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#### STRATEGY AND PLAN OF ACTION ON DEMENTIAS IN OLDER PERSONS: FINAL REPORT

##### Background

1. The *Strategy and Plan of Action on Dementias in Older Persons* for the period 2015-2019 (document CD54/8, Rev. 1) (1), adopted in 2015 during the 54th Directing Council of the Pan American Health Organization (PAHO), took into account the following statement by the Director-General of the World Health Organization (WHO): "[t]he need for long-term care for people with dementia strains health and social systems, and budgets. The catastrophic cost of care drives millions of households below the poverty line. The overwhelming number of people whose lives are altered by dementia, combined with the staggering economic burden on families and nations, makes dementias a public health priority..." (2). PAHO's Strategy and Plan of Action addressed calls in the *Health Agenda for the Americas 2008-2017* regarding "maintaining the quality of life of elderly people" (3), and considered essential "offering the necessary short-, medium-, and long-term care," as outlined in the *Strategy for Universal Access to Health and Universal Health Coverage* (document CD53/5, Rev. 2) (4). Some subsequent globally developed instruments, such as the *Global Action Plan on the Public Health Response to Dementia 2017-2025* (5), recognized the strategic vision and work done around this plan.

2. PAHO's *Strategy and Action Plan on Dementias in the Older Persons* includes five strategic lines of action and a total of eight objectives, each with corresponding indicators and a target for 2019. This final report addresses the progress made by Member States in meeting these objectives and targets.

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## Analysis of Progress Achieved

***Strategic line of action 1: Promote plans, policies, and programs that promote and respect human rights to address risk factor reduction, prevention and reduction of dependence, and provision of care (including long-term care) associated with dementias***

3. The targets envisaged in this strategic line were almost entirely achieved. The countries and territories of the Region reported having policies, plans, and/or programs on dementias, either on an independent basis or included as part of other national programs, (e.g. mental health, older persons, or the disabled). Countries also reported including specific interventions in their plans to reduce stigma and stereotypes, improve knowledge about these disorders, support caregivers, and drive strategies that enable health systems to adapt and respond to these new demographic and epidemiological realities. In partnership with Alzheimer's Disease International (ADI), PAHO launched an awareness campaign on dementias and stigma throughout the Region on 1 September 2019, in honor of World Alzheimer's Month. "Let's Talk About Dementia" was implemented as part of the *Strategy and Plan of Action on Dementias in Older Persons*, aiming to promote universal access to health and universal health coverage with quality interventions for people with or at risk of dementia. Social media (mainly Facebook, Instagram, and Twitter) was the main tool used by PAHO offices to implement the campaign. Data shows that the 237 social media posts reached nearly 800,000 people in the Region.

| <b>Objective 1.1:</b> Formulate or strengthen policies, plans, and programs for risk factor reduction, prevention, and care, including long-term care associated with dementias   |   |
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| <b>Indicator, baseline, and target</b>  | <b>Status</b>   |
| <p><b>1.1.1</b> Number of countries and territories of the Region reporting policies, plans, or programs on dementias, either on an independent basis or included as part of other national programs, (e.g. mental health, older persons, or the people living with disabilities)</p> <p>Baseline (2015): 7<br/>Target (2019): 13</p> | <p>A total of 11 countries reported having policies, plans, or programs on dementias, either on an independent basis or included as part of other national programs, (e.g. mental health, older persons, or the people living with disabilities). The target for this indicator was partially achieved.</p> |

| <b>Objective 1.2:</b> Systematize interventions with a human rights approach to reduce stigma and stereotypes associated with dementias, and educate about the prevention and care of these conditions   |  |
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| <b>Indicator, baseline, and target</b>   | <b>Status</b>  |
| <p><b>1.2.1</b> Number of countries and territories that have included in their plan specific interventions to reduce stigma and stereotypes and improve understanding of these conditions</p> <p>Baseline (2015): 5<br/>Target (2019): 16</p> | <p>A total of 15 countries reported including specific interventions in their plans to reduce stigma and stereotypes, improve knowledge about these disorders, support caregivers, and drive strategies that enable health systems to adapt and respond to these new demographic and epidemiological realities.</p> <p>The target was very close to being reached.</p> |

***Strategic line of action 2: Establish in health systems and health services networks interventions for prevention and quality care for persons with or at risk of dementias***

4. Health services, particularly at the first level of care and in subsequent specialized levels of care, must provide timely, comprehensive, and quality care based on the best available evidence. In this area, the number of countries reporting guidelines or protocols for the care of people with dementias was quite low. Further progress has been made in the second indicator regarding the development of guidelines or protocols for health promotion and for risk prevention and reduction with a life course approach. Multisectoral efforts and integration will be essential in this process, as will the involvement of the community, family, caregivers, and individuals themselves. For nearly a decade, WHO's Mental Health Gap Action Program (known as mhGAP) (6) has been implemented in the Americas. One module is dedicated to dementia management. The program has guidelines for non-specialized health care professionals working in facilities at the first and second level of care; 56% of countries in the Americas have completed training on dementias management guidelines. Interventions aimed at promoting recovery or sustainment of functional capacity and preserving people's independence to stay in their homes and communities for as long as possible are considered essential. Maintaining functional ability is critical in people with cognitive disorders (7, 8). Based on this concept, WHO published recommendations for Integrated Care for Older People (known by the acronym ICOPE) (9) as a strategy to strengthen primary care, as well as social and health services for older adults. The ICOPE approach is important for the aging population in the Americas, as it provides strategies and pathways of care to manage the most common problems faced by older adults, culminating in disability, and including mental health.

| <b>Objective 2.1:</b> Include, in health services, evidence-based interventions for health promotion, prevention, and care for persons with dementias to prevent dependence, as these interventions emerge in the scientific literature |   |
|---|---|
| <b>Indicator, baseline, and target</b>  | <b>Status</b>   |
| <p><b>2.1.1</b> Number of countries and territories with guidelines or protocols for the care of persons with dementias</p> <p>Baseline (2015): 5<br/>Target (2019): 15</p>   | <p>A total of six countries and territories reported having guidelines or protocols for the care of persons with dementias. During this period, training was developed based on the guidelines for dementia management, aimed at non-specialized health care professionals working in facilities at the first and second level of care. A total of 30 countries in the Americas have completed these trainings. The target was not reached.</p> |
| <p><b>2.1.2</b> Number of countries and territories with guidelines or protocols for health promotion and risk prevention and reduction with a life course approach</p> <p>Baseline (2015): 4<br/>Target (2019): 15</p>                 | <p>A total of 11 countries reported having guidelines or protocols for health promotion and risk prevention and reduction with a life course approach. The efforts made and multisectoral integration have been essential in this process, in addition to the involvement of communities, families, caregivers, and individuals themselves. The target was partially reached.</p>   |
| <b>Objective 2.2:</b> Implement evidence-based preventive, community, or intersectoral interventions to help maintain the functional capacity and independence of persons with or at risk of dementias                                  |   |
| <b>Indicator, baseline, and target</b>  | <b>Status</b>   |
| <p><b>2.2.1</b> Number of countries and territories that have evidence-based community interventions to help maintain functional capacity and independence</p> <p>Baseline (2015): 7<br/>Target (2019): 15</p>                          | <p>A total of 10 countries reported having evidence-based community interventions to help maintain functional capacity and independence. WHO's Integrated Care for Older People (ICOPE) is emerging as an important approach for the aging population in the Americas and provides strategies and pathways to manage the most common problems faced by older adults. The target was partially reached.</p>                                      |

***Strategic line of action 3: Implement a quality long-term care system that addresses the needs of dependent persons, their families, and caregivers, based on a primary health care approach, respect for human rights, gender equality, and equity within the strategic framework of universal health access and universal health coverage***

5. People with dementias have a high level of dependence and need for long-term care. Families primarily provide this care in the Region. It is crucial to provide community-level resources, services, and programs to enable caregivers to improve their skills and ability to efficiently care for people with dementias (10). At the end of this Strategy and Plan of Action, more than half of the countries aiming to reach the target in 2019 reported having integrated quality and community-based networks for the care of dependents, and reported progress on care and training programs for caregivers, as well as continuous evaluation systems for long-term care providers (community or care facilities). Increased dependency and Alzheimer disease will be the focus of health and social priorities to be addressed in the countries of the Region in the coming years.

| <b>Objective 3.1:</b> Establish integrated, community-based networks between social and health systems, providing quality care to dependent persons, with family engagement                            |  |
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| <b>Indicator, baseline, and target</b>   | <b>Status</b>  |
| <b>3.1.1</b> Number of countries and territories with quality, integrated, community-based networks for the care of dependent persons<br>Baseline (2015): 5<br>Target (2019): 15                       | A total of eight countries and territories reported having quality, integrated, community-based networks for the care of dependent persons In the Region, people with dementias and high levels of dependence requiring long-term care are mostly being cared for by families. The target was not reached. |
| <b>Objective 3.2:</b> Create multisectoral care and training programs for informal and formal caregivers, to protect their rights, address their needs, and promote their health and social protection |  |
| <b>Indicator, baseline, and target</b>   | <b>Status</b>  |
| <b>3.2.1</b> Number of countries and territories with care and training programs for caregivers<br>Baseline (2015): 12<br>Target (2019): 25  | A total of 13 countries have care and training programs for caregivers. In order to continue progressing, community-level resources, services, and programs are essential for caregivers to improve their skills and ability to efficiently care for people with dementias. The target was not reached.    |

| <b>Objective 3.3:</b> Establish or review legal and regulatory frameworks and implementation mechanisms, based on international standards that allow national authorities to guarantee quality care and protection of rights of persons who receive long-term care in the community or in care facilities |   |
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| <b>Indicator, baseline, and target</b>  | <b>Status</b>   |
| <p><b>3.3.1</b> Number of countries and territories where the national authority has a continuous evaluation system for providers of long-term care (community or care facilities)</p> <p>Baseline (2015): 10<br/>Target (2019): 20</p>   | <p>A total of 10 countries reported having a continuous evaluation system for providers of long-term care (community or care facilities). The target was not reached.</p> |

***Strategic line of action 4: Develop or strengthen the necessary human resources training to address health needs of persons with or at risk of dementias***

6. Caring for people with dementias requires trained and specialized personnel. It is necessary to promote the inclusion of competencies on dementias as part of undergraduate and graduate education, as well as continuing education programs for all health professionals. In this period, 22.2% of countries have included these skills in programs for social and health service personnel.

| <b>Objective 4.1:</b> Integrate basic competencies about dementias into undergraduate and graduate programs, and into continuing education in the social and health sciences   |  |
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| <b>Indicator, baseline, and target</b>   | <b>Status</b>  |
| <p><b>4.1.1</b> Number of countries and territories that have incorporated a set of basic competencies into undergraduate and graduate programs, and into continuing education for social and health services personnel</p> <p>Baseline (2015): 0<br/>Target (2019): 8</p> | <p>A total of 12 countries have incorporated basic competencies on dementias into programs for social and health services personnel. Caring for people with dementias requires trained and specialized personnel, as well as continued inclusion of competencies on dementias as part of undergraduate and graduate education, and continuing education programs for all health professionals. The target has been exceeded.</p> |

***Strategic line of action 5: Improve research and surveillance capacity to generate and collect quality information to address the social and health needs of persons with dementias***

7. Research and surveillance capacity around these health problems remains limited, hindering decision-making and assessment of the impact of interventions. During this period great progress was achieved: 20.37% of countries have included a set of basic indicators on dementias, disability, dependence, and long-term care. Several countries have reported relaunching national dementia research studies. This could mean a substantial improvement in national and regional capacity to generate evidence for decision-making in the near future. Approximately 28% of countries have completed their data at the WHO Global Dementia Observatory, a data and knowledge sharing platform that provides easy access to key dementia data in Member States in the areas of policy, service delivery, and information and research.

| <b>Objective 5.1:</b> Include indicators of dementias, disability, dependence, and long-term care in national health information systems   |  |
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| <b>Indicator, baseline, and target</b>   | <b>Status</b>  |
| <p><b>5.1.1</b> Number of countries and territories that have included a set of basic indicators on dementias, disability, dependence, and long-term care</p> <p>Baseline (2015): 2<br/>Target (2019): 8</p> | <p>A total of 11 countries included a set of basic indicators on dementias, disability, dependence, and long-term care. Although research and surveillance capacity around these health problems remains limited, hindering decision-making and assessment of the impact of interventions, countries are improving in this area. The target has been exceeded.</p> |
| <b>Objective 5.2:</b> Promote research, evaluation, and dissemination of outcomes, good practices, and innovative models of care and treatment for persons with dementias                                    |  |
| <b>Indicator, baseline, and target</b>   | <b>Status</b>  |
| <p><b>5.2.1</b> Number of countries and territories that have conducted national research studies on dementias</p> <p>Baseline (2015): 10<br/>Target (2019): 6</p>   | <p>A total of six countries reported conducting national research studies on dementias. This would mean a substantial improvement in national and regional capacity to generate evidence for decision-making in the near future. Moreover, more than 15 countries have completed their data at the WHO Global Dementia Observatory. The target was reached.</p>    |

## **Future challenges**

8. In the next decade, approximately 18% of the total population of Latin America and the Caribbean will be over the age of 60 (11, 12). Life expectancy in the Region will continue to rise. At the end of 2017, life expectancy at birth was estimated at 77.07 years; at age 60, life expectancy was estimated at 22.4 years; and at age 80, it was estimated at 9.41 years (11, 13). In 2017, healthy life expectancy was estimated at 66.21 years on average (13), showing a gap of 10.86 years between life expectancy and healthy life expectancy in the Americas (13). Since 2009, the number of years lived with disabilities has increased by 12.6% in the Region (13, 14).

9. In the Region of the Americas, the prevalence of dementias in adults over 60 ranges from 6.46% to 8.48% (15). Estimates show that every 20 years the number of people with this disorder will double. Latin America and the Caribbean will be the most affected regions, going from 3.4 million people with dementias in 2010 to 7.6 million in 2030, surpassing the projected 7.1 million people in the United States and Canada (31). Deaths from Alzheimer disease and other dementias in the over-60 age group in the Americas accounted for 3.2% of all deaths in 2000, or nearly 120,600. In 2016, this figure rose to nearly 350,000 (16). There is an upward trend; in 2005, dementias finished sixth among the leading causes of death, later rising to fourth place in 2010, and third in 2016, surpassing causes such as chronic obstructive pulmonary disease and diabetes mellitus. In 2000 they caused 120,600 deaths; however, this figure rose to almost 350,000 in 2016, an increase of more than 150% (16). In 2010, the estimated cost of dementias was US\$ \$604,000 billion<sup>1</sup> worldwide and \$235,800 billion in the Americas (15).

10. Despite significant progress over the past 10 years, the marked impact of dementia on our Region will require accelerated actions and interventions by Member States, the Pan American Sanitary Bureau, and other strategic partners. It is essential to continue disseminating scientific arguments that promote opportunities to prevent Alzheimer disease and other dementias through interventions on risk factors (2), and to promote continued preventive efforts on dementias among Member States, taking into account that these risk factors are common to other health problems (17).

## **Action Necessary to Improve the Situation**

11. Taking into account the outcomes and challenges described in this report, we present the following actions for consideration by the Member States:

- (a) Make dementias a priority for public health in the countries of the Region, increasing their inclusion in policies, plans, and programs that promote comprehensive care for this problem.
- (b) Develop strategies for education, awareness, and adaptation around dementias to improve knowledge about these disorders, reduce stigma and stereotypes, and improve care for people with dementias and their caregivers.

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<sup>1</sup> Unless otherwise indicated, all monetary figures in this report are expressed in United States dollars.



- (c) Promote, on the part of Member States, actions aimed at reducing the risk of dementias, particularly through the commitments established in the *Plan of Action for the Prevention and Control of Noncommunicable Diseases in the Americas* (document CD52/7, Rev. 1) for the period 2013-2019 (18).
- (d) Promote the development of national capacities to improve diagnosis, treatment, care, and support for people with dementias, emphasizing evidence-based actions to maintain the functional capacities of people suffering from this disease.
- (e) Promote multisectoral and community interventions helping to build long-term care systems in our countries that respond to the needs of people living with dementias, as well as their families and caregivers.
- (f) Prioritize training for health sciences personnel in the competencies required to care for people with dementias, including training for caregivers.
- (g) Promote early diagnosis of dementias to provide access to health services and psychosocial care and integrate dementias into the noncommunicable diseases program.
- (h) Develop national capacities to provide information on dementias through a basic set of indicators that gives countries evidence to make informed decisions on the subject.
- (i) Align regional actions with the *Global Action Plan on the Public Health Response to Dementia 2017-2025* (5), its priority actions, and indicators.
- (j) Prioritize the issue of dementia in older people as part of the Decade of Healthy Aging (2020-2030) initiative in the Region of the Americas.

### **Action by the Directing Council**

12. Considering the extraordinary and unprecedented circumstances presented by the COVID-19 pandemic, and in accordance with Resolution CE166.R7, this report will be published for information purposes only, and it will not be discussed by the Directing Council.

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