

The Global Dementia Observatory

Reference Guide

World Health Organization

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INTRODUCTION

Dementia is an umbrella term for several diseases that are mostly progressive, affecting memory, other cognitive abilities and behaviour, and that interfere significantly with a person's ability to maintain daily living activities. Alzheimer's disease, the most common form of dementia, represents 60–70% of cases. Other major forms include vascular dementia, dementia with Lewy bodies, and a group of diseases that contribute to frontotemporal dementia. The boundaries between different forms of dementia are indistinct and mixed forms often co-exist.

Dementia currently affects approximately 50 million people worldwide (or roughly 5% of the world's older population), a figure that is projected to increase to 82 million in 2030 and 152 million by 2050. Recent reviews estimate that, globally, nearly 9.9 million people develop dementia each year; this figure translates into one new case every three seconds. Nearly 60% of people with dementia currently live in low- and middle-income countries and most new cases (71%) are expected to occur in those countries.

Dementia is the seventh leading cause of death globally and a major cause of disability and dependency among older people worldwide, which not only impacts individuals who have dementia but also their carers, families, communities and societies. Dementia accounts for 11.9% of the years lived with disability due to a noncommunicable disease (NCD).¹ In light of the improved life expectancy globally, this figure is expected to increase further.

In 2012, WHO launched the report *Dementia: a public health priority*² in collaboration with Alzheimer's Disease International to raise awareness of dementia as a public health priority and to advocate for action at international and national levels. Subsequently, WHO organized the First Ministerial Conference on Global Action against Dementia, held in Geneva in March 2015. In the conference's "Call for Action", the importance of promoting and monitoring global and national efforts on dementia was highlighted, including the development of the *Global Dementia Observatory (GDO)*.

The GDO's main objective is to collate and disseminate data from Member States on key dementia indicators to strengthen countries' ability to respond to the needs of people with dementia and their carers. Data collected through the GDO will help strengthen relevant policies and legislation, support evidence-based service planning, and facilitate capacity building across health and social care systems.

In May 2017, the Seventieth World Health Assembly adopted the global action plan on the public health response to dementia 2017-2025 that sets out clear actions for Member States, the Secretariat and partners, as well as global targets and key indicators for tracking progress Towards reaching these targets.³ The GDO will provide the monitoring mechanism for the global action plan on the public health response to dementia 2017-2025.

¹ 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 (accessed 2 December 2017).

² *Dementia: a public health priority*. Geneva: World Health Organization; 2012 (http://www.who.int/mental_health/publications/dementia_report_2012/en/), (accessed 2 December 2017).

³ The action plan is available at: http://www.who.int/mental_health/neurology/dementia/action_plan_2017_2025/en/. For the WHA decision on the global dementia action plan, see: [http://apps.who.int/gb/ebwha/pdf_files/WHA70/A70\(17\)-en.pdf](http://apps.who.int/gb/ebwha/pdf_files/WHA70/A70(17)-en.pdf) (accessed 2 December 2017)

THE GLOBAL DEMENTIA OBSERVATORY

Development of the conceptual framework and indicators

The process of developing the conceptual framework and indicators underlying the GDO included systematic reviews of major international source documents as well as national dementia plans, strategies and guidelines, extensive consultations with key stakeholders and experts, including people with dementia and their carers, policy-makers, service providers, academic researchers and civil society representatives. The draft framework and indicators were pilot-tested by 22 representative low-, middle- and high-income countries from all six WHO regions.¹ Data and feedback provided by pilot countries were used to revise the framework and indicators and align them with the action areas and targets of the global action plan on the public health response to dementia 2017-2025. A detailed description of the entire development process can be found here:

http://www.who.int/mental_health/neurology/dementia/action_plan_consultation/en/.

The finalized framework comprises three domains with multiple subdomains across seven strategic themes (see **Figure 1**).

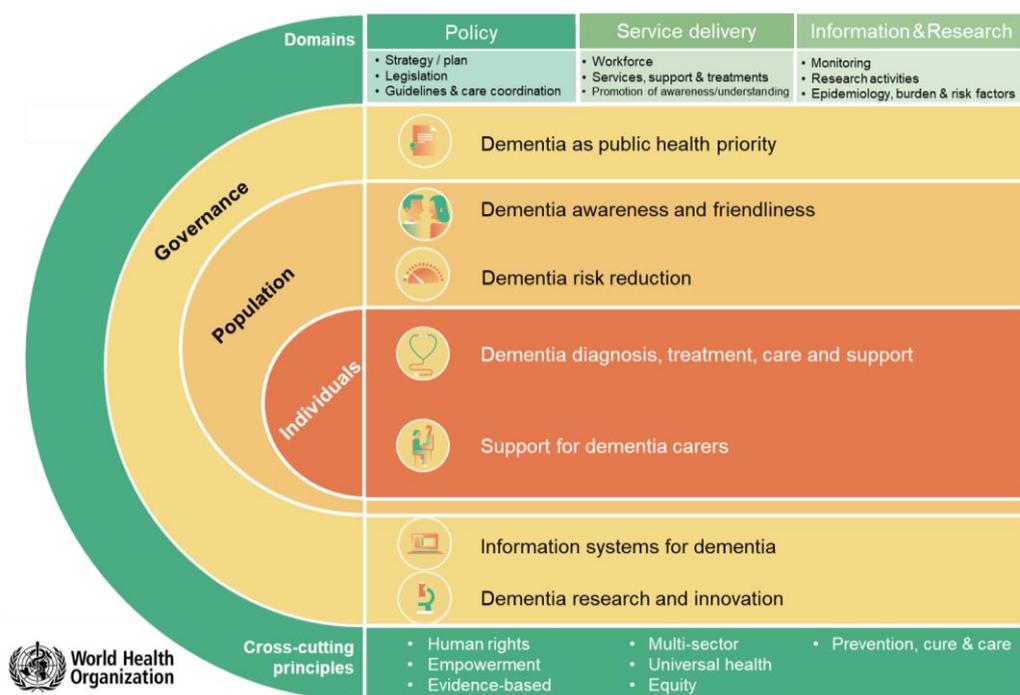


Figure 1.
The Global Dementia Observatory Framework

The **three domains** represent the essential components required for strengthening a country's health and social care system that addresses dementia. These are delineated below.

¹ **African Region:** Mauritius, Swaziland, Togo; **Region of the Americas:** Chile, Costa Rica, Dominican Republic; **Eastern Mediterranean Region:** Jordan, Qatar, Tunisia; **European Region:** France, Hungary, Italy, Netherlands, Sweden, Switzerland, United Kingdom (England); **South-East Asia Region:** Bangladesh, Maldives, Myanmar; **Western Pacific Region:** Australia, Fiji, Japan.

Policy – assesses the availability and implementation of policies, legislation, and guidelines/standards – whether as separate instruments or integrated into policies for NCDs, mental health, ageing or disability (or equivalent). It also determines whether these documents are aligned with the principle of universal health coverage and the standards outlined in the United Nations (UN) Convention on the Rights of Persons with Disabilities.¹

Service delivery – measures available resources to provide sustainable care, from prevention/risk reduction, through diagnosis to end-of-life care. This includes information related to human resources, infrastructure capacity, service provision and utilization, as well as interventions, social protection and benefits for people with dementia and their carers.

Information and research – provides comparative epidemiological data to estimate disease prevalence, incidence, mortality and financial impact, risk factor prevalence, as well as the development, implementation and monitoring of national research agendas and funding for dementia research.

The **seven strategic themes** fully align with the seven action areas of the global action plan on the public health response to dementia 2017-2025. These themes can be viewed as national goals or objectives, which a country can use to introduce, improve or monitor dementia activities.

Together, the three domains and seven strategic themes constitute the GDO framework presented in **Figure 1**. The GDO indicators sit within this framework, each aligning with one of the domains/subdomains and one or more strategic themes. Countries can use the indicators to collect key information on dementia and monitor relevant dementia actions at the national level. Within the core set of GDO indicators, there are also specific indicators to measure individual countries' contribution toward achieving the global targets of the global dementia action plan. Throughout this document, the global target indicators are bolded and/or highlighted in red for easy reference.

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