 2019 was 1.60 deaths per 100,000 population (11). (The 2019 rate is not comparable with the 2010 baseline rate due to the use of different data sources.)</p>
<p>2.2. Percentage of people with epilepsy who are not treated</p> <p>Baseline (2010): 60% (estimated) Target (2020): 30%</p>	<p>There is insufficient data to determine the current treatment gap. These statistics are not reported by countries. A pilot study in Honduras suggested a reduction in the treatment gap from 53% in 1997 to 13% in 2014. The estimated treatment gap in Chile was 46% in 2021.</p>
<p>2.3. Preparation and publication of a regional epilepsy training module (guides), based on the competencies required to meet the needs, targeting primary care workers</p> <p>Baseline (2010): 1 (mhGAP-IG) Target (2020): 1 revised by 2020</p>	<p><i>Achieved.</i> The mhGAP Intervention Guide (mhGAP-IG) Version 2.0 Epilepsy Module (7) meets the requirements of this indicator. MhGAP-IG has been published, adapted, and made available in the four official PAHO languages.</p>

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

10. The target of the indicator for this strategic area was achieved. PASB technical cooperation has an important focus on ensuring that the cross-cutting principles of gender, equity, ethnicity, and human rights underpin all epilepsy policies, plans, legislation, and service provision. Countries have made significant progress in fighting against stigma and discrimination surrounding people with epilepsy.

Indicator, baseline, and target	Status
<p>3.1. Preparation and publication of regional guides for the design and implementation of epilepsy prevention activities in the countries</p> <p>Baseline (2010): 0 Target (2020): 1 revised</p>	<p><i>Achieved.</i> The Management of Epilepsy in the Public Health Sector (12) was published in 2018. This document is a guide to the design and implementation of epilepsy prevention and care activities.</p>

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

11. Major progress was achieved for this strategic area. A significant number of regional investigations have been published, with more than 50 articles, reports, and technical documents produced during the period of the strategy and plan of action. The role of the Collaborating Centers, ILAE, and IBE in the field of research is highlighted. The COVID-19 pandemic has delayed some planned publications on epilepsy, leading to only the partial achievement of two of the three targets.

Indicator, baseline, and target	Status
<p>4.1. 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</p> <p>Baseline (2010): 0 Target (2014): 1</p>	<p><i>Achieved.</i> A guide based on data and indicators from the regional Report on Epilepsy in Latin America and the Caribbean (9) and the WHO Neurology Atlas (2017) (10) has been published.</p>
<p>4.2. Regional report on epilepsy concluded and published (includes data on morbidity and mortality, burden, programs, services, and resources)</p> <p>Baseline (2010): 1 from 2008 Target (2020): 1 for 2020</p>	<p><i>Partially achieved.</i> The Report on Epilepsy in Latin America and the Caribbean was published in 2013 (9), and The Management of Epilepsy in the Public Health Sector was published in 2018 (12). Publication of updated versions of these two reports was postponed due to the COVID-19 pandemic.</p>
<p>4.3. Publication of a collection of epidemiological research on epilepsy in Latin America and the Caribbean</p> <p>Baseline (2010): 0 Target (2020): 1</p>	<p><i>Partially achieved.</i> Epilepsy in Latin America (13) was published in 2016. It compiles the most important experiences and studies on epilepsy based on two regional workshops, one in Chile in 2013 and one in Honduras in 2015. Publication of an updated version of this report for 2020 was postponed due to the COVID-19 pandemic.</p>

Lessons Learned

12. Investment in epilepsy is insufficient to meet the needs of the regional burden due to the disease, especially in light of the growing epilepsy mortality rate in the Region. The feasibility of reducing the treatment gap with community interventions at the PHC level has been demonstrated in several countries. Similarly, the adaptation and implementation of the mhGAP Epilepsy Module, aimed at strengthening PHC for the identification and care of people with epilepsy, has been successful.

13. Data collection and reporting on epilepsy must be strengthened. Quality data on prevalence, incidence, mortality, treatment coverage, and available human and financial resources for epilepsy, disaggregated by key variables such as sex, age, and ethnicity, among others, must be systematically collected and reported to inform policy and improve service quality. Data should also be collected on the impacts of the ongoing COVID-19 pandemic on people with epilepsy and the availability of essential services for epilepsy.

Action Needed to Improve the Situation

14. Considering the outcomes and lessons learned described in this report, we present the following actions for consideration by the Member States:

- a) Invest in programs and services to prevent and control epilepsy and to create and/or strengthen the programmatic and legal framework for the care of people with epilepsy, according to national conditions.
- b) Bearing in mind that approximately 25% of epilepsy cases are preventable, take steps to *i)* strengthen maternal and newborn health care; *ii)* promote healthy brain development; *iii)* prevent and control neurocysticercosis; *iv)* strengthen programs to reduce head injuries; and *v)* prevent central nervous system infections.
- c) Focus attention on areas requiring greater efforts, including *i)* the collection and reporting of epilepsy data, including data on treatment coverage, and *ii)* the prevention of epilepsy-related mortality, which has increased in the Region since 2010.
- d) Improve access to services for people with epilepsy and ensure appropriate services at the first level of care, including the consistent availability of basic anti-epileptic drugs. This will help to close or reduce the treatment gap.
- e) Develop tools and processes for systematically collecting and reporting epilepsy data to inform policies and programs at regional and national levels and strengthen national information and surveillance systems on epilepsy.
- f) Support advocacy efforts in the Region using innovation and social media. Establish an advocacy day to raise awareness of epilepsy and reduce epilepsy-related stigma to support the reduction in disease burden due to epilepsy and improve quality of life.
- g) Adopt the WHO Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders as the guidance document for technical cooperation with Member States and non-State actors (14).

Action by the Executive Committee

15. The Executive Committee is invited to take note of this report and provide any comments it deems pertinent.

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