

**Regional Workshop on Dementia
Final Report
17–18 October 2017
Santo Domingo**



Final Report of the PAHO Regional Workshop on Dementia

Regional Workshop on Dementia. Final Report (Santo Domingo, 17-18 October 2017)
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Executive Summary

On 17–18 October 2017, the Mental Health and Healthy Life Course Units of the Pan American Health Organization (PAHO/WHO) held a regional workshop on dementia in Santo Domingo, Dominican Republic. The two-day workshop featured presentations by the World Health Organization (WHO), PAHO, Alzheimer’s Disease International (ADI) and country Ministry of Health representatives. Two afternoon work groups split participants into smaller discussion groups to answer questions on the seven key areas of the Global Action Plan on the Public Health Response to Dementia and on advancing national strategies and plans for dementia.

In total, 29 representatives from national Ministries of Health and civil society organizations from the following countries participated in or observed the workshop: Argentina, Aruba, Bolivia, Brazil, Chile, Colombia, Costa Rica, Dominican Republic, Ecuador, Mexico, Panama, Paraguay, Peru, Uruguay, and Venezuela. Ministry of Health personnel included staff from Departments of Aging and Mental Health. PAHO partner ADI had a large presence, represented by CEO Paola Barbarino, Joost Martens, Regional Director for the Region of the Americas, and Kate Gordon, Policy Consultant.

PAHO was represented by Dévora Kestel, Chief of the Mental Health and Substance Use Unit; Cristina Alonso, Regional Advisor for Healthy Aging; Alexandra Rodriguez, PAHO consultant on Health Systems; and Amy Tausch, Consultant on Mental Health. Tarun Dua, medical officer in the Department of Mental Health and Substance Abuse, represented the WHO. Katrin Seeher and Saskia Sivananthan, both from the Department of Mental Health and Substance Abuse at the WHO, though not in attendance, delivered virtual presentations from WHO headquarters in Geneva, Switzerland.

Key issues that emerged during the workshop were the challenges of generating political will for dementia, the need to integrate dementia into existing health initiatives, and opportunities for inter-country collaboration. Next steps discussed by participants included the need for a follow-up meeting in the Region and the translation of WHO dementia tools currently available only in English, such as iSupport, into Spanish. The following brief report gives an overview of key themes of the presentations and workgroups from the two-day workshop and concludes with next steps.

Objectives

The objectives of the meeting were as follows:

- To present and discuss the implementation of PAHO’s Regional Action Plan on Dementia in Older Persons and the WHO’s Global Action Plan on the Public Health Response to Dementia;
- To discuss approaches and processes to developing national action plans on dementia and integrating dementia into existing policies for aging, mental health, or noncommunicable diseases;
- To present and discuss the implementation of the WHO’s Global Dementia Observatory; and
- To support the implementation of WHO dementia tools including iSupport, Dementia Friendly Communities, and the mhGAP Intervention Guide.

Sessions and Work Groups

Day 1

The theme of the first day was dementia strategies, policies, and plans. PAHO consultant Alexandra Rodriguez and Dévora Kestel opened the workshop with welcoming remarks. Dr. Kestel introduced the topic of the workshop, and gave an overview of dementia in the Region of the Americas. Dr. Kestel was followed by Dr. Ángel Almánzar, Director of Mental Health for the Ministry of Health in the Dominican Republic, who discussed the national dementia context. The morning sessions introduced global and regional plans for dementia and invited countries with national dementia plans to share their experiences in implementation. An afternoon work group encouraged participants to discuss their own countries' facilitating factors and barriers to designing and/or implementing national dementia strategies or plans. The following is a summary of the day's sessions and work group.

Presentations

1. *Dementia in the Dominican Republic*
Ángel Almánzar, Ministry of Health, Dominican Republic

Nearly 10% of the population in the Dominican Republic is over the age of 60. It is estimated that by 2050, that percentage will more than double. The Dominican Republic is actively involved in various dementia initiatives. The country participated in the pilot testing of the WHO's Global Dementia Observatory. In October 2016, they piloted the WHO's Mental Health Gap Action Programme (mhGAP), which includes a dementia module. The country is now focused on developing a system to monitor and evaluate the program's impact using mhGAP indicators. Additionally, the government has developed a series of actions aimed at improving the living conditions of vulnerable groups such as the elderly, which includes national health insurance (SeNaSa), the National Board on Aging (CONAPE), and the Program Progressing with Solidarity.

2. *Strategy and Plan of Action on Dementias in Older Adults*
Dr. Cristina Alonso, PAHO/WHO

The WHO defines *healthy aging* as the process of developing and maintaining the functional ability that enables well-being in older age, where functional ability represents having the capabilities that enable all people to be and do what they have reason to value. Aging is influenced by both individual factors (e.g. behavior, genetics and illness) as well as environmental factors (e.g. housing and transportation). Alzheimer's and other dementias are a significant source of disability, and as aging progresses from frailty to disability to dependence, the process becomes more difficult to reverse. However, a life course model for dementia shows potentially modifiable risk factors for dementia.

In 2015, the PAHO approved its Strategy and Plan of Action on Dementias in Older Persons (CD54/8). The plan has five strategic lines of action that target dementia policy and planning, interventions for prevention and quality care for persons with or at risk of dementias, implementing long-term quality care systems, developing and strengthening human resources training, and improving research and

surveillance capacity. Some key initiatives for achieving these lines of action include: Age Friendly Cities and Communities; Taking Control of Your Health, a portfolio of evidence-based self-care programs; and a capacity-building course and accreditation in the health of older people.

3. *Global Action Plan on the Public Health Response to Dementia 2017–2025*

Dr. Tarun Dua, WHO

In May 2017, at the Seventieth World Health Assembly, the WHO endorsed the draft Global Action Plan on the Public Health Response to Dementia 2017–2025. The Plan has seven cross-cutting principles (human rights of people with dementia; empowerment and engagement of people with dementia and their carers; evidence-based practice; multisectoral collaboration; universal health and social coverage; equity; and appropriate attention to dementia prevention, cure and care) and the following strategic areas: dementia as a public health priority; dementia awareness and friendliness; dementia risk reduction; dementia diagnosis, treatment and care; support for dementia carers; information systems for dementia; and dementia research and innovation. The global target for the first strategic area is that 75% of countries will have developed or updated national policies, strategies, plans, or frameworks for dementia, either stand-alone or integrated into other policies/plans, by 2025.

4. *Advancing Dementia Plans and Strategies*

Dr. Tarun Dua, WHO

A national or subnational dementia strategy is a societal recognition, in the form of a written document, by government and/or other actors, that policy changes are needed to address dementia. Having a national dementia strategy is important in order to create a coherent framework, signal a political commitment, provide an opportunity for multisectoral collaboration and stakeholder engagement, rationalize service delivery and coordination within health and social care, and build consensus. The main components of a dementia strategy should act to raise public awareness, create a shared understanding of dementia, address population needs, and reduce the burden of dementia.

Dr. Dua presented key components for planning, developing, and implementing national dementia strategies. Examples of these key components in action were presented using Australia, France, South Korea, the United Kingdom, and the United States as case studies. The presentation also assessed current national dementia strategies' alignment with the WHO Action Plan.

5. *Country Experiences with Implementing Dementia Plans*

Three countries with existing national dementia plans (Chile, Costa Rica, and Mexico) shared their experiences of implementing these plans:

Dr. Adrián Martínez Ruiz presented Mexico's Action Plan on Alzheimer's and Other Dementias. Dr. Ruiz outlined the Plan's seven strategic lines, which are aligned with PAHO's Action Plan, and their corresponding activities including the development of education programs for primary healthcare professionals and the development of an evidence base which includes epidemiological and clinical studies. The presentation provided the following recommendations for countries to continue advancing

their national dementia plans: to use current scientific evidence; to continue training human resources at all levels; to maintain and transmit clear messages and objectives; to develop realistic objectives; to generate coalitions; and to create networks (e.g. of NGOs, academics, and governmental).

Dr. Marianela Mora Castro presented Costa Rica's National Plan for Alzheimer's and Related Dementias. Key to the plan's success was the collaborative effort between state and public stakeholders, with active participation by civil society. The three areas initially prioritized by the Plan are the improvement of quality of life of people with neurocognitive disorders and their carers, fostering understanding for action, and promoting the social movement. Two of the Plan's 10 action objectives have been completed, with a total progression of 65%.

Dr. Teresa Abusleme Lama presented Chile's National Plan on Dementia. She gave a detailed background on the prevalence, disease burden, and cost of dementia in the country, in addition to key risk factors for the disorder. The Plan has eight primary components and reflects the underlying principles of autonomy, intrinsic dignity, participation and solidarity. Program interventions are multicomponent, person-centered, dynamic, and implemented by interdisciplinary teams. Key advances since 2015 include the establishment of 10 community support centers for people with dementia across the country; 3,000 people with dementia treated and 3,000 carers supported; and the design of protocols for referral, treatment, training, and monitoring and evaluation among others.

Work Group

Participants were divided into three groups by subregion. Each group was given the same set of questions to facilitate discussion on designing and implementing national dementia plans. The questions encouraged groups to consider strengths, weaknesses, opportunities, and threats to the development of national dementia strategies and plans or the implementation of already existing plans. Additional questions asked about priority action areas in each subregion, recommendations for principal actions, technical support needs, and lessons learned from the country presentations given earlier that day. Afterwards, the groups presented their work to the rest of the participants.

Some common weaknesses expressed by the groups were a lack of specific and stable funding for dementia; weak involvement of people with dementia and their carers; and lack of services including education for carers of people with dementia. Shared strengths included existing epidemiological studies on dementia and capacity-building initiatives. Common threats named were stigma associated with dementia, lack of political support, and fragmentation of efforts or poor coordination. Mutual opportunities included workshops, such as this one, strengthening alliances, and global organizations that have pushed the importance of dementia as a public health issue.

Shared priority areas across subregions were developing and implementing dementia plans and policies, dementia research, and coordination between sectors and countries. Regarding technical support, the groups suggested the continued need for dementia intervention and treatment protocols and mechanisms through which to share successful experiences regionally.

Some of the lessons the work groups took from the country presentations on their national dementia plans were the necessity of involving the government in dementia planning, the need to integrate dementia plans into other policies such as those on aging, and the importance of being realistic for the particular country/region.

Day 2

Day 2 of the workshop focused on tools and strategies to promote diagnosis, treatment, and support in the community for those suffering from dementia and their carers. Katrin Seeher of WHO's Department of Mental Health and Substance Abuse presented via WebEX on the various WHO tools and initiatives related to the Global Action Plan's seven action areas. Other presentations were given by Saskia Sivananthan also from WHO, who presented the Global Dementia Observatory via WebEX, and Kate Gordon of ADI, who spoke on the organization's dementia research and interventions among Hispanic populations in the United States.

A work group in the afternoon divided participants into four groups. Each group was asked to answer a series of five different questions on a different key area of the Global Action Plan. Representatives from each group then shared their work with the entire group.

Presentations

1. *WHO Tools and Initiatives to Strengthen Community Capacity for Dementia*
Katrin Seeher, WHO

The seven global dementia action plan areas were presented along with corresponding WHO activities to support Member States in each of these areas. For *Dementia as a Public Health Priority*, the WHO Policy Guidance Tool is recommended for providing "how to" information concerning the development and implementation of national dementia plans, be they stand alone or integrated into existing policies. For the action area *Dementia Awareness and Friendliness*, countries can take advantage of the Dementia-Friendly Initiatives (DFI) Toolkit, which will guide policy-makers in scaling up grassroots initiatives to create a more dementia-friendly society and assist them in monitoring and evaluating these initiatives. For *Dementia Risk Reduction*, the WHO has Dementia Risk Reduction Guidelines, which include proposed actions on lifestyle factors, effective models of delivery, and cost-effective ways of increasing the uptake and maintenance of healthy lifestyle behaviors. Under the action area *Dementia Diagnosis, Treatment, Care and Support*, WHO tools include mhGAP for training in nonspecialized healthcare settings, and the WPRO dementia toolkit for community workers. iSupport, an e-training program for carers of people with dementia, is a key resource in supporting carers of people with dementia. The Global Dementia Observatory, introduced by Saskia Sivanantha in the next presentation, is the primary WHO initiative to strengthen information systems for dementia. The presentation also outlined additional resources to support the implementation of the Global Dementia Action Plan created by organizations such as ADI, Alzheimer Europe, and the Organisation for Economic Co-operation and Development (OECD).

2. *The WHO Global Dementia Observatory*
Saskia Sivanantha, WHO

The WHO Global Dementia Observatory (GDO) was launched in December 2017. The GDO is a mechanism to monitor the Global Dementia Action Plan and national dementia plans, strategies, and policies. Its objectives are to support countries in reducing the disease burden and cost of dementia; to support countries' needs in service planning and policies to strengthen dementia capacity; to monitor progress in dementia within countries and globally; and to allow sharing of best practices on a knowledge exchange platform. The platform will consist of data visualizations (dashboards with graphs and indicators), and a repository of global and country profiles, reports and policy briefs. Phase 1 of data collection took place in 18 countries. Countries are currently being recruited to participate in Phase II based on level of interest and readiness.

3. *Successful Interventions in the Community*
Kate Gordon, ADI

Latino populations in the United States have a 1.5 times greater chance of developing Alzheimer's disease, and the number of Latinos with the disease is expected to rise rapidly, producing greater economic costs and burden on caregivers. More than one in five people cares for someone with dementia. Being a caregiver can create high levels of both physical and emotional stress, and caregivers often do not receive the additional support they need. This presentation highlighted some effective evidence-based interventions shown to reduce caregiver burden and depression, minimize behavioral problems, and increase carers' perception of being supported. Key training areas that these programs have in common include: conflict resolution, communication, managing difficult behaviors, and maintain caregiver health. ADI encouraged participants to learn more about the impact of these programs for caregivers and to try a small pilot study in their countries.

Work Group

In this work group, participants were asked to divide themselves into four groups. Each group was given a set of questions on a different action area of the Global Dementia Action Plan: dementia as a public health priority; dementia diagnosis, treatment, care, and support; dementia awareness, friendliness, and risk reduction; or dementia research, innovation, and information systems.

Common themes that were shared by the groups in their answers were the need for integration of dementia into other sectors, health programs, and topics (e.g. heart health, risk factors, etc.); the strong coordination of efforts; and the representation and inclusion of all people affected by dementia in the various phases of initiatives targeting different action areas.

Next Steps

The meeting concluded with an open discussion of next steps. Many participants shared their appreciation for the opportunity to participate in this first regional meeting on dementia. Not only were participants pleased to meet and collaborate with dementia counterparts in other countries, but also to

engage in discussions with PAHO and ADI on the subject. They expressed a desire to arrange a follow-up meeting.

A large part of the discussion centered on working within countries' current situations and with resources already available to them. A representative from Colombia noted the value of leveraging PAHO's 2017 World Health Day campaign on depression to integrate dementia into the conversation. Other participants recommended integrating dementia into other health topics, such as smoking and nutrition, which are both risk factors for the disease. While motivated by the workshop, some participants questioned how to move forward in situations where the government had shown little political will in addressing the issues of aging and dementia.

Another point agreed upon was the value of the WHO dementia tools presented at the meeting and the need to translate those tools which are not yet available in Spanish. PAHO representatives encouraged countries to be vocal in expressing their desire for Spanish translation of the materials, which would help catalyze the initiative.

Annexes

Annex A: Participant Photo and List

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Asociacion Dominicana de Alzheimer
Dominican Republic

Victor Adorno
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Paraguay

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Annex B: Workshop Agenda

AGENDA

Day 1

8:30-9:00 a.m.	Registration
9:00-9:30 a.m.	Welcome/Introduction on the topic of dementia in the Region Alexandra Rodriguez, Master of Ceremonies, National Consultant, Health Systems and Services, PAHO/WHO Dévora Kestel, Unit Chief, Mental Health and Substance Use, PAHO/WHO
9:30-9:50 a.m.	Presentation by Dominican Republic Ángel Almánzar, Director of Mental Health, Ministry of Health, Dominican Republic
9:50-10:30 a.m.	Introduction to PAHO's Strategy and Plan of Action on Dementia in Older Persons Cristina Alonso, Advisor on Healthy Aging, PAHO/WHO Introduction to the WHO's Global Action Plan on the Public Health Response to Dementia 2017–2025 Tarun Dua, Neurological Disorders and Public Health, WHO
10:30-11:00 a.m.	Break
11:00–12:00 p.m.	Advances in dementia plans and strategies <i>(In-depth examples of countries with successful implementation)</i>
12:30-1:00 p.m.	Lunch
1:00-1:30 p.m.	Advancing dementia plans and strategies Tarun Dua, Neurological Disorders and Public Health, WHO
1:30-3:00 p.m.	Working groups <i>(Work on designing national/regional plans and incorporating dementia into other national plans using WHO/PAHO dementia plans as a reference)</i>
3:00-3:30 p.m.	Break
3:30-4:30 p.m.	Presentation of group work
4:30-5:00 p.m.	Reflection on Day 1/Conclusion

Day 2

8:30-9:00	Introduction to Day 2
9:00-10:45 a.m.	Present WHO tools/initiatives to strengthen community capacity for dementia

Katrin Seeher, Department of Mental Health & Substance Abuse, WHO

10:45-11:00 a.m.

Break

11:00-12:00a.m.

Global Dementia Observatory

Saskia Sivananthan, Department of Mental Health & Substance Abuse, WHO

12:00 –1:00 p.m.

Lunch

1:00-2:00 p.m.

Successful interventions in the community

Kate Gordon, Policy Advisor, Alzheimer’s Disease International (ADI)

2:00-3:00 p.m.

Working groups

Group 1: Dementia as a public health priority

Group 2: Dementia awareness, dementia friendliness and risk reduction

Group 3: Diagnosis, treatment, care and support for dementia

Group 4: Research, innovation and information systems for dementia

3:00-3:30 p.m.

Break

3:30-4:30 p.m.

Presentation of group work

4:30-5:00 p.m.

Reflection on Day 2/Conclusion