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### **G. STRATEGY AND PLAN OF ACTION ON EPILEPSY: MIDTERM REVIEW**

#### **Background**

1. The purpose of this document is to report to the Governing Bodies of the Pan American Health Organization (PAHO) on the progress achieved in the implementation of the Strategy and Plan of Action on Epilepsy, adopted in September 2011 (document CD51/10, Rev. 1 (1) and Resolution CD51.R8) (2). This strategy and plan of action lays the foundation of technical cooperation to tackle epilepsy in the Region, complementing the Strategy and Plan of Action on Mental Health approved by the Directing Council of PAHO in 2009 (3), the PAHO Strategic Plan 2014-2019 (4), and the Plan of Action on Mental Health 2015-2020 (5). Other related documents include several resolutions and regional technical documents on epilepsy adopted by PAHO and the Member States, as well as the Mental Health Gap Action Programme (mhGAP), initiated by WHO in 2008, and its corresponding intervention guide (2010), which includes a module on the treatment of epilepsy in primary health care settings (6-12). In 2015, the World Health Assembly adopted a resolution concerning the need for coordinated action at the country level to address the social and health implications of the burden associated with epilepsy (Resolution WHA 68.20) (13). It should be noted that the action plan does not present a precise logical framework and not all strategic areas have targets and corresponding indicators.

#### **Progress update**

2. The countries of the Region have made progress toward many objectives with important advances in the implementation of strategic areas 2 and 4. Despite evident and significant progress, barriers persist. In particular, at the country level, the discussion of strategies and service models for epilepsy is often under the responsibility of professional associations. Ministries of health have difficulties managing the issue directly with their own resources. PAHO focuses its efforts in this direction, promoting and facilitating the involvement of authorities, and working in regular contact with the ministries and medical associations of Latin America and the Caribbean.

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3. Data on the Member States (see table below) were obtained through the report on Epilepsy in Latin America and the WHO Project Atlas for Neurological Disorders (14, 15). These instruments, together with the information available in Mortality Data for Health in the Americas 2012, constitute the main references in the preparation of this report (16).

<i>Strategic area 1: Programs and legislation for the care of people with epilepsy and protection of their human rights.</i>		
<b>Objective</b>	<b>Indicator, baseline, and target</b>	<b>Situation</b>
<b>1.1</b>	1.1.1 Number of countries with a national epilepsy plan in place.  Baseline: 10 countries in 2010 Target: 20 by 2015; 30 by 2020	18 countries in 2016 (14, 15). The targets were too ambitious. Proposal: adjust target to 25 countries by 2020.
<b>1.2</b>	1.2.1 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: not defined in 2012 Target: 10 countries by 2015; 25 by 2020	10 countries in 2016 (14, 15). Agreement among countries on the need for specific legislation on epilepsy is not unanimous. Proposal: reduce target to 15 countries by 2020.
	1.2.2 Instrument and methodology for comprehensive evaluation of national epilepsy programs and services developed and published.  Baseline: no instrument published in 2010 Target: 1 instrument published by 2012; 1 revised by 2020	Questionnaire on basic information about programs, services, and resources, prepared in 2013 (14).  Questionnaire now under revision in light of the WHO Neurology Atlas.
	1.2.3 Number of countries that have evaluated their national epilepsy program and/or services.  Baseline: 0 countries in 2010 Target: 25 countries by 2014; 30 by 2020	Specific information is not available. It is proposed to align this indicator with 1.1, and to reformulate the target to 20 countries by 2020

	<p>1.2.4 Regional epilepsy mortality rate (per 100,000 population).</p> <p>Baseline: 0.8 in 2010 Target: &lt; 0.8 (plan does not specify year).</p>	<p>Rate per 100,000 population in 2012 (most recent information available): 0.50 in North America; 1.04 in Latin America and the Caribbean; 0.84 in the Americas (16).</p>
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<b>Strategic area 2: Health services network for the treatment of people with epilepsy, with emphasis on primary health care and the provision of drugs.</b>		
<b>Objective</b>	<b>Indicator, baseline, and target</b>	<b>Situation</b>
<p><b>2.1</b></p>	<p>2.1.1 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: 1 guide in 2010 (mhGAP-IG) Target: 1 guide adapted to the regional level by 2013; 1 guide reviewed by 2020</p>	<p>The mhGAP Intervention Guide/ Epilepsy Module prepared by WHO in 2010 meets the requirements of the regional training module proposed in this indicator. This guide, including the epilepsy module, has been published and made available to the countries of the Region in English (2010), French (2011), Spanish (2012), and Portuguese (2015). In addition, this module has been adapted at the country level and is being used in around 30 countries and territories, according to the WHO methodology (12).</p>
<p><b>2.2</b></p>	<p>2.2.1 Percentage of people with epilepsy who are not treated.</p> <p>Baseline: 60% in 2009 Target: 30% by 2020</p>	<p>Pilot study in Honduras with a program for community-based intervention. Treatment gap reduced from 53% in 1997 to 13% in 2014 (14).</p> <p>A new regional study of the treatment gap is planned for 2017, similar to the one carried out in 2013 on the mental health treatment gap. All countries in the Region that have available data will be included.</p>

<b>Strategic area 3: Education and sensitization of the population, including people with epilepsy and their families.</b>		
<b>Objective</b>	<b>Indicator, baseline, and target</b>	<b>Situation</b>
<b>3.2</b>	<p>3.2.1 Preparation and publication of regional guides for the design and implementation of epilepsy prevention activities in the countries.</p> <p>Baseline: no guide in 2010 Target: 1 guide by 2013; revised by 2020</p>	The document on regional guides for the design and implementation of epilepsy prevention activities was prepared in 2016. It is expected to be completed by the first semester of 2017.

<b>Strategic area 4: Strengthening of the ability to produce, assess, and use information on epilepsy.</b>		
<b>Objective</b>	<b>Indicator, baseline, and target</b>	<b>Situation</b>
<b>4.1</b>	<p>4.1.1 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: no document in 2010 Target: 1 document by 2014</p>	<p>Partially achieved through the use of data/indicators from the PAHO Regional Report and the WHO Atlas for Neurological Disorders (14, 15).</p> <p>It should be completed in the 2017-2020 period.</p>
	<p>4.1.2 Regional report on epilepsy, concluded and published.</p> <p>Baseline: 1 report in 2008 Target: 1 by 2015; 1 by 2020</p>	Report on Epilepsy in Latin America and the Caribbean, 2013 (14).
<b>4.2</b>	<p>4.2.1 Publication of a collection of epidemiological research on epilepsy in Latin America and the Caribbean.</p> <p>Baseline: no publication in 2010 Target: 1 by 2015; 1 by 2020</p>	A technical document was published on the most important Latin American experiences in the field of epilepsy (programs, services, and epidemiological research), based on two regional workshops held in Chile (2013) and Honduras (2015) (14).

### **Actions needed to improve the current situation**

- a) Adjust the targets of the Strategy and Plan of Action on Epilepsy to reflect more realistic goals.
- b) Consolidate and implement instruments and studies to evaluate the contents and standards included in the Strategy and Plan of Action on Epilepsy.
- c) Support joint efforts by the Pan American Sanitary Bureau (PASB) and the Member States in the development of health systems, human resources, and services in order to improve the quality of care, and bridge the gap of treatment.
- d) Promote resource allocation consistent with the identified needs and established goals.
- e) Strengthen information and surveillance systems, improve epidemiological information, and increase survey coverage of marginalized populations and other vulnerable groups.

### **Action by the Executive Committee**

4. The Committee is requested to take note of this report, approve the adjustments of the targets for indicators 1.1.1 and 1.2.1, and formulate the recommendations it considers relevant.

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