

## CONSULTATION ON THE DEVELOPMENT OF THE GLOBAL DEMENTIA OBSERVATORY

*World Health Organization, Geneva  
5-6<sup>th</sup> July, 2016*



**World Health  
Organization**



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**Suggested citation.** Consultation on the Development of the Global Dementia Observatory. Geneva: World Health Organization; 2017.

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# Acknowledgements

This document presents a summary report on 'Consultation on the Development of the Global Dementia Observatory' organized by the World Health Organization.

Valuable material, help and advice was received from delegates from Member States, representatives from nongovernmental organizations (NGOs) and civil society, foundations, academia, institutions and WHO Collaborating centres and people with dementia and their carers.

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We gratefully acknowledge all participants who attended the consultation and shared their insights throughout the meeting. In alphabetical order:

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Rossor (National Hospital for Neurology and Neurosurgery, United Kingdom); Charlotte Roberts (International Consortium for Health Outcomes Measurement, United Kingdom); Paritosh Kumar Sarkar (National Institute of Neurosciences & Hospital, Bangladesh); Stefan Schreck (European Commission, Luxembourg); Ameenah Sorefan (Ministry of Health & Quality of Life, Mauritius); Angelina Sosa Lovera (Ministry of Health, Dominican Republic); Ana Luisa Sosa Ortiz (Instituto Nacional de Neurologica y Neurocirogi, Mexico); Kate Swaffer (Dementia Alliance International, Australia); Yuda Taruna (Atma Jaya Catholic University of Indonesia, Indonesia); Gavin Terry (Alzheimer's Society, United Kingdom); Eliane Vanhecke (Ministère de la santé et des affaires sociales, France); Mathew Wahnsiedler (World Innovation Summit for Health, Qatar); Huali Wang (Peking University Institute of Mental Health/Sixth Hospital, China); Amanda Wilson (Public Health Agency of Canada, Canada); Anders Wimo (Care Sciences and Society, Sweden); Raphael Wittenberg (London School of Economics and Political Science, United Kingdom); Marc Wortmann (Alzheimer's Disease International, United Kingdom)

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## FUNDING

The development of WHO's Global Dementia Observatory is supported by Canada, Japan, Switzerland, Netherlands and the United Kingdom

## Introduction

Dementia poses a burden to individuals, communities, and societies. It is one of the major causes of disability and dependency among older people worldwide. It is overwhelming not only for the people who have it, but also for their carers and families. There is often a lack of awareness and understanding of dementia, resulting in stigmatization and barriers to diagnosis and care.

Dementia currently affects more than 47 million people worldwide, and this figure is expected to rise to 75 million by 2030. Dementia costs billions – 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 or more, which would undermine social and economic development globally.<sup>1</sup> Sixty percent of people with dementia live in low- and middle- income countries, and this proportion is projected to only increase over the next decade, which will widen inequalities between countries and populations.<sup>2</sup>

To address the global challenges posed by dementia, a number of national and international efforts have been undertaken in recent years. Although such efforts have generated momentum, there is a need to have a more concerted and unified response in order to maximise the impact and reach of efforts. To this end, WHO hosted the First Ministerial Conference on the Global Action against Dementia in Geneva in March 2015<sup>3</sup>, with active participation of Member States, academia and civil societies. The conference was supported by the UK Department of Health and Organization for Economic Cooperation and Development (OECD). It aimed to raise awareness that the global burden due to dementia can be reduced, if there is a shared commitment among WHO Member States and stakeholders of all resource levels, to put in place the necessary policies and resources for dementia care, finding disease-modifying treatments or cure, and to place action against dementia higher on national and global political agendas.

In the conference's 'Call for Action' the importance of promoting and monitoring global and national efforts on dementia was highlighted, including the need to develop a WHO Global Dementia Observatory (GDO).

## Background and Rationale for Meeting

In order for service planning to be based on accurate scientific evidence and public health needs, a mechanism for continuous monitoring of the dementia landscape is necessary. To date, however, there has been no systematic attempt at collecting global data on dementia as part of the efforts to reduce the burden due to dementia.

A coordinated, systematic and continual surveillance is needed for the following reasons:

- to assess the disease burden
- to make the case and to assist in planning to allocate resources for prevention, treatment and care of dementia
- to create policies to address the impact of dementia
- to conduct research towards dementia cure and care (e.g. finding cure or targeting existing therapies, or other innovations in health and social care delivery).

The GDO is being developed with the primary function of an international knowledge and data exchange platform to support evidence-based service planning and strengthening of policies as well as health and social care systems on four major strategic domains: policy, resource, research and epidemiology.

The GDO will offer easy access to comparable data at a country-level with the ability to integrate with statistics from other available resources such as the Global Health Observatory (GHO). It will also have a knowledge translation and exchange function including the creation of country profiles on dementia readiness and progress.

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<sup>1</sup> WHO. The epidemiology and impact of dementia: Current state and future trends. Geneva: World Health Organization; 2015, Document WHO/MSD/MER/15.3, available at: [http://www.who.int/mental\\_health/neurology/dementia/dementia\\_thematicbrief\\_epidemiology.pdf](http://www.who.int/mental_health/neurology/dementia/dementia_thematicbrief_epidemiology.pdf) (accessed 22 November 2016)

<sup>2</sup> Prince M, Wimo A, Guerchet M, Ali GC, Wu Yutzu, Prina M. World Alzheimer Report 2015. The global impact of dementia: an analysis of prevalence, incidence, cost and trends. London: Alzheimer's Disease International, October 2015.

<sup>3</sup> Who First Ministerial Conference on the Global Action Against Dementia [http://www.who.int/mental\\_health/neurology/dementia/conference\\_2015/en/](http://www.who.int/mental_health/neurology/dementia/conference_2015/en/)

An active surveillance system will ensure this database is kept up to date and regular reports will disseminate information summaries in a user-friendly format to stakeholders and ministries.

## Objectives and Expected Outcomes

A two-day meeting on the GDO was organized by the Department of Mental Health and Substance Abuse to bring key stakeholders together (see Appendix 1 for Agenda). The objectives of the consultation were as follows:

- To present the landscaping for the development of the Global Dementia Observatory
- To discuss the conceptual framework underpinning the Global Dementia Observatory
- To present information and feedback from pilot testing a draft of the Observatory instrument
- To discuss the next phase for further development of the Observatory

The expected outcome was a common vision of the conceptual framework, the interactive knowledge exchange platform of the GDO and a way forward for the further development of the GDO.

The meeting had a range of stakeholders attend including Member States, representatives from nongovernmental organizations (NGOs) and civil society, foundations, academia, institutions and WHO Collaborating centres and people with dementia and their carers (see Appendix 2 for list of delegates).

## Declaration of Interests

Invited experts to the consultation completed the WHO form for declaration of interest prior to the meeting. No conflicts of interest were declared by any of the participants to the Secretariat.

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