



Technical Meeting on the Public Health Aspects of Dementia in the Americas

18 November, 2021 (virtual)
Meeting Report

PAHO



Pan American
Health
Organization



World Health
Organization
REGIONAL OFFICE FOR THE
Americas

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Meeting Report



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Abbreviations and Acronyms

ADI	Alzheimer's Disease International
ALMA	Asociación de Lucha contra el Mal de Alzheimer
ASCADA	Asociación Costarricense de Alzheimer y otras Demencias Asociadas
DALYs	disability-adjusted life years
GDO	Global Dementia Observatory
mhGAP	Mental Health Gap Action Programme
NCD	noncommunicable diseases
PAHO	Pan American Health Organization
STRiDE	Strengthening Responses to Dementia in Developing Countries
TASE	Fundación Trascender con Amor Servicio y Excelencia (Ecuador)
WHO	World Health Organization

Introduction

In 2019, the World Health Organization (WHO) classified dementia as a leading public health challenge, affecting an estimated 55 million persons globally (1). This brain condition is among the top ten causes of death worldwide and is the third leading cause of death in the Americas, affecting the lives of over 10 million individuals and costing the Region an estimated US\$ 379 billion (2). In response to the growing number of people living with dementia, WHO Member States adopted the [Global Action Plan on the Public Health Response to Dementia 2017–2025](#)(1), prioritizing dementia as a major public health concern. In 2021, WHO assessed global progress towards the implementation of the Action Plan (1) and identified opportunities for accelerated actions to achieve the global targets by 2025.

The Pan American Health Organization (PAHO) made dementia a public health priority in 2015 by adopting the [Strategy And Plan Of Action On Dementias In Older Persons](#) for 2015–2019 (3). Through this Regional Strategy, PAHO provided a blueprint for action by prioritizing the inclusion of dementia in policies, educational plans, and promoted early diagnosis to ensure timely access to health services (2).

Since 2020, PAHO has been a regional leader in the implementation of the United Nations Decade of Healthy Aging (2021–2030) (4), which mobilized a global movement to engage stakeholders to work together to improve the lives of older persons, their families, and communities. The Decade’s plan of action highlights the need to deliver comprehensive, person-centered, integrated health and social care for people with dementia. The proposal also calls for developing dementia-friendly and inclusive strategies that provide supportive environments for older adults’ abilities (5).

On 18 November 2021, PAHO conducted a [Technical Meeting on the Public Health Aspects of Dementia in the Americas](#). The virtual meeting, simulcasted in English, Spanish & Portuguese, hosted 167 decision-makers from regional and national associations, foundations, academic institutions, and PAHO Member States.

Meeting Aims, Objectives, and Topic Areas

Aims

The aims of the Technical Meeting on the Public Health Aspects of Dementia in the Americas were to exchange lessons learned, showcase achievements and enable Member States and territories of the Americas to better understand how the Global dementia action plan ¹ can be implemented at the country level.

Objectives

1. Improve country-level understanding of the regional burden of dementia and promote awareness of the Global Action Plan on the Public Health Response to Dementia 2017–2025¹ and other WHO tools and resources.
2. Highlight the urgent need for countries to collect and analyze national data on dementia and present submissions to the Global Dementia Observatory (GDO).

3. Strengthen the quality and generalizability of research studies on dementia, especially in low- and middle-income countries.
4. Facilitate the engagement of participants with lived experience of dementia, and dementia carers in dementia-inclusive initiatives.
5. Share lessons learned and good practices between countries to inform the development of Regional and country-specific responses to dementia.

Topic areas

1. Dementia as a public health priority (Global context and progress to date)
2. The importance of a timely diagnosis, spotting the early signs of dementia, and advances in risk reduction
3. The Regional context of dementia
4. Panel Discussions
 - a. Country experiences and lessons learned from selected action areas of the WHO Global Plan of Action
 - b. Research for coordinated responses to dementia
 - c. Persons with dementia and their carers
5. The Global Dementia Observatory and how systematic monitoring can support the implementation of the global action plan ¹ both globally and country levels

Meeting Summary

Welcome Remarks

In opening remarks, **Dr. Renato Oliveira**, Unit Chief, Mental Health and Substance Use Unit, PAHO commented on the importance of a multisectoral discussion on dementia as a public health priority. Dr. Oliveira emphasized the importance of engaging Member States, civil society, people living with dementia and their carers in a dialogue on solutions to reduce the treatment gap and increase access to early identification and care for dementias in the Region of the Americas. He also elaborated on the devastating consequences of the COVID-19 pandemic on the Region, particularly for the mental health of populations and the provision of services for mental, neurological, and substance use disorders. COVID-19 highlighted the need for improved access to quality services and support for people living with dementia and their carers.

Global context of dementia - A public health matter:

Dr. Tarun Dua, Unit Head, Brain Health, Mental Health and Substance Use Department (WHO), presented on the *Global context of dementia as a public health matter*, noting increased rates of cognitive deterioration post-COVID-19 infection in people with lived experience of dementia. She also provided insight into how the pandemic continues to change the world's health profile. In addition, her overview of the global targets, established as part of the Global Action Plan on the Public Health Response to Dementia 2017–2025 ¹, emphasized that more must be done to meet the 2025 targets. In closing, Dr. Dua reemphasized the need to refocus Member States on the seriousness of this life-changing medical condition and the burden that dementia causes at the individual, country, and regional levels.

The importance of a timely diagnosis, early signs & advances in risk reduction:

Ms. Paola Barbarino, CEO of Alzheimer's Disease International (ADI), presented on *The importance of a timely diagnosis, spotting the early signs of dementia and advances in risk reduction*. She delivered a recorded presentation on ADI's approach to addressing dementia in 105 countries. Her presentation focused on the importance of early diagnosis of dementia and the critical role skilled medical care providers have in aiding persons with lived experience cope with the diagnosis and adjusting to their new way of life.

Dementia in the Americas: Regional context:

Dr. Enrique Vega Garcia, Unit Chief, Healthy Life Course (PAHO/WHO), made a presentation titled, *Regional context of dementia*. Dr. Garcia provided a comparative overview of the rapidly-increasing rate of dementia within the Region due to the epidemiological and demographic transition of the population when compared to global profiles. In summary, he reaffirmed that an essential change in the care of the aging population is needed to better address the effects of dementia. Components of this change include shifts in the general population's mindset and the increased availability of dementia-friendly environments.

Panel discussions

Three panel discussions on the WHO Global Plan of Action for dementia focused on:

1. Country experiences and lessons learned on key action areas
2. Research for coordinated responses to dementia
3. Persons with lived experience of dementia and their carers

The summary below provides an insight into how countries from each subregion are addressing dementia in response to action areas specified in the Global Plan.

Country experiences and lessons learned on key action areas of the WHO Global Plan of Action for dementia:

Costa Rica: Dementia awareness and friendliness

Dr. Norbel Román of the Asociación Costarricense de Alzheimer y otras Demencias Asociadas (ASCADA), provided an overview of the current state of dementia response within Costa Rica and identified key areas where the country has made advances. One area of advancement—research on dementia—has been led by members of the civil society. The study, which captures a grassroots perspective of dementia in Costa Rica, resulted in the ratification of five laws supporting people with lived experience of this brain condition. However, Dr. Román emphasized that more could be done in Costa Rica to address the needs of this vulnerable population; and the further inclusion of civil society on dementia matters can be beneficial to the Region.

Argentina: Country experience on Dementia risk reduction

Mr. Juan Linares of the Asociación de Lucha contra el Mal de Alzheimer (ALMA) in Argentina, echoed the thoughts of Dr. Román. Mr. Linares, an economist, emphasized the importance of dementia research and noted the need for countries to keep a data repository. These data sets will facilitate the accurate analysis of the state of dementia within the Region, and also allow intergovernmental agencies such as PAHO/WHO to better assess and formulate collaboration and technical support with Member States. In addition, the collection of valid data on dementia will also enable countries to formulate much-needed interventions.

Suriname: Dementia as a Public Health Priority

Dr. Kristine Luckham, Chairman of the Foundation Alzheimer and other dementia in Suriname provided a first-hand experience of the fear and economic hardship people with lived experience of dementia face. Due to this increasing concern and the lack of guidelines, her foundation vigorously lobbies to establish a national plan for dementia.

Research on Coordinated Responses to Dementia:

Caribbean Institute for Health Research (Jamaica)

Dr. Ishtar Govia, Senior Lecturer in Epidemiology at the Caribbean Institute for Health Research, The University of the West Indies, Mona Campus in Jamaica, presented on the stakeholder co-development and co-monitoring of a Theory of Change to guide a three-year project called Strengthening Responses to Dementia in Developing Countries (STRiDE). Dr. Govia's presentation emphasized the benefits of implementing rigorous scientific research to ensure that people with this brain condition live well and that their carers do not shoulder excessive costs or burden. STRiDE's approach included situation analyses, stigma reduction and awareness, study of the costs that family and other carers bear, and delineation of the current and future projected burden of dementia. The approach co-developed with people living with dementia, their carers, health and social care workers, governmental representatives and other stakeholders can facilitate sustainable change to address the burden of dementia in the Region. The approaches that the STRiDE Jamaica team used, can be replicated within the Region of the Americas.

Dementia in Latin America (Brazil)

Dr. Cleusa Ferri, Professor at the Department of Psychiatry at Federal University of São Paulo addressed the importance of structured and valid dementia research within the Region. Dr. Ferri discussed the lack of quality research on dementia within the Americas, citing a lack of epidemiological studies on aging and dementia. In her presentation, she noted that approximately 25 studies on the prevalence of dementia from 14 countries within the Region had been published, with most of the research conducted in urban areas in Brazil, Cuba, and Mexico. Speaking specifically about her work in Brazil, she noted that the lack of regional prevalence data results in the under-representation of the burden of dementia on Brazil and the entire Region.

Persons and Carers of people with Lived Experience:

Carers and relatives around Alzheimer's (A Social Campaign)

Ms. María Verónica Faini of Ecuador's Fundación Trascender con Amor Servicio y Excelencia (TASE) presented on how the TASE foundation supports people with lived experience of dementia and their carers. One area is prevention, training, and awareness of dementia. The other area of support is the improvement of essential health care services and the reduction of stigma against people living with dementia and their carers. Offering both a digital and in-person approach to service care and including both the government and private sector has been a key component to TASE's success.

Virgin Islands Alzheimer's Association (A Grassroots Movement)

Ms. Edna Williams, Director of the British Virgin Islands (BVI) Alzheimer's Association, provided a contextual description of dementia in the BVI, and the impact grassroots movements and civil society have in spotlighting dementia as a significant public health concern. In her presentation, Ms. Williams showcased the collaborative partnership her organization has with local stakeholders (e.g., the Red Cross & Rotary club of the BVI). In addition, she showed pictures of the trainings her association provided to frontline workers which featured the Alzheimer's Society's *Dementia Friends* approach to changing peoples' perceptions of dementia.

Global Dementia Observatory (GDO)

Dr. Katrin Seeher, Technical Officer, WHO Mental Health and Substance Use Department, Brain Health Unit, discussed the importance of Member States utilizing the Global Dementia Observatory (GDO) platform as a tool for the systematic monitoring of the seven strategic action areas in the Global Dementia Action Plan. The GDO platform provides a guided approach to Member States for capturing essential information on their country's specific advances towards meeting the 2025 global targets. In her presentation, Dr. Seeher emphasized the importance of having a central repository on dementia, such as the newly launched [GDO Knowledge Exchange Platform](#), to share best practices that have been implemented which could be adapted to a specific country's context.

Final considerations:

The meeting concluded with an open discussion led by the session's moderator on the proposed next steps for 2022 and reaffirming PAHO's commitment for further collaboration with Member States and civil society organizations to address the growing burden of this medical condition. During the closing segment of the meeting, many participants shared their appreciation for the opportunity to participate in this first Regional technical meeting on dementia. Participants were pleased to meet and collaborate with counterparts within the Americas and engage in discussions with PAHO and other relevant stakeholders working on issues related to dementia.

A key point presented was the value of the WHO dementia monitoring tools presented at the meeting and the need to have them in several languages. PAHO representatives encouraged countries to be vocal in expressing to their governments the importance of capturing valid data to increase the tool's usefulness.

Although motivated by the technical workshop, some participants questioned how to move forward in situations where there is little political will in addressing the issues of aging and dementia. A significant part of the discussion focused on working within countries' current situations and available resources. Several participants recommended integrating dementia into other health topics (such as smoking cessation and substance use campaigns), which are both risk factors for the disease. It is paramount that countries are supported in reaching the Global Action Plan targets.

Meeting Outcomes

The information provided in this technical meeting allowed PAHO:

- To improve awareness of the regional burden of dementia, the Global Action Plan on the Public Health Response to Dementia 2017–2025¹, and WHO tools and resources that countries, organizations, and individuals can use to support persons with dementia and their carers.
- To improve awareness about the GDO as a vital tool for strengthening dementia monitoring and data gathering to inform tailored country-level responses.
- To improve awareness of the need for research and the capturing of national data while also ensuring the accurate reporting of diagnosis and costs of dementia in low- and middle-income countries.
- To promote dementia-inclusive environments as a way of understanding dementia, stigma reduction, and caregiver support.
- To foster discussions on opportunities for and barriers to developing national dementia plans, policies, and responses.

Conclusions

The rationale for this technical meeting was to foster the exchange of lessons learned and achievements made in dementia treatment and support. Participants discussed efforts related to the action areas of the Global Dementia Action Plan¹ and the importance of accelerating progress towards the global targets. Additionally, the session provided critical information on the regional burden of dementia while also highlighting the rapid epidemiological and demographic transformations in the Region. The meeting also emphasized the importance of addressing dementia in the context of the recently launched United Nations Decade of Healthy Aging (2020–2030)⁴.

The COVID-19 pandemic not only affected people living with dementia but also disrupted the provision of essential mental health services. Although dementia remains a public health priority for the Region, there are limited resources and insufficient capacity to implement national dementia policies. Advances have been noted in some countries in the Americas. However, more needs to be done to meet the targets set in the Global Dementia Action Plan for 2017–2025¹.

Given the stigma and discrimination experienced by people living with dementia and their carers, it is crucial to advocate for a heightened public awareness campaign to improve the general understanding this neurological condition. This aligns with the Global Plan's action areas of building dementia awareness and dementia-friendly environments, increasing accessibility of care and creating community facilities where older people can socialize. WHO's Global Dementia Action Plan¹ also recommends developing programs to encourage positive attitudes.¹⁰ Therefore,

it is essential to support countries in capacity building of non-health and social professionals establish dementia-friendly initiatives.

The continued technical cooperation with Member States to improve access to quality services and support for people living with dementia and their carers remains a high priority for PAHO. During the session's closing discussion, most participants identified the following priority areas for future collaboration (support for dementia carers, promoting dementia as a public health priority and increasing dementia awareness and inclusiveness). During panel discussions on the country experience and discussions on lessons learned, participants presented positive experiences and also addressed barriers and gaps experienced when implementing activities designed to increase dementia awareness.

The ability to provide early diagnosis, treatment and care has been identified as the main challenge experienced by stakeholders in many countries within the Region. Therefore, PAHO is actively supporting countries in capacity-building in the use of the Mental Health Gap Action Intervention Guide (mhGAP-IG)⁶. This document, which includes a module on dementia, guides primary health care providers on the integrated management of mental, neurological and substance use disorders (MNS) in non-specialized health settings, using algorithms for clinical decision making.

The development of a national dementia plan is an important commitment demonstrated by governments. While some countries have a plan on dementia, several indicated that their respective countries had not established a national policy on dementia or had not yet incorporated such a policy into a national plan. Therefore, there is a need to support countries to prepare a plan that guides a strategic response to this medical condition to avoid delays of essential services.

In addition, the routine collection of health information on people with dementia is limited. WHO initiatives, such as the GDO facilitates the collection of key data on dementia by Member States, which in turn can be used to strengthen their response to the needs of people living with dementia and their carers.

Next Steps and follow-up

Below are key actions that emanated from the meeting, which the technical unit can support, based on technical requests from the Ministries of Health of the Region.

1. Organize a follow-up meeting to provide information on specific activities that support countries with implementation of the WHO Global Dementia Action Plan.
2. Provide technical cooperation to countries to prepare, update and implement national dementia plans or integrate dementia into other plans and programs in coordination with civil society associations.
3. Provide technical support in capacity-building in mhGAP and introducing available tools for training such as *iSupport*; a Self-Learning Virtual Course through the PAHO Virtual Campus of Public Health, delivered in both English and Spanish.

4. Collaborate with the countries in organizing training for dementia carers, as well as training of primary health care providers to improve diagnosis, treatment, care and support for people with dementia with an emphasis on boosting the response capacity in primary health care.
5. Support the integration of dementia care and response into national documents such as Mental Health Strategies and/or Policies and Plans of Action for noncommunicable diseases (NCDs).
6. Cooperate with countries to formulate and execute regular implementation of dementia education and awareness programs, and public awareness campaigns.
7. Provide technical cooperation to Member States, civil society, people with lived experience, and their carers, to introduce and improve the reporting of data on dementia to national health information systems.

Annex

Session attendees

Representatives from the following countries:

Argentina, Bahamas, Belize, Bermuda, Bolivia, Brazil, British Virgin Islands, Canada, Chile, Colombia, Costa Rica, Cuba, Curaçao, Dominican Republic, Ecuador, El Salvador, Guatemala, Guyana, Haiti, Honduras, Jamaica, Mexico, Mozambique, Nicaragua, Panamá, Paraguay, Puerto Rico, Saint Vincent and the Grenadines, Suriname, Trinidad and Tobago, United States, Uruguay, Venezuela

Participating partners & national associations and foundations

Alzheimer's Disease International (United Kingdom)

Asociación Costarricense de Alzheimer y otras Demencias Asociadas (Costa Rica)

Asociación de Lucha contra el Mal de Alzheimer (Argentina)

The Foundation Alzheimer and Other Dementia in Suriname

Fundación Trascender con Amor Servicio y Excelencia (Ecuador)

British Virgin Islands Alzheimer's Association

Participating academic organizations

Caribbean Institute for Health Research (Jamaica)

Federal University of São Paulo (Brazil)

Media

Click on the following images to access the websites.

About dementia (<https://www.paho.org/en/topics/dementia>)

The Global Dementia Observatory (GDO)(<https://globaldementia.org/en>)

Session Recording (Select the language to access the video recording)

(<https://www.youtube.com/watch?v=FIOAlfYTjsI>)

[English](#) [Spanish](#) [Portuguese](#)

Moderators: Dr. Claudina Cayetano and Dr. Patricia Morsch

Agenda

Time	Session	Speaker
9 :00 – 9:30 am	Welcome Remarks	Dr. Renato Oliveira - Unit Chief, Mental Health and Substance Use (PAHO/WHO)
	Dementia, a public health priority; global context and progress to date	Dr. Tarun Dua - Unit Head, Brain Health, Mental Health and Substance Use Department (WHO)
	The importance of a timely diagnosis, spotting the early signs of dementia and advances in risk reduction	Ms. Paola Barbarino - CEO Alzheimer's Disease International
9:30 – 9:40 am	Regional context of dementia-	Dr. Enrique Vega Garcia - Unit Chief, Healthy Life Course (PAHO/WHO)
9:40 – 10:10 am	Panel discussions: Country experiences and lessons learned on selected action areas of the WHO Global Plan of Action	Dr. Norbel Román - Asociación Costarricense de Alzheimer y otras Demencias Asociadas (ASCADA)
		Mr. Juan Linares -Asociación de Lucha contra el Mal de Alzheimer (ALMA) en Argentina
		Dr. Kristine Luckham - Chairman of the Foundation Alzheimer and Other Dementia in Suriname
10:10 - 10:40 am	Research for Coordinated Responses to Dementia	Dr. Ishtar Govia - Professor- Caribbean Institute for Health Research (Jamaica)
		Dr. Cleusa Ferri - Federal University of São Paulo (Brazil)
10:40 – 11:10 am	Panel discussions: Persons and Carers of people with Lived Experience	Ms. María Verónica Faini - Fundación Trascender con Amor Servicio y Excelencia (Ecuador)
		Ms. Edna Williams Director of the British Virgin Islands Alzheimer's Association
11:10– 11:25 am	The Global Dementia Observatory (GDO) – How systematic monitoring can support the implementation of the Action Plan ¹ globally and at country level.	Dr. Katrin Seeher - Technical Officer, Brain Health Unit, Mental Health and Substance Use Department, (WHO)
11:25 – 11:50 am	Q/A & Comments	Dr. Patricia Morsch - Advisor, Healthy Aging, Healthy life Course Unit, (PAHO/WHO)
11:50 – 12:00 pm	Post meeting assessment Next Steps	Dr. Claudina Cayetano – Advisor, Mental Health Regional (PAHO/WHO)

References

1. World Health Organization. Global Action Plan on the Public Health Response to Dementia 2017 – 2025. Geneva: WHO; 2017. Available from <https://www.who.int/publications/i/item/global-action-plan-on-the-public-health-response-to-dementia-2017---2025>
2. Pan American Health Organization. Burden of Neurological Conditions Data Portal. Washington, DC: PAHO; 2021 [cited 1 March 2022]. Available from: <https://www.paho.org/en/enlace/technical-notes>.
3. Pan American Health Organization. Strategy and Plan of Action on Dementias in Older Persons [Working Document CD54/8, Rev. 1]. 54th PAHO Directing Council, 67th Session of the Regional Committee of WHO for the Americas; 28 September – 2 October 2015. Washington, DC: PAHO; 2015. Available from: <https://www.paho.org/hq/dmdocuments/2015/CD54-8-e.pdf>
4. World Health Organization. The Decade of Healthy Aging in the Americas (2021-2030). Washington, DC: PAHO; 2021. Available from: <https://www.paho.org/en/decade-healthy-aging-americas-2021-2030>
5. World Health Organization. WHO reveals leading causes of death and disability worldwide: 2000 – 2019. Geneva: WHO; 2020 [cited 2022, March 1]. Available from: <https://www.who.int/news/item/09-12-2020-who-reveals-leading-causes-of-death-and-disability-worldwide-2000-2019>
6. World Health Organization. mhGAP Intervention Guide – Version 2.0. Geneva: WHO; 2017 [cited 1 March 2022]. Available from: <https://www.who.int/publications/i/item/9789241549790>
7. World Health Organization. Global Status Report on the Public Health Response to dementia. Geneva: WHO; 2021 [cited 1 March 2022]. Available from: <https://asogeromed.es/wp-content/uploads/INFORME-OMS.pdf>