Meeting on the implementation of the global action plan on the public health response to dementia

- Meeting report -

11-12 December 2017 World Health Organization, Geneva, Switzerland



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Introduction

Dementia is one of the major causes of disability and dependency among older people worldwide. It is overwhelming not only for people who have it, but also for their carers and families. As the global population ages, the number of people with dementia is expected to triple from 50 million to 152 million by 2050.

There is often a lack of awareness and understanding of dementia, resulting in stigmatization and barriers to diagnosis and care. Evidence suggests that up to 90% of people with dementia in low- and middle- income countries (LMICs) do not receive a diagnosis, preventing them from accessing services and receiving support.¹

Dementia, particularly in the later stages, is associated with high levels of dependency and disability, leading to increased long-term care costs for governments, communities, families and individuals, and to losses in productivity for economies. In 2015, the global cost of caring for people with dementia was estimated to be US\$818 billion – 1.1% of global gross domestic product (GDP). By 2030, this cost could be a staggering US\$2 trillion, which would undermine social and economic development globally. The fact that dementia is not yet a national priority in most countries has led to a lack of systematic monitoring and evaluation of dementia efforts and to fragmented health and social care services for people with dementia. For example, only 15% of Member States currently have a national plan to address dementia.

To address this global challenge, the Seventieth World Health Assembly endorsed the global action plan on the public health response to dementia 2017-2025² in May 2017; thereby committing to reaching global targets across seven key action areas, including the development of national strategies and plans. The global action plan emphasizes the need to integrate health and social care approaches and align actions with ongoing strategic developments in mental health, noncommunicable diseases (NCDs) and ageing.

To further address the global challenges posed by dementia and to support the implementation of the global action plan on the public health response to dementia 2017-2025, WHO hosted a two-day meeting in Geneva, Switzerland on the 11th and 12th of December 2017.



WHO Deputy Director-General for Programmes, Dr Soumya Swaminathan, opening the meeting

¹ Alzheimer's Disease International and World Health Organization. Dementia: a public health priority. Geneva: World Health Organization; 2012, available at:

http://www.who.int/mental_health/publications/dementia_report_2012/en/ .

² The global plan aims to improve the lives of people with dementia, their families and the people who care for them, while decreasing the impact of dementia on communities and countries. Areas for action include: reducing the risk of dementia; diagnosis, treatment and care; research and innovative technologies; and development of supportive environments for carers. For more details see:

http://www.who.int/mental_health/neurology/dementia/action_plan_2017_2 025/en/

Meeting objectives and expected outcomes

The two-day meeting brought together 86 key stakeholders including policymakers, academic researchers, civil society as well as people with dementia and their carers to discuss mechanisms to strengthen countries' capacity to work toward reaching global targets in line with the global action plan on the public health response to dementia 2017-2025 and monitoring their responses. The purpose of the meeting was also to present the Global Dementia Observatory (GDO), an interactive web-based data and knowledge exchange platform - which will serve as the monitoring mechanism for the global dementia action plan.

The list of delegates and detailed agenda can be found in **Appendices 1 and 2**, respectively.

Executive summary

The meeting was opened by WHO Deputy Director-General for Programmes, Dr Soumya Swaminathan, and Assistant Director-General for Noncommunicable Diseases and Mental Health, Dr Svetlana Akselrod. Both highlighted the importance of global coordinated action to address the growing impact of dementia and emphasized that dementia remains a high priority for WHO and for attaining the Sustainable Development Goals (SDGs).

Day 1 of the meeting focused on the global action plan on the public health response to dementia 2017-2025, its seven strategic action areas and associated global targets (**Figure 1**). It also demonstrated how the newly launched Global Dementia Observatory (GDO) can support countries in monitoring their responses to dementia and track the progress toward reaching the global targets.



Figure 1: Seven strategic action areas of the global dementia action plan and associated global targets.



Figure 2: Strategic action areas of the global dementia action plan and tools to support their implementation.

Day 2 was facilitated in small groups and organized along the following themes: (1) Developing national dementia plans, (2) Dementia awareness, friendliness and risk reduction, (3) Dementia diagnosis, treatment, care and carer support, and (4) Dementia research and innovation.

Discussions centered on operationalizing the actions outlined in the global dementia action plan at national level and the mechanisms and tools available to do so (**Figure 2**).

The meeting also highlighted the importance of dementia-specific monitoring to enable countries to track their progress and facilitate reporting.

Topics and themes of the meeting

This part of the meeting report provides more detailed descriptions of the individual topics and themes.

Theme 1: Information systems for dementia

The meeting provided the opportunity to present the recently launched **Global Dementia Observatory (GDO)**. The GDO is available here: <u>http://www.who.int/mental health/neurology/dem</u> <u>entia/Global Observatory/en/</u>

The GDO has been designed, in consultation with international stakeholders and country focal points, to support countries in strengthening policies, service planning and health and social care systems for dementia. It can assist countries in measuring progress towards reaching national and global targets across the seven action areas of the global dementia action plan (**Appendix 3**).



Dr Tarun Dua (WHO, MSD/MER) presenting the conceptual framework of the GDO

The GDO has two components: a data portal and a knowledge exchange platform.

GDO data portal

The GDO data portal is available here: <u>http://apps.who.int/gho/data/node.dementia</u>

The data portal currently features data from 21 countries of all income levels and from all six WHO regions. The portal offers interactive access to national-level dementia data across 35 different indicators (**Appendix 4**), aggregated reports and interactive visualizations and graphs. The GDO data collection will continue throughout 2018 and 2019 to include data for more countries.



Screenshot of the GDO data portal

Aggregated analyses of currently available GDO data were presented during the meeting, accompanied by invited expert commentaries to contextualize the data.

GDO knowledge exchange platform

The GDO knowledge exchange platform contains key resources and tools to support the implementation of the global action plan and enhance countries' response to dementia. It facilitates mutual learning and the exchange of good practices in the area of dementia.

Good practice examples for each of the seven action areas will continuously be identified and upon satisfactory peer-review shared via the knowledge exchange platform.

Theme 2: Developing national dementia policies

This theme concerned action area 1 of the global dementia action plan aiming at making dementia a public health priority. Proposed actions for Member States include: developing national dementia policies, strengthening existing policies; establishing a government unit, department or focal point with clear responsibility for dementia; strengthening legislation that protects the rights of people with dementia and developing supportive regulatory frameworks such as standards, guidelines and protocols for dementia care and service delivery.

The specific objectives of this session were to:

- discuss entry points for, and ways of, developing national dementia plans, or integrating dementia into other national plans; and
- share explicit implementation successes and challenges with respect to developing national dementia plans.

Entry points for developing dementia plans

Identified entry points for developing dementia plans included NCDs and associated risk factors, mental health, ageing, disability, research and health system strengthening. Emphasis was placed on the importance of identifying, leveraging and linking dementia to strategic political priorities. These are country-specific and influence the decision of developing a stand-alone dementia plan or integrating dementia into an existing plan.

The capacity to align dementia with current global priorities, including universal health coverage, the 2030 Agenda for Sustainable Development and its associated SDGs, and human rights, was also identified as a significant entry point, particularly when coupled with global commitment and accountability provided by WHO and other relevant international agencies.

Challenges in developing or implementing dementia plans and strategies to overcome them

Grounded in country experience, participants discussed key barriers and enablers to developing and implementing dementia plans, as well as strategies to overcome identified challenges. While the need for strong political commitment and dedicated funding was identified, participants also shared experiences related to the stigma associated with dementia and the lack of harmonization between sectors and government levels as major challenges. A participatory approach right from the start and the involvement of people with dementia and carers in the development and implementation of a dementia plan was seen as absolutely critical. For more suggestions see Table 1 below.

Barriers	Strategies to overcome barriers
Stigma/lack of public awareness	 country-specific advocacy and public awareness raising by civil society, academia, health professionals, individuals and/or communities; public health education and prevention for dementia embedded in educational system.
Lack of polifical will	 political and social champions (e.g. Head of State, celebrities) that can drive multisectoral and cross-party approval; consistent and reliable data, particularly related to social and economic costs of dementia;
	 linkages to national and global priorities, e.g. universal health coverage, equity, SDGs;
	 legislatively mandated national/sub-national dementia plans and/or dementia tasks force;
	 strong advocacy from civil society and WHO, including accountability through WHO monitoring.
Lack of human and financial resources	 national/sub-national dementia plans that include earmarked funding that is either dementia-specific or included into other budget items (e.g. mental health, NCDs, ageing);
	 identification of "quick wins", i.e. short-term actions, to demonstrate impact and mobilize further funding;
	 multi-stakeholder collaboration and partnerships between government, civil society and private sector;
	 cross-country learning, enabled by the GDO.
Lack of integration across	dedicated focal point and support within government that can lead to
government levels and sectors	multisectoral collaboration across and beyond government;
	regular monitoring and evaluation.

Table 1: Barriers to developing and implementing dementia plans, and strategies to overcome them

WHO's role in supporting the development and implementation of dementia plans

Participants discussed WHO's role in supporting countries in developing and implementing national or sub-national dementia plans. The GDO was highlighted as a key mechanism in doing so, particularly for monitoring and benchmarking purposes. Other suggestions for WHO's role included advocacy at global level by emphasizing the importance of dementia plans, and sharing lessons learned between countries through regional/global workshops, capacity building programmes and the online GDO knowledge and exchange platform. Participants also suggested that WHO develops specific tools to guide countries through the process of developing and implementing plans.

A WHO policy guide entitled **Towards a dementia plan: A WHO guide** – was welcomed by participants with specific suggestions on content. The guide organizes the process of developing a dementia plan into three phases, presents essential steps within each phase, and links closely to the GDO as a means to collate data for situational analysis, priority setting and monitoring and evaluation. The guide will also include a checklist to guide the preparation, development and implementation of a dementia plan, as well as country case studies featuring good practices.



Meeting delegates during one of the break-out sessions

Theme 3: Dementia awareness, friendliness & risk reduction

Discussions in this session related to action areas 2 and 3 of the global dementia action plan. With its adoption. Member States committed to supporting Characteristics of successful public awareness campaigns

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