World Health Organization

The Global Dementia Observatory

Reference Guide

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Vision and conceptualization
The *World Health Organization Global Dementia Observatory Reference Guide* (GDO Reference Guide) was developed under the overall guidance of and conceptualized by Shekhar Saxena and Tarun Dua, WHO Department of Mental Health and Substance Abuse.

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The development of the document, including writing and editing, was coordinated by the dementia team comprising of (in alphabetical order) Neerja Chowdhary, Stefanie Freel, Anne Margriet Pot, Katrin Seeher, and Saskia Sivananthan.

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Contents

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 (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**).

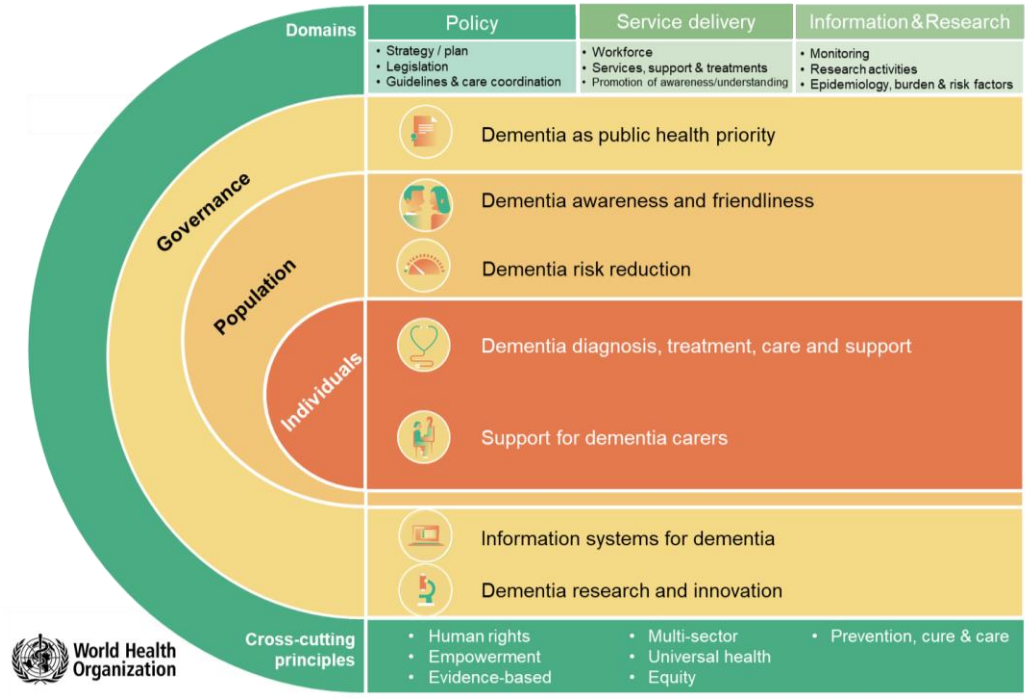

Figure 1. The Global Dementia Observatory Framework

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.

[1] Convention on the Rights of Persons with Disabilities [A/RES/61/106]. New York: United Nations Division for Social Policy and Development Disability; 2007 (https://www.un.org/development/desa/disabilities/resources/general-assembly/convention-on-the-rights-of-persons-with-disabilities-ares61106.html, accessed 26 October 2017).

Table 1. Alignment of the GDO with the global action plan on the public health response to dementia 2017-2025

Domain	Indicator	Action Area
Policy	1. Dementia governance 2. **Dementia plan*** 3. Dementia legislation 4. Dementia standards/guidelines/ protocols 5. Dementia care coordination	**Public health priority** 
Service delivery	6. Dementia health and social care workforce 7. **Dementia diagnostic rate*** 8. Community-based services for dementia 9. Dementia health and social care facilities 10. Anti-dementia medication and care products availability 11. Dementia-specific NGO	**Dementia diagnosis, treatment, care and support** 
	12. **Dementia carer support services***	**Support for dementia carers** 
	13. **Dementia awareness & risk reduction campaigns*** 14. **Dementia-friendly environments*** 15. **Dementia education and training of non-health professionals***	**Dementia awareness & friendliness** 
Information & research	17. Dementia research agenda 18. Dementia research investments 19. Dementia research participation 20. **Published dementia output***	**Dementia research & innovation** 
	16. **Dementia information systems*** 21.-22. Estimated dementia prevalence & incidence 23.-24. Total deaths and YLL due to dementia 25.-26. YLDs and DALYs due to dementia 27. Total economic cost of dementia	**Information systems for dementia** 
	28.-35. **Prevalence of dementia risk factors***	**Dementia risk reduction** 

Legend

* **Red and bold indicators** are used to measure progress toward reaching global targets outlined in the global action plan on the public health response to dementia 2017-2025.

DALYs: Disability adjusted life years; **NGO**: nongovernmental organization, **YLDs**: Years Lived with Disability due to a disease; **YLLs**: Years of Life lost due to a disease.

Purpose and structure of the GDO Reference Guide

The GDO Reference Guide has been designed to **standardize data collection** across Member States and **assist country focal points** in collating relevant national-level data that enable them to monitor progress concerning dementia actions.

The document is divided into **three main chapters**, each addressing one of the three GDO domains (i.e. Policy, Service delivery and Information & Research) and their related subdomains; and a **Glossary** for technical terms.

Indicators are listed under their corresponding domain/subdomain together with an indicator definition, indicator rationale, method of estimation, and potential data sources. To assist countries in collating the relevant information, indicators are articulated as questions and subquestions, along with possible response options.

For the purpose of streamlining the GDO data collection further, all indicator questions are available in an online data collection instrument, the **GDO e-tool**. It is available in English, French and Spanish. Other translations are planned.

Guidance for data collection

Where should I start?

The first step is to identify a person to serve as a **country's focal point** for GDO data collection. Focal points are advised to begin by reviewing the GDO framework (**Figure 1**) in order to understand the GDO's underlying structure. The framework provides an overview of the GDO, the three major domains and the seven strategic themes that it comprises.

Next, it is recommended to **review all indicators and their definitions** in this Reference Guide in order to become familiar with the scope of the data required.

How do I provide data?

To assist focal points in collating all relevant information, an online data collection survey has been developed, **the GDO e-tool**. It guides users in providing data with specific questions and subquestions in a stepped manner. To increase the user-friendliness and efficiency of data collection, the e-tool is available in English, French and Spanish. Subquestions will be automatically skipped if they are not relevant based on responses to previous questions or if data are already available through other sources.

The GDO e-tool can be accessed at https://extranet.who.int/dataform/892154 using a country-specific token. The WHO dementia team will share the country-specific tokens with focal points and provide further instructions on how to log-on to the e-tool. If, as a country focal point, you have not yet received or forgotten your country token please contact the WHO dementia team at whodementia@who.int.

The token allows users to enter data, save entries and return later to resume data entry. A log is provided in the e-tool to record any additional information/feedback that users may feel is relevant to their data entry.

Note, data will only be finalized and uploaded to WHO upon final submission and confirmation at the end of the e-tool. In line with the WHO *Policy on the use and sharing of data collected in*

Member States by WHO, outside the context of public health emergencies[1], the person submitting the data confirms, he/she has the authority to do so and agrees to the "Terms for data provision to WHO by Member States". Please refer to Annex 1 of this Reference Guide for a copy of these Terms.

How is dementia defined?

For the purpose of this document and unless otherwise specified, dementia is defined as any of the following ICD 9/10 codes:

ICD9: 290, 330-331

ICD9 BTO: B222, B210

ICD10: F00, F01, F02, F03, G30 - G31

ICD refers to the International Classification of Diseases:
http://www.who.int/classifications/icd/en/

If data by diagnostic group is incomplete or reported differently in your country, please contact the WHO dementia team at whodementia@who.int to discuss the completion.

Which data sources should I access or contact?

It may be necessary to proactively contact key personnel at different institutes, agencies and facilities in your country to understand what data are available and what their limitations are. Key personnel include stakeholders from the health and social care sector but may also extend to other relevant sectors such as education, academia and/or civil society.

A list of possible data sources is provided for each indicator in this Reference Guide. These sources are recommendations and some may not be relevant to your country depending on the organization of your health and social care system. Use all relevant data sources in order to provide the most comprehensive feedback. If you use a data source other than the recommended ones, please include this information in the comment box provided for that indicator.

Several national bodies can possibly be contacted to obtain data. Examples include:

- the **National Health Information System** for data on health facilities and human resources.
- the **financial department of the Ministry of Health** for data on government spending.
- the **Ministry of Social Affairs:** for data on the range of social services for people with dementia and their carers.
- **professional institutes and other bodies** for data on human resources, guidelines and training programmes available.

It is recommended to first identify data at the national (central government) level. However, if data are being aggregated from other levels (e.g. provinces, states, districts or facilities), it is recommended to list those sources in the feedback space provided. It should also be noted that some data may already be compiled while other data may require aggregation from a variety of sources.

[1] Available here: http://www.who.int/publishing/datapolicy/en/

What if my response to a measure only partially addresses the question or has caveats?

Always select the response that best corresponds to your country's setting. In certain instances, you will be able to enter additional information in the e-tool's comment field associated with a specific indicator or in the log section at the end of the tool.

What if the definition in the Glossary differs from that commonly used in my country?

Use the definition provided in the **Glossary** even if it differs from the definition used in your country. If it is not possible to reconcile these, state this in the e-tool's comment fields where available or in the log field at the end of the tool. Alternatively, you can contact the WHO dementia team at whodementia@who.int.

What if data are already collected from other international sources for my country?

To reduce the burden of data collection on countries wherever possible, WHO is working very closely with international partners, and linking to international databases for data that are already collected such as WHO's Global Health Observatory, the Organisation for Economic Co-operation and Development (OECD) and the European Union's (EU) Joint Programme-Neurodegenerative Disease Research (JPND). Relevant indicators have been marked with an asterisk to indicate that data might already be available. If you are providing country data to other international organizations on measures that are relevant to the GDO but have not been marked, please indicate this in the e-tool's comment field, where available.

How are the indicators related to the action plan measures?

As shown in **Table 1**, there are indicators used to monitor the global targets of the global dementia action plan. All other indicators in the GDO are closely aligned with the proposed actions of the action plan but are not used for direct monitoring of the global targets. Some indicators are cross-cutting, aligning with multiple action areas.

Throughout this Reference Guide and the GDO e-tool, indicators/subindicators in bold and/or highlighted in red indicate that they will be used for monitoring countries' progress toward the global targets.

What if my question is not answered here?

If your question is not answered in this document, do not hesitate to contact the WHO dementia team (whodementia@who.int).

The WHO dementia team will work as closely as possible with you to support you in providing the most comprehensive data available from your country.

DOMAIN 1 – POLICY

SUBDOMAIN 1.1: POLICY, STRATEGY, OR PLAN

Indicator 1: dementia governance

Indicator 2: dementia plan

SUBDOMAIN 1.2: LEGISLATION

Indicator 3: dementia legislation

SUBDOMAIN 1.3: GUIDELINES AND CARE COORDINATION

Indicator 4: dementia standards/guidelines/protocols

Indicator 5: dementia care coordination

SUBDOMAIN 1.1: POLICY, STRATEGY OR PLAN

Dementia requires a broad public health approach involving the whole of government and multiple stakeholders, in order to develop a comprehensive response from the health and social care system (both public and private) and other government sectors. The development and coordination of policies, strategies, plans and integrated dementia programmes through a multisectoral approach will support the recognition of the complex needs of people with dementia and address those needs within the context of each country.

The inclusion of people with dementia and their carers with other relevant stakeholders and partners is crucial for the success and buy-in of this process.

This subdomain links directly to action area 1 in the global action plan on the public health response to dementia 2017-2025.

Indicator 1: dementia governance	
Rationale	Setting up a focal point, unit or functional sector responsible for dementia or a coordination mechanism for dementia will facilitate the coordination of a comprehensive all-of-government multisectoral response to dementia that is required.
Method of estimation	Existence of a focal point, unit, sector or other body within the Ministry of Health (or equivalent) provided by the national authority's response.
Data source	National or regional government agencies, such as the Ministry of Health, Ageing, Social Affairs, or Welfare; Department of Public Health, Mental Health or Social Services; Federal Office of Public Health.
Data type representation	Categorical
Data collected elsewhere	No

Subindicator: inclusion of dementia in ministry portfolio

Definition	Dementia is formally recognized within a ministry portfolio as a condition that is actively monitored and for which a government department or agency is responsible.	
E-tool question	**Q1x1** Is dementia included within the portfolio of one or more ministries in the national government?	Yes/No

Subindicator: branch of government with responsibility for dementia

Definition	The primary branch of government in which dementia is formally recognized as a condition that is actively monitored.	
E-tool question	**Q1x1x1** In which branch is dementia primarily included? (Select the response that best fits)	Health/Ageing/Social services/Mental health/NCDs

Subindicator: existence of dementia representative in ministry

Definition	The presence of a government unit or a government official in the country who is responsible for policy regarding the awareness, treatment and care of dementia. If present, this could be for dementia only or in combination with other conditions.	
E-tool question	**Q1x2** Is there a dementia-specific representative[1] within your ministry?	Yes/No

[1] Examples of representatives include a focal point, unit or department sector

Indicator 2: dementia plan	
Rationale	The development and coordination of policies, strategies, plans or frameworks through a comprehensive, multisectoral approach will support the recognition of people with dementia and address their complex needs and rights within the context of each country.
Method of estimation	Existence of a written policy, strategy, plan or framework provided by the national authority's response.
Data source	Administrative sources
Data type representation	Categorical and numerical
Data collected elsewhere	No
Comments/notes	If, for example, a dementia policy and a plan are both available, countries should assess both documents as one entity. This indicator is linked to the measurement for global target 1: "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." Subquestions that are highlighted are used to measure the global target.

Subindicator: existence of dementia national plan

Definition	A written organized set of principles, objectives or actions for reducing the burden attributable to dementia in a population in a stand-alone, demenia-specific document. They are considered valid if they have been approved / published by the Ministry of Health (or equivalent) or parliament.	
E-tool question	**Q2x1** Is there a dementia-specific national document[1]? If yes, please respond to the questions below:	Yes/Under development/ No

Subindicator: date range of the national plan

Definition	The date range covered by the latest version of the dementia-specific national policy, strategy, plan or framework, given in start and end year.	
E-tool question	**Q2x1x2** What is the date range of the document (latest version)?	Year - Year

Subindicator: availability of funding for the national plan

Definition	Indicates whether funding was assigned to operationalize the latest dementia-specific national policy, strategy, plan or framework. For funding allocation, refer to the budget of the most recently published policy, strategy, plan or framework document.	
E-tool questions	**Q2x1x2** Has funding been allocated to its implementation?	Yes/No
	Q2x1x2x1_How much funding has been allocated (in local currency)?	Currency (in million local currency)

[1] Note: document refers to a policy, strategy, plan or framework

Subindicator: targets for monitoring implementation of dementia plan

Definition	Indicates whether or not the latest dementia-specific national policy, strategy, plan or framework includes targets or milestones that will be monitored during the implementation phase.	
E-tool question	**Q2x1x3** Are there any targets or milestones for monitoring implementation?	Yes/No

Subindicator: dementia integrated into related national plan

Definition	A written organized set of principles, objectives or actions for reducing the burden attributable to dementia in a population that are integrated into general mental health, ageing, NCDs or disability policies, strategies, plans or frameworks. They are considered valid if they have been approved / published by the Ministry of Health (or equivalent) or parliament.	
E-tool question	**Q2x2** Is dementia **integrated into** or covered by a different **national** plan (such as a mental health plan)?	Yes/No/Under development

Subindicator: identification of other plans in which dementia is integrated

Definition	Indicates into which national policy, strategy, plan or framework (general mental health, ageing, NCD, disability and/or other) dementia is integrated. They are considered valid if they have been approved / published by the Ministry of Health (or equivalent) or parliament.	
E-tool questions	**Q2x2x1** In which area is dementia covered?	Mental health/Ageing/ NCDs/Disability/Other

Subindicator: existence of dementia subnational plan(s)

Definition	Indicates whether the country has a comprehensive subnational dementia-specific policy, strategy, plan or framework with principles and actions. A subnational policy, strategy, plan or framework will be assessed as "operational" if it is used and implemented in the country, has funds and resources and is being monitored or evaluated for implementation.	
E-tool question	**Q2x3** Are there dementia-specific documents operationalized at **subnational** levels (i.e. for individual states, territories, provinces or regions)?" If yes, please respond to the question below:	Yes/No

Subindicator: percentage of subnational regions covered by dementia plan

Definition	The percentage of states or provinces covered by comprehensive subnational dementia-specific policies, strategies, plans or frameworks.	
E-tool question	**Q2x3x1** What percentage of the states/territories/ provinces/regions are covered by subnational dementia documents?	Percentage

Subindicator: range of cross-cutting principles of dementia plan

Definition	Checklist indicating the extent to which the national/subnational plan aligns with the cross-cutting principles outlined in the global action plan on the public health response to dementia 2017-2025. **Human rights based approach.** The dementia plan is sensitive to the needs, expectations and human rights of people with dementia, consistent with the Convention of the Rights of Persons with Disabilities[1] and other international and regional human rights instruments **Equity.** The dementia plan supports gender equity and takes a gender-sensitive perspective, keeping in mind all vulnerabilities specific to each national context, consistent with the 2030 Agenda for Sustainable Development, which recognizes that people who are vulnerable, including people with disabilities, older people, and migrants, must be empowered. **Empowerment**. The dementia plan empowers people with dementia, their carers and families, and organizations that represent them and they are involved in advocacy, policy, planning, legislation, service provision, monitoring, and research of dementia. **Multisectoral collaboration.** The dementia plan encourages collaboration among all stakeholders to improve prevention, risk reduction, diagnosis, treatment and care. It engages all relevant public sectors at the government level, such as health (including alignment of existing NCD, mental health, and ageing efforts), social services, education, employment, justice, and housing, as well as partnerships with relevant civil society and private sector entities. **Universal Health Coverage**. The dementia plan includes support for universal health coverage including financial risk protection and ensures equitable access to a broad range of promotive, preventive, diagnostic and care services (including palliative, rehabilitative and social support) for all people with dementia and their carers.
E-tool questions	**Q2x4** Please complete the following checklists for your document(s): Your document includes/follows/is in line with…

- Human rights based approach	Yes/No
- Equity	Yes/No
- Empowerment	Yes/No
- Multisectoral collaboration	Yes/No
- Universal Health Coverage	Yes/No

[1] United Nations Convention on the Rights of Persons with Disability; see: http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx

Subindicator: range of action areas of dementia plan

Definitions	Checklist indicating which of the following actions areas are covered by the dementia plan: **Dementia awareness, stigma reduction and dementia-friendly communities.** The dementia plan supports dementia awareness, stigma reduction and dementia-friendly communities that are tailored to cultural contexts and the particular needs of a community, which can promote enhanced health and social outcomes that reflect the wishes and preferences of people with dementia, as well as improve their quality of life, that of their carers, and the broader community. **Dementia prevention and risk reduction.** The dementia plan links dementia with other programmes, policies, and campaigns on NCD, risk reduction and health promotion across relevant sectors and promotes evidence-based interventions and training to health professionals to be proactive in modifying dementia risk factors. **Timely dementia diagnosis, post-diagnostic supports and care.** The dementia plan promotes the development of sustainable care systems across the continuum from diagnosis to end of life care, which includes timely diagnosis, post-diagnostic supports and care (this includes case-finding, diagnosis, treatment including pharmacological and psychosocial, rehabilitation, palliative/end-of-life care and other support such as home help, transportation, nutrition, post diagnostic supports and care). **Workforce training on dementia.** The dementia plan provides a mechanism to build the knowledge and skills of general and specialized staff in the health workforce to deliver evidence-based, culturally-appropriate and human rights-oriented health and social care. **Support for carers and families.** The dementia plan provides accessible and evidence-based information, training programmes, respite services, and other resources tailored to the needs of carers to improve knowledge and caregiving skills. **Improved monitoring and information systems for dementia.** The dementia plan promotes the development, implementation, and improvement of national surveillance and monitoring systems in order to improve availability of high-quality, multisectoral data on dementia. **Dementia research and innovation.** The dementia plan promotes the development, implementation, and monitoring of a national research agenda on prevention, diagnosis, treatment and care of people with dementia in collaboration with academic and research institutions.
E-tool questions	**Q2x5** Please complete the following checklists for your document(s): - Dementia awareness, stigma reduction and dementia-friendly communities — Yes/No - Dementia prevention and risk reduction — Yes/No - Timely dementia diagnosis, post-diagnostic supports and care — Yes/No - Workforce training on dementia — Yes/No - Support for dementia carers and families — Yes/No - Improved monitoring or information systems for dementia — Yes/No - Dementia research and innovation — Yes/No

SUBDOMAIN 1.2: LEGISLATION

Mechanisms to monitor the protection of human rights of people with dementia – including respect for their wishes and preferences and the implementation of relevant legislation, in line with the UN Convention on the Rights of Persons with Disabilities and other international and regional human rights instruments – are essential. These mechanisms should include provisions for areas such as legal capacity, self-determination, supported decision-making, power of attorney, and protection against exploitation and abuse in institutions as well as in the community.

Indicator 3 is designed to determine the extent to which the rights of people with dementia are considered and protected either under explicit legislation regarding dementia or mental health or, more generally, under legislation on human rights, disability or other relevant areas.

This subdomain links to cross-cutting principles and action area 1 in the global action plan on the public health response to dementia 2017-2025.

Indicator 3: dementia legislation	
Rationale	Specific legislation and laws provide safeguards for concepts such as legal capacity, self-determination, supported decision-making, power of attorney, and protection against exploitation and abuse of people with dementia in institutions and in the community. Laws and legislative provisions may be dementia-specific or as part of universal law integrated into other general health or disability laws.
Method of estimation	Existence of documented legislative provisions provided by the national authority's response.
Data source	Legal Office of the Ministry of Health (or equivalent); Ministry of Justice, Social Welfare, Employment, Education etc.; library/archives of parliament; parliamentary publications; national human rights institutions; nongovernmental human rights associations.
Data type representation	Categorical
Data collected elsewhere	No
Comments/notes	Legal provisions may also define principles for the management of people with dementia in treatment and care facilities, as well as the personnel, professional training and service structures. For countries with a federated system, the indicator will refer to the laws of the majority of states/provinces within the country.

Subindicator: existence of dementia legislation

Definition	Legislation in this context refers to adopted legal provisions specifically for the context of dementia	
E-tool questions	**Q3x1** Is there **dementia-specific** legislation in your country?	Yes/No
	Q3x1x1 Is this national or subnational legislation?	National/ subnational

Subindicator: existence of other laws that apply to the rights of people with dementia

Definition	Legislation in this context refers to adopted legal provisions which typically focus on issues such as human rights of older people, people with cognitive impairment, mental disorders, disabilities or impaired mental capacity or include other human rights based approaches.	
E-tool question	**Q3x2** Are there provisions in other laws related to, or that apply to, protecting the rights of people with dementia?	Yes/No

Subindicator: range of legislation pertaining to dementia

Definition	Checklist assessing the extent to which legislation aligns with, and makes provisions pertaining to, aspects related to **international human rights** of people with dementia. It also assesses whether legislative provisions exist to **support advance care planning** for all people with dementia to document their wishes so that, should circumstances arise in which they no longer are able to make decisions regarding medical treatment, their preferences are respected. Checklist also assesses whether legislative provisions exist which aim to end **discrimination** against people with dementia and their carers in many areas of public life, including but not limited to employment, education and use of services.	
E-tool questions	**Q3x3** Please complete the following checklist in order to assess compliance of legislation with international human rights instruments:	
	- Provisions exist which promote supported decision-making, the ability for people with dementia to nominate a trusted person or network of persons for discussing issues and making decisions.	Yes (dementia-specific)/Yes (universal law)/No
	- Provisions exist which provide for procedures to enable people with dementia to protect their rights (safeguards against exploitation, violence or abuse) and to file appeals and complaints to an independent legal body.	Yes (dementia-specific)/Yes (universal law)/No
	- Provisions exist which promote the transition of dementia care to community-based services.	Yes (dementia-specific)/Yes (universal law)/No
	- Provisions exist which provide for regular inspections of human rights conditions (safeguards against exploitation, violence or abuse) and/or care quality[1] by an independent body in facilities where people with dementia reside.	Yes (dementia-specific)/Yes (universal law)/No
	- Provisions exist which aim to end coercive practices, including seclusion and mechanical/ physical/ chemical restraints for people with dementia.	Prohibited; regulated/limited, allowed/not covered
	Q3x4 Is there specific legislation pertaining to the following:	
	- Advance care directives	Yes (dementia-specific) / Yes (universal law) / No
	- Provisions which aim to end discrimination against people with dementia (including in the workplace)	Yes (dementia-specific) / Yes (universal law) / No
	- Provisions which aim to end discrimination against family carers	Yes (dementia-specific) / Yes (universal law) / No

[1] See Glossary for definition.

SUBDOMAIN 1.3: GUIDELINES AND CARE COORDINATION

Clinical dementia guidelines and practice recommendations provide evidence-based advice to physicians and other health and social care professionals working in the field. They serve as a means of quality assurance and standardization of care.

Guidelines for dementia care should include guidance on clinical elements such as diagnosis, assessment and treatment, as well as quality long-term care. They should also include guidance on any legal and ethical issues that could compromise quality care.

This subdomain links to actions proposed under action area 4 in the global action plan on the public health response to dementia 2017-2025.

Indicator 4: dementia standards/guidelines/protocols	
Rationale	Dementia standards, guidelines and protocols ensure the appropriate use of evidence and that consistent care and treatment are provided to all people with dementia accessing the health and social care system.
Method of estimation	Existence of standards, guidelines or protocols; response provided by the national authority.
Data source	Community care/hospital/residential care departments within the Ministry of Health (or equivalent); national health service authorities; professional associations or schools such as physicians', nurses' and pharmacists' associations; nongovernmental organizations (NGOs) such as Alzheimer's associations; university departments of medicine or social science (e.g. departments of psychiatry, public health, psychology, social care).
Data type representation	Categorical
Data collected elsewhere	No
Comments/notes	For countries with a federated system, please refer to the guidelines of the majority of states/provinces or the majority of the population in the country (i.e. national guidelines take precedence over subnational guidelines). For more details see the Glossary. If several guidelines exist within one jurisdiction, countries should assess all documents as one entity (e.g. if separate national guidelines exist on dementia diagnosis, pharmacological treatment).

Subindicator: existence of dementia standards/ guidelines/ protocols

Definition	Indicates the existence of standards, guidelines, and protocols for dementia. These documents are evidence-based and can be general (i.e. for all health professionals and multi-disciplinary teams), or adopted by a specific professional body and apply to different settings. For detailed descriptions of standards/ guidelines/ protocols see the Glossary.	
E-tool questions	**Q4x1** Are there standards, guidelines or protocols for dementia?	Yes/No
	Q4x1x1 Are they national or subnational standards/ guidelines/ protocols? (Select any that apply)	National/subnational

Subindicator: existence of approved government dementia standards/ guidelines/ protocols

Definition	Indicates whether or not the standards, guidelines or protocols on dementia are government approved.	
E-tool question	**Q4x1x2:** Are they approved by government?	Yes/No

Subindicator: range of dementia standards/guidelines/protocols

Definition	Checklist assessing the areas that are covered by standards, guidelines or protocols.	
E-tool questions	**Q4x2** Indicate the areas that are covered by standards, guidelines or protocols:	
	- Prevention and risk reduction of dementia	Yes/No
	- Diagnosis of dementia	Yes/No
	- Management of dementia (including treatment, medication management, non-cognitive symptoms[1] and comorbidities)	Yes/No
	- Other post-diagnostic supports of people with dementia. If yes, please respond below:	Yes/No
	o Advance care directives, power of attorney or guardianship	Yes/No
	o Palliative and end-of-life care	Yes/No
	o Care in nursing and residential care facilities	Yes/No
	o Care in hospitals	Yes/No
	- Treatment and support for carers and families	Yes/No

Indicator 5: dementia care coordination

Rationale	Continuity[2] and coordination of care between different care providers, multiple sectors and system levels are crucial for people with dementia, from the first symptoms of dementia until the end of life. This includes a range of health and social care professionals such as doctors, nurses, home & community workers, allied health professionals and other professionals. Care coordination integrates multiple services seamlessly to ensure quality care and management and enhances the capacity and functional ability of people with dementia.
Method of estimation	Existence of processes and means to coordinate dementia care across the continuum of care provided by the national authority's response.
Data source	Ministry of Health; Ministry of Social Services/Welfare (or equivalent); primary health care districts; mental health/aged care authorities; national health institutes; list of national care acts or frameworks.
Data type representation	Categorical
Data collected elsewhere	No
Comments/notes	Examples of care coordination models include integrated care pathways, care networks, multidisciplinary or interdisciplinary teams and case management. Refer to the Glossary for detailed descriptions of individual care coordination mechanisms. Please provide information on care coordination mechanisms at the national level if available. If not, then please provide this information at the subnational level.

[1] See Glossary for description
[2] See Glossary for description

Subindicator: availability of mechanisms to coordinate dementia care across sectors

Definition	Existence of a structured framework or model that outlines the coordinated planning and resourcing of continuing care for people with dementia across the continuum of care, with involvement of relevant sectors beyond health and social care.	
E-tool question	**Q5x1** Is there a mechanism to coordinate care across sectors in government for people with dementia?	Yes/No

Subindicator: identification of different sectors in dementia care coordination

Definition	Sectors included in the coordinated planning and resourcing of care for people with dementia across the continuum of care.	
E-tool questions	**Q5x1x1** Which of the following sectors are included? (check all that apply)?	Health/social/education/ employment/justice/ housing/civil society/private sector/other
	Q5x1x2 What is the level of implementation?	National/ subnational

Subindicator: presence of formal agreement/joint plan for dementia care coordination

Definition	Existence of a formal agreement or joint plan in the coordinated planning and resourcing of continuing care for people with dementia across the continuum of care.	
E-tool question	**Q5x1x3** Is there a formal agreement or joint plan?	Yes/No

Subindicator: identification of components of dementia care coordination

Definition	The existence of different models, components or processes that are involved to implement care coordination **Multi or interdisciplinary teams:** Interdisciplinary teams consist of members who work together interdependently to develop goals and a common treatment plan, although they maintain distinct professional responsibilities and individual assignments. In contrast to multidisciplinary teams, leadership functions are shared. Multidisciplinary teams consists of members of different disciplines, sometimes from one or more organizations, involved in the same task (assessing people, setting goals and making care recommendations) and working alongside each other, but functioning independently. **Task shifting/sharing** is defined as delegating selected tasks to existing or new health professional cadres with either less training or more narrowly-focused training. **Responsive referral protocols or pathways** outline clear indications for referrals and responsibilities of each healthcare professional and department involved. **Continuity information** is, for example, continuous flow of information from community to acute care as a person with dementia is admitted to a hospital, as well as from acute care back to the community (e.g. in the form of effective discharge planning). Continuity of information is best achieved by a single information system, or by shared access to medical records and highly effective communication. **Provider continuity** Seeing the same professional each time, with the opportunity to establish a therapeutic, trusting relationship (a role often filled by the primary care physician, a care worker, or case manager). **Community-based approach** refers to care networks that integrate social and health systems and provide quality care and evidence-based interventions within the community.

E-tool question	**Q5x2x1** What are the components of care coordination? (Select any that apply). Note: this is not a comprehensive list	Multi or interdisciplinary teams Task shifting/sharing Responsive referral protocols or pathways Continuity of information Provider continuity Community-based approach Other

Subindicator: care process levels in dementia care coordination

Definition	Indicates at which levels of health care (i.e. primary, secondary or tertiary care) care coordination is implemented **Primary care**. Is the first point of contact for the patient, generally provided in the local community. Professionals tend to be generalists, dealing with a broad range of psychological, physical and social problems. For more information see the Glossary. **Secondary care**. Specialist care provided on an ambulatory or inpatient basis, usually following a referral from primary care **Tertiary care**. The provision of highly specialized services in ambulatory and hospital settings or in a facility that has personnel and facilities for advanced medical investigation and treatment	
E-tool questions	**Q5x2x2** Where does the care coordination process occur?	Primary care/secondary care/tertiary care

DOMAIN 2 – SERVICE DELIVERY

SUBDOMAIN 2.1: HEALTH AND SOCIAL CARE WORKFORCE

Indicator 6: dementia health and social care workforce

SUBDOMAIN 2.2: SERVICES, SUPPORT AND TREATMENT PROGRAMMES

Indicator 7: diagnostic rate of dementia

Indicator 8: community-based services for dementia

Indicator 9: dementia health and social care facilities

Indicator 10: antidementia medication and care products availability

Indicator 11: dementia-specific nongovernmental organization

Indicator 12: dementia carer support services

SUBDOMAIN 2.3: PROMOTION OF AWARENESS AND UNDERSTANDING

Indicator 13: dementia awareness and risk reduction campaign

Indicator 14: dementia-friendly initiatives

Indicator 15: dementia education and training of non-health professionals

SUBDOMAIN 2.1: HEALTH AND SOCIAL CARE WORKFORCE

In this document, the health and social care workforce is broadly defined as all persons engaged in actions which are primarily intended to enhance the health and well-being of people with dementia and their carers. In light of changing population demographics and increasing dementia burden – as well as exponential progress in technology, diagnostic tools and treatment options – health and social care workers need to stay abreast of the evolving health needs, policies, technologies and knowledge. Consequently, it is more important than ever to update and maintain the knowledge and skills needed to provide quality dementia care and support throughout one's professional life.

The transformation and scaling-up of education and training of the health and social care workforce is a multidimensional process. It involves not only increasing the number of health and social care professionals (through increased intake in pre-service education) but also ensuring that health and social care workers have the knowledge, skills and competencies relevant to the needs of people with dementia and their carers. Thus, the inclusion of dementia care competencies in pre-service (undergraduate and graduate) curricula, as well as in continuing professional development/continuing education will contribute to increased awareness of dementia, higher diagnostic rates, improved care and better service integration and coordination.

This subdomain links to action area 4 in the global action plan on the public health response to dementia 2017-2025.

Indicator 6: dementia health and social care workforce	
Rationale	Adequately trained and qualified workforces are required to provide high-quality, evidence-based dementia diagnosis, treatment, care and support. The principles underlying these care competencies can include an understanding of person-centred dementia care, communication, collaboration, ethics, evidence-based practice and cultural diversity. Current evidence indicates that a combination of classroom instruction, case studies paired with supervised interactive training and multiple exposures make for effective training. Ideally, the development of a care certificate with national minimum training standards, a common core curriculum on dementia and assessment of care competencies would help ensure consistency of care across settings and professions.
Method of estimation	Responses provided by the national authority.
Data source	Professional associations; doctors' and nurses' associations; university departments of medicine and social science (e.g. departments of psychiatry, public health, psychology, social care etc.); nursing schools and professional schools; training centres in aged care, geriatrics, mental health.
Data type representation	Categorical, numerical
Data collected elsewhere	The following data are already collected as part of WHO Global Health Observatory: total number of physicians, psychiatrists, nursing personnel, social workers, pharmaceutical personnel and personal care workers, expressed as densities (i.e. per 1 000; 10 000; or 100 000 population).
Comments/notes	In this document, dementia care competencies are defined as diagnosis, assessment of comorbidities, assessment and treatment of behavioural and psychological symptoms of dementia (BPSD), risk reduction, palliative care, and assessment and treatment of carer distress.

	Health and social care professionals include physicians, specialist medical doctors (including neurologists, psychiatrists, geriatricians and psycho-geriatricians), nurses, social workers, personal support workers and pharmaceutical personnel. Many other professionals are involved in the care of people with dementia but not listed here for the sake of brevity. Include specialized professionals working partly or fully in general and specialist health-care settings.

Subindicator: number of neurologists (per 100 000)

Definition	Total (absolute) number of neurologists in the country. Note density per 100 000 population will be calculated centrally using each country's latest UN population estimate as denominator.	
E-tool question	**Q6x1** Neurologists	Number

Subindicator: number of geriatricians or psychogeriatricians (per 100 000)

Definition	Total (absolute) number of geriatricians and psychogeriatricians in the country. Note density per 100 000 population will be calculated centrally using each country's latest UN population estimate as denominator.	
E-tool question	**Q6x1** Geriatricians/Psychogeriatricians	Number

Subindicator: dementia training of health and social care workforce

Definition	The portion of medical doctors (registered physicians)/ specialist medical doctors/ nurses/ pharmaceutical personnel/ social workers / personal support workers in the country who are trained in dementia core competencies, which include: Diagnosis, comorbidities, assessment and management of behavioural and psychological symptoms (i.e. BPSD), risk reduction, palliative care, assessment and treatment of carer distress. Training is defined as undergraduate or graduate curricula training, residency programmes, continuing education programmes, specialist certification or clinical practice on dementia care competencies. The amount and extent of training will vary depending on the context, profession and care demands.	
E-tool questions	**Q6x2** Are basic competencies on dementia included for the following health and social care professionals?	
	- Physicians/medical doctors	All/some/none
	- Specialist medical doctors	All/some/none
	- Nurses	All/some/none
	- Pharmaceutical personnel	All/some/none
	- Social workers	All/some/none
	- Personal support workers	All/some/none

SUBDOMAIN 2.2: SERVICES, SUPPORT AND TREATMENT PROGRAMMES

Dementia is associated with complex needs and high levels of dependency and morbidity in its later stages, requiring a range of long-term health and social care services. These services include identification, diagnosis, treatment (including pharmacological and psychosocial), rehabilitation, palliative/end-of-life care and other support such as home help, transport, food and the provision of a structured day with meaningful activities.

Integrated, evidence-based, person-centred care is required in all settings where people with dementia live – including their homes, the community, assisted-living facilities, nursing homes, hospitals and hospices.

Providing sustainable care across the continuum of the disease from diagnosis to end-of-life requires timely diagnosis, the integration of dementia treatment and care into primary care, coordinated continuity of long-term health and social care between different providers and system levels, and multidisciplinary collaboration and active cooperation between paid and unpaid carers.

NGOs can empower people with dementia and their families through advocacy and the provision of information so that people with dementia can make informed choices and decisions about their care. In many countries, NGOs constitute the backbone of service delivery for people with dementia and their carers.

The indicators in this subdomain link to proposed actions in action areas 4 and 5 in the global action plan on the public health response to dementia 2017-2025.

Indicator 7: diagnostic rate for dementia	
Rationale	Dementia is associated with complex needs and high levels of dependency and morbidity in its later stages, requiring a range of health and social care, including long-term care services. A diagnosis is the first step to accessing these services.
Method of estimation	Diagnostic rate for dementia will either be provided by country focal points or calculated using the best estimate of the total number of persons diagnosed with dementia (numerator) and the estimated total number of people with dementia aged 60 years and over (denominator). Alternatively, the denominator will be based on WHO prevalence estimates (see Indicator 21).
Data source	Dementia register, insurance register, other register-type dataset, administrative data, survey data
Data type representation	Numerical
Data collected elsewhere	No
Comments/notes	This indicator links to the **measurement for global target 4**, which states: "In at least 50% of countries, as a minimum, 50% of the estimated number of people with dementia are diagnosed by 2025."

Subindicator: dementia diagnostic rate

Definition	The proportion of people with dementia in the country that received a diagnosis for dementia	
E-tool question	**Q7x1** What is your country's dementia diagnostic rate (if available)?	Rate
	Q7x1x1 Description of methodology used to calculate the rate	String

Subindicator: dementia diagnostic rate (numerator)

Definition	The total number of persons diagnosed with (all-cause) dementia in a given year (i.e. reference year). This includes the following ICD 9/10 codes: ICD9: 290, 330-331; ICD9 BTO: B222, B210; ICD10: F00, F01, F02, F03, G30 - G31	
E-tool questions	Please provide the following:	
	Q7x2 Numerator: The number of people 60+ years with a diagnosis of dementia (all-cause) during the reference year	Number
	Q7x2 Please provide the year for this data	Year

Subindicator: dementia diagnostic rate (denominator)

Definition	Denominator: The estimated total number of people with dementia aged 60 years and over during the reference year.	
E-tool question	**Q7x2** Denominator (if available): dementia prevalence estimate	Number
	Q7x2 Please provide the year for this data	Year

Indicator 8: community-based services for dementia

Rationale	The needs and preferences of people with dementia can be met and their autonomy from diagnosis to the end of life respected through integrated, culturally-appropriate, person-centred, community-based health, psychosocial, long-term care and support and, where appropriate, the inputs of families and carers.
Method of estimation	Inventory of currently implemented and available services and supports for people with dementia provided by the national authority's response
Data source	National or regional government agencies (e.g. Ministry of Health, Department of Social Services); Mental Health and Community Care Services; NGOs; consumer associations; family associations; Department of Family Medicine, Faculty of Medicine; private and public providers of community and aged care.
Data type representation	Categorical
Data collected elsewhere	No
Comments/notes	Consider all community-based health and social care services and supports that are available in your country to assist people with dementia. Examples of community-based services include (but are not necessarily restricted to) diagnostic services in primary care, assessment and management of behavioural and psychological symptoms of

	dementia, psychosocial services and rehabilitation, day-care services,[1] home-care services and palliative/end-of-life care services. Include only services/supports that are implemented (not just planned coverage).	

Subindicator: availability of health or social care services for dementia

Definition	**Health care service:** Any service (i.e. not limited to medical or clinical services) aimed at contributing to improved health or to the diagnosis, treatment and rehabilitation of sick people. **Social care service:** Assistance with activities of daily living (such as personal care, maintaining the home); synonym is home and community care.	
E-tool question	**Q8x1** Does your country provide health and social care services to support people with dementia in community-based settings?	Yes/No (Comments or context)

Subindicator: range of community-based health or social care services for dementia

Definition	Checklist indicating which of the following community-based services for dementia are available: - **Diagnostic services (primary care)** are available in primary care to support people with dementia to maintain functional capacity and independence and to remain in the community. Initial diagnostic services include assessment of memory and cognitive functioning using simple tests/locally validated tools and interviewing a key informant who knows the person well. Other services can include physical examination, baseline investigations (blood tests, imaging etc.) and possible referral for secondary services if symptoms are severe or difficult to manage. - **Assessment & Management of behavioural and psychological symptoms of dementia (BPSD)** identifies whether the assessment and management of (BPSD) in community-based settings are available to support people with dementia to maintain functional capacity and independence and to remain in the community. BPSD or neuropsychiatric symptoms are a heterogeneous group of non-cognitive symptoms and behaviours that may occur in individuals with dementia. They include symptoms such as agitation, aberrant motor behaviour, anxiety, elation, irritability, depression, apathy, disinhibition, delusions, hallucinations, and sleep or appetite changes - **Psychosocial services and rehabilitation** identifies the availability of psychosocial services and rehabilitation in community-based settings are available to support people with dementia to maintain functional capacity and independence and to remain in the community. Psychosocial support interventions address the ongoing psychological and social needs of people with dementia, their carers, partners, and families. - **Activities of daily living support services** identifies whether or not supports for activities of daily living in community-based settings are available to people with dementia to maintain functional capacity and independence and to remain in the community. - **Palliative and end-of-life care services** identifies whether or not palliative and end-of-life care services in community-based settings are available to people with dementia to maintain functional capacity and independence and to remain in the community. Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

[1] Specific examples of day-care activities include: services such as diversional therapy and group activities such as painting, cooking, gardening, reading the newspaper, music and daily exercise, as well as transportation to and from the centre.

	- **Social & financial protection and benefits** identifies whether social and financial protections and benefits are available to people with dementia to maintain functional capacity and independence. Social and financial protection benefits refer to financial transfers received by households for the purpose of providing for a range of needs due to circumstances or events such housing, education, family circumstances or sickness, retirement and unemployment. This also includes economic benefit provided by the government (such as paid or unpaid leave, credited social contributions, or price subsidies such as tax allowances, duty rebates, discount transportation fares, free companion fares) to support people with dementia and their carers.	
E-tool questions	***Q8x2*** *Do you have any of the following:*	
	- Diagnostic services (in primary care)	Yes/No
	- Assessment & management of behavioural and psychological symptoms of dementia	Yes/No
	- Psychosocial services and rehabilitation	Yes/No
	- Activities of daily living support services	Yes/No
	- Palliative and end-of-life care services	Yes/No
	- Social & financial protection and benefits	Yes/No

Subindicator: accessibility of available services in the community for dementia

Definition	Specifies for all available services (selected above) the accessibility in different locations.	
E-tool question	**Q8x3** What is the accessibility of these services?	Capital city only/capital and main cities only/capital, main cities and rural areas

Subindicator: majority provider of available services in community for dementia

Definition	Identifies the majority provider for all available services (selected above) as public, private or both sectors. Majority provider of care is defined as providing care to 50% or more of users.	
E-tool question	**Q8x4** Majority provider of this service?	Public/private sector/both

Subindicator: estimated percentage of people receiving these community-based services for dementia

Definition	Approximates the percentage of people with dementia who receive the services selected above.	
E-tool question	**Q8x5** Approximately how many people with dementia received this service in your country?	Percentage

Indicator 9: dementia health and social care facilities	
Rationale	Dementia is associated with complex needs and high levels of dependency and morbidity in its later stages, requiring a range of health and social care services. Facility availability and capacity indicate the ability to provide care to people with dementia and to meet their needs and preferences.
Method of estimation	Listing of facilities available in a country to provide support and inpatient/outpatient care for people with dementia provided by the national authority's response.
Data source	National or regional government agencies (e.g. Ministry of Health, Department of Social Services/Affairs); community care/hospital/ residential care departments within the Ministry; facility registration and funding bodies; primary health care districts; NGOs; group of expert advisors.
Data type representation	Categorical
Data collected elsewhere	The following data are already collected as part of WHO Global Health Observatory: total number of hospitals and hospital beds, expressed as densities per 100 000 and 10 000 population, respectively. Some information is also collected by OECD for OECD Member States, and Eurostat for European countries, marked with (**).

Subindicator: range of types of health and social care facilities available

Definition	Checklist indicating which of the following health and social care facilities for dementia are available - **Hospitals.** Identifies the availability of hospitals, including the following hospital categories: rural and district, provincial (second level referral), regional/specialized/teaching and research hospitals (tertiary care), from the public and private sectors. - **Residential long-term care facilities.** Existence of establishments primarily engaged in providing residential long-term care that combines nursing, supervisory or other types of care as required by the residents. - **Hospice centres.** Existence of locations where end-of-life care is provided by health professionals and volunteers in tertiary care facilities or in community health centres. They give medical, psychological and spiritual support. The goal of the care is to help people who are dying have peace, comfort and dignity. The caregivers try to control pain and other symptoms so a person can remain as alert and comfortable as possible. Hospice programmes also provide services to support a patient's family. - **Adult day centres.** Existence of a facility that typically provides care for users during the day. The facilities are generally: (i) available to groups of users at the same time (rather than delivering services to individuals one at a time), (ii) expect users to stay at the facilities beyond the periods during which they have face-to-face contact with staff (i.e. the service is not simply based on users coming for appointments with staff and then leaving immediately after the appointment) and (iii) involve attendances that last half or one full day. - **Outpatient health centres.** Existence of facilities that focus on the management of clinical care on an outpatient basis. Composed of hospital outpatient departments, primary health care and community-based health care facilities, including day centres - **Outpatient (community) social centres.** Existence of a centre focused on the social management of dementia in the community on an outpatient basis. These centres often provide services in the patient's home. They include independent or government-funded social welfare associations, home-care provider centres/organizations, and NGOs providing home care.

E-tool question	**Q9** Are the following types of health and social care facilities available in your country?	
	- Hospitals	Yes/No
	- Residential long-term care facilities	Yes/No
	- Hospice centres	Yes/No
	- Adult day centres	Yes/No
	- Outpatient health centres	Yes/No
	- Outpatient (community) social centres	Yes/No

Hospitals

Subindicator: dementia-specific hospital beds (per 10 000 population)

Definition	Total number of dementia-specific beds in general hospitals Dementia-specific beds in hospitals are dedicated entirely to people with dementia Note density per 10 000 population will be calculated centrally using each country's latest UN population estimate as denominator.	
E-tool question	**Q9x1** Total number of dementia specific beds	Number

Subindicator: geriatric-specific hospital beds (per 10 000 population)

Definition	Total number of geriatric-specific beds in general hospitals Geriatric-specific beds are specialized to accommodate the needs of older patients (65+) and can be separate from the general population in the hospital. Often includes being managed by a specialized inpatient geriatric staff team. Note density per 10 000 population will be calculated centrally using each country's latest UN population estimate as denominator.	
E-tool question	**Q9x1** Total number of geriatric-specific beds	Number

Subindicator: total dementia hospital admissions

Definition	Number of people with dementia admitted to hospitals in the most recent year with complete data available.	
E-tool question	**Q9x1** Total number of dementia admissions in the most recent year for which complete data are available	Number
	Year for which data are available	Year

Subindicator: estimated percentage of hospitals following national dementia standards

Definition	Percentage of hospitals with standards for dementia, which are aligned with a national standard. A standard is an established, accepted and evidence-based technical specification or basis for comparison. National standards provide a set of principles for the foundation on which care can be based and how to measure progress. They generally do not need to be adapted to the local context.	
E-tool question	**Q9x1** Percentage of facilities following national dementia standards (if available)	Percentage

Residential long-term care facilities

Subindicator: density of residential long-term care facilities (per 100 000 population)

Definition	Total number of residential long-term care facilities. Note density per 100 000 population will be calculated centrally using each country's latest UN population estimate as denominator.	
E-tool question	**Q9x2** How many facilities are there in total?	Number

Subindicator: residential long-term care beds (per 10 000 population)

Definition	Total number of beds in all residential long-term care facilities (i.e. long-term nursing care facilities and other residential long-term care facilities). Exclude beds in hospitals dedicated to long-term care and beds in residential settings such as adapted housing that can be considered as people's home. Note density per 10 000 population will be calculated centrally using each country's latest UN population estimate as denominator. ** Note data already collected by the OECD for OECD countries.	
E-tool question	**Q9x2** Total number of long-term beds	Number **

Subindicator: dementia-specific residential long-term care beds (per 10 000 population)

Definition	Total number of dementia-specific beds in residential long-term care facilities. Note density per 10 000 population will be calculated centrally using each country's latest UN population estimate as denominator.	
E-tool question	**Q9x2** Total number of dementia-specific beds	Number

Subindicator: estimated number of people with dementia living in residential long-term care

Definition	Number of people with dementia living in residential long-term care facilities in the previous year. ** Note data already collected by the OECD for OECD countries.	
E-tool question	**Q9x2** Total number of residents with dementia as of 31 Dec of the previous year	Number **

Subindicator: estimated percentage of residential long-term care facilities following national dementia standards

Definition	Percentage of residential long-term care facilities with standards for dementia, which are aligned with a national standard.	
E-tool question	**Q9x2** Percentage of facilities following national dementia standards (if available)	Percentage

Hospice centres

Subindicator: density of hospice centres (per 100 000 population)

Definition	Total number of hospice centres. Note density per 100 000 population will be calculated centrally using each country's latest UN population estimate as denominator.	
E-tool question	**Q9x3** How many centres are there in total?	Number

Subindicator: hospice centre beds (per 10 000 population)

Definition	Total number of beds in hospice centres. Note density per 10 000 population will be calculated centrally using each country's latest UN population estimate as denominator.	
E-tool question	**Q9x3** Total number of beds	Number

Subindicator: dementia-specific hospice care beds (per 10 000 population)

Definition	Total number of dementia-specific beds in hospice centres. Note density per 10 000 population will be calculated centrally using each country's latest UN population estimate as denominator.	
E-tool question	**Q9x3** Total number of dementia-specific beds	Number

Adult day centres

Subindicator: density of adult day centres (per 100 000 population)

Definition	Total number of adult day centres. Note density per 100 000 population will be calculated centrally using each country's latest UN population estimate as denominator.	
E-tool question	**Q9x4** How many centres are there in total?	Number

Subindicator: adult day centre places (per 10 000 population)

Definition	Total number of places in adult day centres. Note density per 10 000 population will be calculated centrally using each country's latest UN population estimate as denominator.	
E-tool question	**Q9x4** Total number of places	Number

Subindicator: dementia-specific adult day centre places (per 10 000 population)

Definition	Total number of dementia-specific places in adult day centres. Note density per 10 000 population will be calculated centrally using each country's latest UN population estimate as denominator.	
E-tool question	**Q9x4** Total number of dementia-specific places	Number

Outpatient health centres

Subindicator: density of outpatient health centres (per 100 000 population)

Definition	Total number of outpatient health centres. Note density per 100 000 population will be calculated centrally using each country's latest UN population estimate as denominator.	
E-tool question	**Q9x5** How many centres (including local branches) are there in total?	Number

Subindicator: estimated number of people with dementia receiving services at outpatient health centre

Definition	Total number of patients with dementia who received care/treatment at the outpatient health centres.	
E-tool question	**Q9x5** Number of patients served with dementia	Number

Outpatient (community) social centres

Subindicator: density of outpatient social centres (per 100 000 population)

Definition	Total number of outpatient social centres. Note density per 100 000 population will be calculated centrally using each country's latest UN population estimate as denominator.	
E-tool question	**Q9x6** How many centres (including local branches) are there in total?	Number

Subindicator: estimated number of people with dementia receiving services at outpatient social centre

Definition	Total number of patients with dementia who received care/treatment at the outpatient social centres.	
E-tool question	**Q9x6** Number of patients served with dementia	Number

Indicator 10: antidementia medication and care products

Rationale	Antidementia medication may be offered for the treatment of Alzheimer's disease and certain other types of dementia, where evidence is available. The availability of reimbursable medication and care products supports the care of people with dementia and improvements in their quality of life.
Method of estimation	All antidementia medication, care products and equipment that are used in the management of dementia, provided by the national authority's response.
Data source	National drug administrative and regulatory body; pharmaceutical department in Ministry of Health; pharmaceutical industry; home-care organizations; NGOs.
Data type representation	Categorical
Data collected elsewhere	No

Subindicator: national regulator approval of antidementia medication

Definition	Existence of nationally approved medication used in the treatment of Alzheimer's disease as well as products for the care of people with dementia. Antidementia medication refers to the cholinesterase inhibitors donepezil, galantamine and rivastigmine as well as to the NMDA-receptor blocker memantine.	
E-tool question	**Q10x1** Are any antidementia medications approved by your National Medicines Regulatory Authority?	Yes/No

Subindicator: availability of generic antidementia medication

Definition	Existence of nationally approved generic medication used in the treatment of Alzheimer's disease and dementia.	
E-tool question	**Q10x1x1** Generic version(s) available for any of the drugs?	Yes/No

Subindicator: availability of at least one antidementia medication approved for on-label use reimbursement

Definition	Indicates whether any of the nationally approved medications used in the treatment of Alzheimer's disease and dementia are reimbursable for on-label usage.	
E-tool question	**Q10x1x2** Is at least one of the antidementia drugs reimbursable for on-label use?	Yes/No/Partial

Subindicator: range of care products, equipment, or assistive technologies

Definition	Checklist indicating whether the following product categories are reimbursable, not reimbursable or not available in your country. - **Adult hygiene products.** Indicates whether hygiene products are available (e.g. diapers, disposable cloths, underpads) or reimbursable for people with dementia. Please select 'reimbursable' if *any* of the possible products are reimbursable. - **Assistive technology.** Indicates whether technologies (e.g. walking frames, wheelchairs, spectacles, hearing aids) are available or reimbursable for people with dementia. Please select 'reimbursable' if *any* of the possible products are reimbursable.

	- **Housing adjustments.** Indicates whether housing adjustments (e.g. ramps, grab bars, smoke detectors) are available or reimbursable for people with dementia. Please select 'reimbursable' if *any* of the possible products are reimbursable.	
E-tool questions	**Q10x2** Which of the following care products, equipment, or assistive technologies are available for people with dementia in your country? - Adult hygiene products - Assistive technology- Housing adjustments	reimbursable /not reimbursable/ not available

Indicator 11: dementia-specific nongovernmental organization

Rationale	In many countries, nongovernmental organizations (NGOs) represent the main advocacy body for people with dementia and their carers. They also often constitute the backbone of community service delivery for people with dementia and their carers.
Method of estimation	Existence of nongovernmental, non-profit or consumer organization provided by the national authority's response
Data source	National register of NGOs, national register of corporations, national register of associations
Data type representation	Categorical
Data collected elsewhere	No
Comments/notes	If more than one national dementia-specific NGO exists, assess them all as one entity.

Subindicator: existence of dementia NGO

Definition	Existence of an NGO dedicated to supporting and advocating for people with dementia and their carers.	
E-tool question	**Q11x1** Is there at least one national nongovernmental dementia association such as an Alzheimer Association/Society?	Yes/No

Subindicator: dementia NGO office

Definition	Indicates whether the national NGO has an office.	
E-tool question	**Q11x2x1** Is the association equipped with an office?	Yes/No

Subindicator: dementia NGO branches

Definition	Indicates whether the national NGO has subnational and/or local offices or branches.	
E-tool question	**Q11x2x2** Does the association have subnational (i.e. state/territory/provincial/regional), or local offices?	Subnational/ local/ none

Subindicator: dementia NGO staff primarily salaried/volunteer

Definition	Indicates whether the majority (50% or more) of staff at the national NGO is salaried or voluntary.	
E-tool question	**Q11x2x3** Are the majority of staff (50% of more) salaried or volunteers?	Salaried/voluntary

Subindicator: type of activities/services provided by dementia NGO

Definition	Indicates the dementia-specific activities and services provided by the national NGO.	
E-tool question	**Q11x2x4** What dementia specific activities and/or services does the association provide?	Awareness raising/ home health and social care services/carer training

Subindicator: provision of governmental funding to dementia NGO for activities/services

Definition	Indicates whether the government provides funding for dementia-specific activities and services provided by the national NGO dedicated.	
E-tool question	**Q11x2x5** Does the government provide funding to the association for any of the activities or services identified in above?	Yes/No

Subindicator: dementia NGO's involvement in policy development

Definition	Indicates whether the national NGO is involved with developing dementia-related policy. Policy development is defined as formal involvement in the advancement or implementation of policies, laws or regulations, for example in the development of national dementia plans or consultation for development of dementia legislation.	
E-tool question	**Q11x2x6** Is the association involved in policy development related to dementia?	Yes/No

Indicator 12: dementia carer support services

Rationale	The creation and implementation of means to deliver multisectoral care, support and services for carers will help to meet the needs of carers, and prevent a decline in their physical and mental health and social well-being.
Means of estimation	Inventory of currently implemented programmes for carers provided by the national authority's response.
Data source	National or regional government ministries, departments and agencies (e.g. Ministry of Health, Department of Social Services/ Affairs, mental health services, community and social care services); NGOs; consumer associations; family associations; universities.
Data type representation	Categorical
Data collected elsewhere	No
Comments/notes	This indicator links to the **measurement for global target 5**, which states: "75% of countries provide support and training programmes for carers and families of people with dementia by 2025." For countries with a federated system, this refers to the availability of provincial or state-wide services or programmes with complete geographical coverage for 50% or more of the provinces or states within the country.

Subindicator: existence of dementia carer support services

Definition	Measures the availability and accessibility of existing carer support services. These services include information, training programmes, respite services and other resources tailored to the carers' needs and aim to improve their knowledge and caregiving skills to enable people with dementia to live in the community and to prevent stress and health problems for their carers. Programmes are considered functional if they have dedicated financial and human resources, an implementation plan and documented evidence of progress or impact.	
E-tool questions	**Q12x1** Do you have any services, supports or programmes for **carers** of people with dementia?	Yes/No
	Q12x1x1 What is the highest level of implementation?	National/ subnational

Subindicator: existence of dedicated resources for dementia carer support services

Definition	Indicates whether there are dedicated financial and human resources to make available, accessible or implement services, supports or programmes for carers of people with dementia.	
E-tool question	**Q12x1x2** Are there dedicated financial and human resources?	Yes/No

Subindicator: existence of implementation plan for dementia carer support services

Definition	Indicates whether there is a defined plan of implementation to make services, supports or programmes for carers of people with dementia available and accessible.	
E-tool question	**Q12x1x3** Is there a defined implementation plan?	Yes/No

Subindicator: range of dementia carer services and accessibility

Definition

Checklist indicating which of the following dementia carer services are available:

- **Carer training and education.** Availability of educational training and interventions to support caring for the person with dementia such as care techniques, nonverbal communication, patient-carer relationship development across the course of the disease.
- **Psycho-social support for carers.** Availability of psychosocial supports for carers of people with dementia such as carer support groups, online supports, peer-to-peer supports, self-help, dementia national help line, counselling from mental health and non-(mental) health professionals across the course of the disease and beyond the death of the person with dementia.
- **Respite services for carers.** Availability of respite for carers of people with dementia. Respite care is defined as time away from the caring role to engage in other activities of choice, knowing the care recipient is happy and receiving quality care. This contributes to the ultimate aims of supporting ageing in place for all people, including people with dementia, ensuring that they receive high-quality care, and reducing the likelihood of health problems in carers.
- **Information or advice on legal rights.** Availability of legal information or advice for carers of people with dementia
- **Financial benefits or social (security).** availability of protection for carers of people with dementia such as employment protection, carers' benefit, paid or unpaid leave, credited social contributions, respite care, training or price subsidies such as tax allowances, duty rebates, discount transportation fares, free companion fares.

E-tool questions	**Q12x2** Do you have any of the following?	
	- Carer training and education on dementia management across the course of the disease	Yes/No
	- Psycho-social support for carers across the course of the disease and beyond the death of the person with dementia	Yes/No
	- Respite services for carers	Yes/No
	- Information or advice on legal rights	Yes/No
	- Financial benefits/social (security) protection	Yes/No

Subindicator: accessibility of dementia carer services

Definition	Specifies for all available services (selected above) the accessibility in different locations	
E-tool question	**Q12x2x1x1** What is the accessibility of these services?	Capital city only/capital and main cities only/capital, main cities and rural areas

Subindicator: majority provider of dementia carer services

Definition	Identifies the majority provider for all available services (selected above) as public, private or NGO sectors. Majority provider of care is defined as providing care to 50% or more of users.	
E-tool question	**Q12x2x1x2** Who is the majority *provider* of this service?	Public/ private sector/ NGO

Subindicator: estimated percentage of dementia carers receiving carer services

Definition	Approximates the percentage of dementia carers who receive the services selected above. Utilization of all services is measured as of 31 December of the previous year only.	
E-tool question	**Q12x2x1x3-Q12x2x5x3** Approximately how many carers received this service in your country?	Don't know, Percentage

SUBDOMAIN 2.3: PROMOTION OF AWARENESS AND UNDERSTANDING

A society with inclusive and accessible community environments optimizes opportunities for health, participation and security for all people, which can enhance quality of life and dignity for people with dementia, their carers and families.

Key aspects of a dementia-friendly society include safeguarding the human rights of people with dementia, tackling the stigmatization associated with dementia, promoting a greater involvement of people with dementia in society, and supporting families and carers of people with dementia. The concept of dementia friendliness is tightly linked to societies also being age-friendly. Both age- and dementia-friendly initiatives should take into account the fact that a significant number of older people are living alone and are sometimes very isolated.

This subdomain links to action area 2 in the global action plan on the public health response to dementia 2017-2025.

Indicator 13: dementia awareness and risk reduction campaign	
Rationale	Dementia-awareness and risk-reduction campaigns that are tailored to the cultural contexts and particular community needs can promote enhanced health and social outcomes that reflect the wishes and preferences of people with dementia, as well as improve the quality of life of people with dementia, their carers and the broader community.
Method of estimation	Inventory of currently implemented and functioning dementia-awareness and risk reduction campaigns, described project by project, provided by national authority's response.
Data source	Ministry of Health, local authorities, civil society organizations, mental health authorities, mental health services, NGOs.
Data type representation	Categorical
Data collected elsewhere	No
Comments/notes	The objective of dementia-awareness and risk-reduction campaigns should be to foster an accurate understanding of dementia and its various subtypes as clinical diseases, reduce stigmatization and discrimination associated with dementia, educate people about the human rights of people with dementia and the UN Convention on the Rights of Persons with Disabilities[1] enhance the general population's ability to recognize early symptoms and signs of dementia, and increase the public's knowledge of risk factors associated with dementia, thereby promoting healthy lifestyles and risk-reduction behaviour in all. This indicator links to the **measurement for global target 2.1**, which states: "100% of countries will have at least one functioning public-awareness campaign on dementia to foster a dementia-inclusive society by 2025."

Subindicator: existence of at least one functioning dementia awareness campaign

Definition	Existence of public awareness campaign to improve understanding and reduce stigma and discrimination against people with dementia in the past year. Awareness-raising campaigns may and preferably should – cover both universal, population-level strategies (e.g. mass media campaigns

[1] Convention on the Rights of Persons with Disabilities [A/RES/61/106]. New York: United Nations Division for Social Policy and Development Disability; 2007 (https://www.un.org/development/desa/disabilities/resources/general-assembly/convention-on-the-rights-of-persons-with-disabilities-ares61106.html, 26 October 2017).

	against dementia stigmatization and discrimination) and those aimed at locally-identified vulnerable groups (e.g. older people, women, people with low educational attainment, high-risk populations such as smokers and ethnic minorities). Functioning is defined as having the following components: dedicated financial resources, programme management, documented evidence of progress and impact.	
E-tool questions	**Q13x1** Was at least one functioning dementia public awareness campaign to improve understanding and reduce stigma and discrimination carried out during the past year?	Yes/No
	Q13x1x1 What is the level of programme implementation?	National/ subnational

Subindicator: details of existing awareness raising programmes

Definition	Checklist assessing aspects of individual awareness raising programmes such as level of implementation, existence of progress monitoring, financial resources, management responsibility, target audience and main delivery channels.	
E-tool questions	Add details for all existing awareness raising programmes	
	Q13x2 Programme name	String
	Q13x2x1 Level of programme implementation	National/ subnational
	Q13x2x2 Documented evidence of progress or milestones reached	Yes/No
	Q13x2x3 Dedicated financial resource	Yes/No
	Q13x2x4 Programme management (Select any that apply)	Government/NGO/private
	Q13x2x5 Audience	Targeted/universal
	Q13x2x6 Delivery channel (Select any that apply)	Television/radio/print media/billboards/social

Subindicator: existence of one functioning dementia risk reduction campaign

Definition	Existence of multi-sectoral dementia prevention and risk reduction campaign in the past year. Risk reduction campaigns may and preferably should – cover both universal, population-level strategies (e.g. mass media campaigns) and those aimed at locally-identified vulnerable groups (e.g. older people, women, people with low educational attainment, high-risk populations such as smokers and ethnic minorities). Functioning is defined as having the following components: dedicated financial resources, programme management, documented evidence of progress and impact.	
E-tool questions	**Q13x3** Have there been functioning, multisectoral prevention/risk reduction[1] programmes for dementia in the past year?	Yes/No
	Q13x3x1 What is the level of programme implementation	National/ subnational

[1] Note, a list of risk factors associated with dementia are available in subdomain 3.4

Subindicator: details of risk reduction programmes

Definition	Checklist assessing aspects of individual risk reduction programmes such as level of implementation, existence of progress monitoring, financial resources, management responsibility, target audience and main delivery channels.	
E-tool questions	Add details for all existing risk reduction/prevention programmes	
	Q13x3 Programme name	string
	Q13x3x1 Level of programme implementation	National/ subnational
	Q13x3x2 Documented evidence of progress or milestones reached	Yes/No
	Q13x3x3 Dedicated financial resource	Yes/No
	Q13x3x4 Programme management (Select any that apply)	Government/NGO/private
	Q13x3x5 Audience	Targeted/universal
	Q13x3x6 Delivery channel (Select any that apply)	Television/radio/print media/billboards/social

Indicator 14: dementia-friendly initiatives

Rationale	Making the physical and social environment dementia-friendly will enable people with dementia to participate in the community and maximize their autonomy through improved social participation, and will improve the quality of life for people with dementia, their carers and the broader community.
Method of estimation	Inventory of currently implemented dementia initiatives, described project by project, provided by the national authority's response.
Data source	Ministry of Health, local authorities, family and social service services, civil societies, NGOs, universities.
Data type representation	Categorical
Data collected elsewhere	No
Comments/notes	This indicator links to the **measurement for global target 2.2**, which states: "50% of countries will have at least one dementia-friendly initiative to foster a dementia-inclusive society by 2025"

Subindicator: availability of dementia-friendly initiatives (DFIs) that improve accessibility

Definition	Indicates if there are initiatives to improve accessibility of the physical and social environment for people with dementia. DFIs should aim to change the physical and social environment, including the provision of amenities, goods and services, in order to make a community more inclusive, accessible and age- and dementia-friendly. Accessibility is defined as the ability for older people, people with dementia and people with disabilities to use public physical and social environments safely.	
E-tool question	**Q14x1** Are there initiatives to improve accessibility of the physical and social environment, including for people with dementia?	Yes/No

Subindicator: range of dementia-friendly initiatives

Definition	Existence of initiatives to improve the ability for older people, people with dementia and people with disabilities to: use public spaces and buildings/ public transportation vehicles/ receive assistance with home modification/ assistive technology to compensate for loss of capacity/ community places where older people can meet/ have social opportunities as well as accessible information on leisure and social activities. See above for definition of accessibility.	
E-tool questions	**Q14x2** Indicate which of the following dimensions are covered in your dementia-friendly initiatives:	
	- Accessibility of public spaces and buildings	Yes/No
	- Accessibility of public transportation vehicles	Yes/No
	- Assistance with home modification	Yes/No
	- Assistive technology[1] to compensate for loss of capacity	Yes/No
	- Availability of community places where older people can meet	Yes/No
	- Availability of social opportunities as well as accessible information on leisure and social activities	Yes/No

Indicator 15: dementia education and training for non-health professionals

Rationale	Dementia training and education of the wider community that account for the cultural contexts and particular needs of a community and specific audiences can promote increased public awareness and understanding of dementia. This can make the societal environment more dementia-friendly by enhancing dementia care.
Means of estimation	Existence of dementia training and education programmes, provided by national authority's response.
Data source	Employers' associations, workers' unions, local authorities, courts, police departments, fire services, school boards, financial institutes, department for education, national and local Alzheimer's associations, NGOs, civil society groups.
Data type representation	Categorical
Data collected elsewhere	No
Comments/Notes	This indicator links to the **measurement for global target 2.2:** "50% of countries will have at least one dementia-friendly initiative to foster a dementia-inclusive society by 2025"

Subindicator: inclusion of dementia training and education for non-health professionals

Definition	Population groups outside the health and social care sector who receive dementia-specific education to enable them to increase awareness of, recognize someone with and the training to assist a person with dementia.	
E-tool questions	**Q15x1** Do population groups outside the health and social care sector receive training and education in dementia to enable them to increase awareness of, recognize someone with, and assist a person with dementia?	Yes/No

[1] See Glossary for description

Subindicator: existence of dementia training for non-health professionals and level of implementation

Definition	Indicates whether a list of professionals outside the health and social care sector (volunteers/ police and fire services/ first responders and paramedics/ judges, solicitors, and notaries/ community and city workers/ school children/ bankers and financial service staffs/ retail and hospitality staff) receive dementia-specific education and training to enable them to increase awareness of, recognize someone with dementia and assist a person with dementia. Level of implementation of training and education for list of professionals outside of the health and social care sector to enable them to increase their awareness, recognition, and ability to assist people with dementia.	
E-tool questions	**Q15x2** Please indicate which of the following groups of people receive education and training:	
	- Volunteers	Yes/No
	- Police and fire services	Yes/No
	- First responders / paramedics	Yes/No
	- Judges, solicitors, notaries	Yes/No
	- Community/city workers (e.g. public transport staff, librarians)	Yes/No
	- School children	Yes/No
	- Bankers, financial service staff	Yes/No
	- Retail and hospitality staff (e.g. restaurants, grocery stores)	Yes/No
	Q15x3 Select the highest level of implementation:	National/subnational/local

DOMAIN 3 – INFORMATION AND RESEARCH

SUBDOMAIN 3.1: MONITORING FOR DEMENTIA

Indicator 16: dementia monitoring

SUBDOMAIN 3.2: RESEARCH ACTIVITIES

Indicator 17: dementia research agenda

Indicator 18: dementia research investment

Indicator 19: dementia research participation

Indicator 20: published dementia research output (centrally generated data)

SUBDOMAIN 3.3: EPIDEMIOLOGY AND IMPACT (centrally generated data)

Indicator 21: estimated population prevalence rate of dementia

Indicator 22: estimated population incidence rate of dementia

Indicator 23: total deaths (due to) Alzheimer's disease and other dementias

Indicator 24: years of life lost (YLLs) due to dementia

Indicator 25: years of life lived with disability (YLDs) due to dementia

Indicator 26: disability-adjusted life years (DALYs) due to dementia

Indicator 27: total estimated economic costs

SUBDOMAIN 3.4: RISK FACTORS (collected as part of other WHO monitoring activities)

Indicator 28: insufficient physical exercise

Indicator 29: tobacco use

Indicator 30: harmful use of alcohol

Indicator 31: obesity

Indicator 32: diabetes mellitus

Indicator 33: hypertension

Indicator 34: high cholesterol

Indicator 35: depression

SUBDOMAIN 3.1: MONITORING FOR DEMENTIA

Systematic, routine population-level monitoring of dementia core indicators provides the data needed to guide evidence-based actions to improve services and to measure progress towards implementing national dementia policies. By building and/or strengthening information systems for dementia, the functional trajectories of people with dementia, their carers and families can be improved. However, this will require significant changes to the routine collection, linkage and disaggregation of data, while respecting existing regulatory frameworks for sharing health and administrative data.

This subdomain links to action area 6 in the global action plan on the public health response to dementia 2017-2025.

Indicator 16: dementia monitoring	
Rationale	Systematic monitoring and evaluation of health and social care data provide evidence for policy development and service delivery, improve accessibility to, and coordination of, care for people with dementia, and allow a better understanding and detection of population-level changes and trends.
Method of estimation	Can occur by means of a patient registry, aggregate data or medical records from various sources measured at a system level (national, subnational or local level). Responses provided by the national authority.
Data source	Administrative data; National Institute of Statistics; medical records, patient registries, population household surveys.
Data type representation	Categorical
Data collected elsewhere	No

Subindicator: routine monitoring of people with dementia

Definition	Indicates whether the ongoing, systematic collection and analysis of measures that include performance of activities in the health system occurs for people with dementia. Monitoring and reporting can be in the form of a specific report focused on dementia, or if not a dedicated report, a chapter on dementia integrated into a mental health, NCD or ageing report. For countries with a federated system, refer to the monitoring systems of the majority of states/provinces or the majority of the population in the country.	
E-tool questions	**Q16x1** Is the number of people with dementia routinely monitored in your country?	Yes/No

Subindicator: data sources used to routinely monitor people with dementia

Definition	Indicates the data sources used for ongoing, systematic collection and analysis of measures for monitoring the health system for people with dementia.	
E-tool question	**Q16x1x1** What are the data sources currently used to routinely monitor people with dementia?	Clinical records/ household surveys/ administrative data/ facility surveys or records/ other

Subindicator: electronic availability of data sources used to routinely monitor people with dementia

Definition	Indicates whether the data sources are available electronically.	
E-tool question	**Q16x1x2** Are the data sources available electronically?	Yes/No

Subindicator: data used to routinely monitor people with dementia can be disaggregated

Definition	Indicates whether the data can be disaggregated (for example by sex, age, type of dementia).	
E-tool question	**Q16x1x2** Can the number of people with dementia be disaggregated?	Yes/No

Subindicator: availability of a range of details monitored of people with dementia

Definition	Identifies whether a range of details indicated below are monitored for people with dementia.	
E-tool questions	**Q16x2** Are the following details monitored for people with dementia in your country?	
	- Number of hospital admissions	Yes/No
	- Number of outpatient visits	Yes/No
	- Types of outpatient interventions and treatments received	Yes/No
	- Medications/pharmaceutical treatment	Yes/No
	- Prescriptions of antipsychotics	Yes/No
	Q16x2x5 Clinical indicators for the quality of care [1]	Quality of life/ Adverse events/ Disability or functional status/ Other

Subindicator: availability and status of dementia reporting

Definition	The availability and status of dementia reporting within the country. Monitoring and reporting can be in the form of a specific report focused on dementia, or if not a specific report, a chapter on dementia integrated into a mental health, NCD or ageing report. Alternatively, dementia data may be complied but not reported in a report.
E-tool question	**Q16x3** Concerning the availability and status of dementia reporting, please select one response that best describes your country: a) A specific report focusing on dementia activities in both the public and private sector has been published by the Health Department or another responsible government unit in the last two years. b) A specific report focusing on dementia activities in the public sector only has been published by the Health Department or another responsible government unit in the last two years. c) Dementia data (in either the public system, private system, or both) have been compiled for general health statistics in the last two years, but not in a specific dementia report. d) No dementia data have been compiled in a report for policy, planning or management purposes in the last two years.

[1] These can include measures such as patient or carer report outcomes (including well-being, quality of life), adverse events (such as falls), physical and cognitive functional status

SUBDOMAIN 3.2: RESEARCH ACTIVITIES

If the incidence of dementia is to be reduced and the lives of people with dementia are to be improved, research and its translation into informed interventions, daily practices and policies are crucial. In addition to developing a dementia research agenda, there are other ways that countries can make dementia a research priority. It is important that both dedicated funding and an appropriate infrastructure for dementia research are available, that communities are sensitized to the importance of participation in and support for dementia research, and that mechanisms are in place to assist the appropriate recruitment of people with dementia and their carers into research studies.

Compared to other NCDs, dementia receives disproportionately little research funding, both in absolute terms and particularly relative to its burden on people affected and on society. Likewise, dementia research generates significantly less research output compared to other NCDs.

The implementation of strategic national dementia research agendas, based on the identification of gaps and research priorities, is needed to inform the design and conduct of sound and far-reaching research. Such research, if effectively disseminated, can provide the evidence base for policy, health and social service planning, and can contribute to increasing the likelihood of effective progress toward better prevention, diagnosis, treatment and care for people with dementia, and better support for carers.

This subdomain links to action area 7 in the global action plan on the public health response to dementia 2017-2025.

Indicator 17: dementia research agenda	
Rationale	Developing, implementing and monitoring the realization of a national research agenda on prevention, diagnosis, treatment and care of people with dementia, in collaboration with research institutions, will facilitate filling evidence gaps in policy or practice.
Method of estimation	Government statement, official government document, policy document, research plan documents, and related legislation, laws or official directives. Responses provided by the national authority.
Data source	Ministry of Health; Ministry of Research (or equivalent); national research councils/institutes.
Data type representation	Categorical
Data collected elsewhere	No

Subindicator: existence of a current dementia research plan/programme

Definition	A published government policy, statement, document or part thereof detailing the government's plan or programme for dementia research, published within the last five years	
E-tool questions	**Q17x1** Does your country have a current (i.e. within the last 5 years) research plan or programme dedicated to dementia?	Yes/No
	Q17x1x1 Is it a national or subnational research plan?	National/ subnational

Subindicator: date range of dementia research plan/programme

Definition	Years covered by the dementia-specific national research plan or programme.	
E-tool question	**Q17x1x1x1** If national, what years does it cover (latest version)?	Year - Year

Subindicator: dementia integrated into other national research plan/ programme

Definition	Indicates whether dementia is included within the research plan or programme of a different area (such as mental health research, NCDs research, health research in general)	
E-tool question	**Q17x2** Is dementia included in another research plan (e.g. mental health research, NCDs research, health research in general)?	Yes/No

Subindicator: identification of other research plans in which dementia is integrated

Definition	Indicates the area of the research plan or programme in which dementia is included.	
E-tool questions	**Q17x2x1** In which research plans is dementia covered?	Mental health/ ageing/ neurodegenerative disease/NCDs
	Q17x2x2 Is it a national or subnational research plan?	National/ subnational

Subindicator: date range of research plan/programme in which dementia is integrated

Definition	Years covered by any other national research plan or programme which includes dementia.	
E-tool question	**Q17x2x2x1** If national, what years does it cover?	Year - Year

Indicator 18: dementia research investment

Rationale	Government research investments are needed not only to find a cure for dementia, but also in other areas such as prevention, risk reduction, diagnosis, treatment and care - including the disciplines of social science, public health and implementation research. Increasing the investment in research is an integral component of the national response to dementia. It is important to allocate budgets to support collaborative national and international research to promote sharing of, and open access to, research data, to generate knowledge on how to translate what is already known about dementia into action, and to support the retention of the research workforce.
Method of estimation	Existence of a government statement, budgetary document, policy document, or research plan document on the specific government budget (GBAORD) as a way of measuring government support for R&D activities. Responses provided by the national authority.
Data source	Ministry of Health/Research/Education/Science/Finance; National Statistics Office/ National Institute of Statistics; National Research/ Science Foundation; National Research Council; National Documentation Centre/ European Union's Joint Programme on Neurodegenerative Disease Research.
Data type representation	Categorical and numerical

Data collected elsewhere	The WHO Global Observatory on Health R&D includes the "Gross domestic R&D expenditure in the health and medical sciences (health GERD) as a percentage of gross domestic product (GDP). This information is collected from the United Nations Educational, Scientific and Cultural Organization (UNESCO). The gross domestic product (GDP) data are collected from the Global Health Expenditure Database. Non-dementia-specific R&D funding information available for OECD countries is marked as (**). Dementia-specific R&D funding information available for countries belonging to the European Union's Joint Programme on Neurodegenerative Disease Research (JPND) and the National Institute on Aging's Common Alzheimer Disease Research Ontology (CADRO), though not on an annual basis, is marked as (**).
Comments/notes	The indicator is a measure of public funding only. Private and public partnerships resulting in spending through public institutions should nevertheless be included. However, private-only funding or spending is not included.

Subindicator: availability and total expenditure on dementia-specific research

Definition	Dedicated research funding is defined as "Government budget appropriations or outlays for research and development" (GBAORD) for dementia. GBAORD include all appropriations (i.e. government spending) given to Research and Development (R&D) in central (or federal) government budgets. Provincial (or state) government posts are included only if the contribution is significant. Local government funds are excluded. Note, dementia-specific R&D funding information available for countries belonging to the European Union's Joint Programme on Neurodegenerative Disease Research (JPND) and the National Institute on Aging's Common Alzheimer Disease Research Ontology (CADRO), though not on an annual basis, is marked as (**). For a list of conditions/diseases that can be included within the term "dementia", refer to the Glossary.	
E-tool question	**Q18x2** Has your government been allocating money specifically for dementia research in the last fiscal year? If yes, please reply to the following:	Yes/No/Don't know**

Subindicator: total expenditure on dementia research (as a percentage of gross domestic product)

Definition	Government's combined national and subnational dementia-specific research expenditure in the last year for which data is available. Note, percentage of gross domestic product (GDP) will be calculated centrally using each country's latest data collected from the Global Health Expenditure Database. Note, where available, data collected by the EU Joint Programme – Neurodegenerative Disease Research (JPND) for the JPND mapping exercise of research in neurodegeneration is marked as (**).	
E-tool question	**Q18x2x1** What is the governments' total expenditure on dementia research (combined national and subnational government expenditures in national currency for the latest year for which data are available)?	Million (national currency) **

Subindicator: dementia-specific research investments

Definition	Year for which data on government's combined national and subnational dementia-specific research expenditure is available.	
E-tool question	**Q18x2x2** Year for which these data are available	Year

Subindicator: total expenditure on dementia research

Definition	**Basic research.** Total government research expenditure on discovery research that underpins investigations into the cause, development, detection and treatment of dementia. **Clinical/Translational research**. Total government research expenditure on dementia-specific research conducted in/on living humans that is patient-oriented. **Implementation research**. Total government research expenditure on dementia-specific research on the provision and delivery of health and social care services to individuals. Note, that where available, data collected by the EU Joint Programme – Neurodegenerative Disease Research (JPND) for the JPND mapping exercise of research in neurodegeneration is marked as (**).	
E-tool questions	**Q18x2x3** Please provide the breakdown of expenditure on dementia research by the following categories:	
	- Basic	Million (national currency)**
	- Clinical/Translational	Million (national currency)**
	- Implementation	Million (national currency)**

Indicator 19: dementia research participation

Rationale	Research participation is crucial to conducting studies in humans and to monitoring and contributing to the research process. It has also been shown to be potentially beneficial due to an improved understanding of dementia, its impact on both people with dementia and their carers, and more regular health checks involved in trial protocols.
Method of estimation	Existence of relevant opportunities to participate in research through access to longitudinal cohort studies, clinical trials, selection of successful grant applications or formal contributions to the research process. Provided by the national authority's response.
Data source	Registries; National Alzheimer's Association and other NGOs; National Regulatory Authority; universities
Data type representation	Categorical
Data collected elsewhere	No

Subindicator: involvement of people with dementia in research process

Definition	Existence of opportunities for people with dementia and their carers to contribute to the research process or participate in ongoing dementia research. Examples include setting research priorities, grant applications, research review opportunities	
E-tool question	**Q19x1** Are people with dementia involved in the research development process?	Not at all/ Rarely/ Sometimes/ Frequently

Subindicator: number of people with dementia involved in research routinely monitored

Definition	Indicates whether the number of people with dementia who participate in the research process are monitored	
E-tool question	**Q19x2** Is the number of people with dementia who participate in research monitored in your country?	Yes/No

Subindicator: estimated number of people with dementia involved in research

Definition	Total number of people with dementia who were involved in research in the last year. Includes participants from all ethically approved research studies related to dementia diagnosis, treatment or care. Excludes count of healthy volunteers who may serve as controls/matches or carers of people with dementia. Research examples include clinical, social or epidemiology research. Availability of stratification of data (e.g. sex, type of research) on the total number of people with dementia who participate in research.	
E-tool question	**Q19x2x1** If yes, how many people with dementia were involved in research in the last year?	Number
	Q19x2x2 Can the number be stratified by any of the following? (Select any that apply)	Sex/ type of research

Subindicator: availability of investigational pharmaceutical trials for dementia

Definition	Existence of investigational pharmaceutical trials for dementia. This includes multi-centre trials or trials headquartered /coordinated elsewhere with a site in the country	
E-tool question	**Q19x3** Are investigational pharmaceutical trials for dementia (Phase II to IV) available in your country?	Yes/No

Subindicator: number of investigational pharmaceutical trials for dementia

Definition	Number of investigational pharmaceutical trials for dementia in the past year. This includes multi-centre trials or trials headquartered /coordinated elsewhere with a site in the country	
E-tool question	**Q19x3x1** If yes, how many were ongoing in the last year?	Number

From this point onwards, no country inputs are required, all data will be centrally generated

Indicator 20: published dementia research output		
Rationale	The annual published research output in peer-reviewed and indexed journals is a proxy for the amount (and quality) of dementia research being conducted in a country. It indirectly assesses a country's commitment to dementia research, which will ultimately have an impact on people with dementia and their carers.	
Method of estimation	Centrally-conducted literature searches, stratified by country of origin every two years. Data for this indicator will be generated centrally, using a standardized methodology for all countries. Briefly, the annual published dementia research output will be determined for each country for the most recent calendar year using bibliometric data sourced from two literature databases: • PubMed (capturing general biomedical research, biased towards medical research, English-speaking literature and research from high-income countries) • WHO's Global Index Medicus (collating research output from low- and middle-income countries not necessarily captured by other databases, and stratified by country and WHO region). Separate searches will be conducted of the different databases. Results will be reported by WHO at global, regional and national levels.	
Data source	WHO centrally generated bibliometric data	
Data type representation	Numerical	
Data collected elsewhere	No	
Comments/notes	This indicator links to the **measurement for global target 7**, which states: "The output of global research on dementia doubles between 2017 and 2025."	
Definition	The number of published articles on dementia research in the country (defined as research articles published in the databases).	
Measurement:	Number of published articles on dementia research conducted in the country (defined as research articles published in the databases)	Number

SUBDOMAIN 3.3: EPIDEMIOLOGY & IMPACT

Dementia is a major cause of disability and dependency among older people worldwide. It has a significant impact not only on individuals but also on their carers, families, communities and societies.
Epidemiology is considered the cornerstone of public health because epidemiological data provide the evidence base to inform the design and implementation of relevant policies and plans that support population needs. Collecting and using the necessary epidemiological data, therefore, is crucial.

This subdomain links to action area 6 in the global action plan on the public health response to dementia 2017-2025.

Indicator 21: estimated population prevalence rate of dementia	
Rationale	Systematic, routine population-level monitoring of dementia indicators provide the data needed to guide evidence-based actions to improve services and to measure progress.
Definition	Estimated population prevalence rate of dementia (number of existing cases of dementia) stratified by age and sex.
Method of estimation	**Centrally-conducted.** Briefly, full systematic reviews of all prevalence studies conducted worldwide will be assessed and systematically coded for study design and quality according to pre-developed criteria. *Inclusion criteria:* Population-based studies of dementia prevalence among people aged 60 years and over (according to DSM-IV or ICD-10 criteria, or similar pre-existing clinical criteria), for which the field work started on or after 1st January 1980. Weighted and unweighted prevalence data are extracted with age and gender-specific prevalence. Within each region where data are sufficient, a meta-analysis will be conducted using a random effect exponential (Poisson) model. Where sufficient data are lacking for a meta-analysis, relevant estimates from Delphi consensus representing the best available estimates will be applied. Results will be reported by WHO at global, regional and national level.

Indicator 22: estimated population incidence rate of dementia	
Rationale	Systematic, routine population-level monitoring of dementia indicators provide the data needed to guide evidence-based actions to improve services and to measure progress.
Definition	Estimated population-based dementia incidence rate (number of new cases of dementia) stratified by age and sex.
Method of estimation	**Centrally-conducted.** Briefly, full systematic reviews of all incidence studies conducted worldwide will be assessed and systematically coded for study design and quality according to pre-developed criteria. *Inclusion criteria*: Population-based studies of the incidence of dementia, including people aged 60 years and over (according to DSM-IV or ICD-10 criteria, or similar pre-existing clinical criteria), for which the fieldwork started on or after 1 January 1980. Numerator (case) and denominator (person years), incidence and standard error, or incidence and 95% confidence intervals, are extracted with age- and gender-specific incidence. Within each region where data are sufficient, a meta-analysis will be conducted using a

	random effect exponential (Poisson) model. Where sufficient data are lacking for a meta-analysis, relevant estimates from Delphi consensus representing the best available estimates will be applied. Results will be reported by WHO at global, regional and national levels.

Indicator 23: total deaths (due to) Alzheimer's disease and other dementias	
Rationale	Systematic, routine population-level monitoring of dementia indicators provide the data needed to guide evidence-based actions to improve services and to measure progress.
Definition	Ranking of dementia among the other causes of death in adults aged ≥ 60 years
Method of estimation	**Centrally-conducted**. Results will be reported by WHO at global, regional and national levels.

Indicator 24: years of life lost (YLLs) due to dementia	
Rationale	Systematic, routine population-level monitoring of dementia indicators provide the data needed to guide evidence-based actions to improve services and to measure progress.
Definition	Years of Life Lost (YLL) from premature mortality due to dementia in the population (corresponds to the number of deaths multiplied by the standard life expectancy at the age at which death occurs).
Method of estimation	**Centrally-conducted**. The basic formula for YLL for a given cause, age and sex is the following: YLL = N x L where: N = number of deaths, and L = standard life expectancy at age of death in years. Results will be reported by WHO at global, regional and national levels.

Indicator 25: years of life lived with disability (YLDs) due to dementia	
Rationale	Systematic, routine population-level monitoring of dementia indicators provide the data needed to guide evidence-based actions to improve services and to measure progress.
Definition	Years of Life Lived with Disability (YLD) due to dementia
Method of estimation	**Centrally-conducted**. To estimate YLD for dementia in a particular time period, the number of incident cases in that period is multiplied by the average duration of the disease and a weight factor that reflects the severity of the disease on a scale from 0 (perfect health) to 1 (dead). The basic formula for YLD is the following (without applying social preferences): YLD = I x DW x L Where: I = number of incident cases; DW = disability weight; L = average duration of the case until remission or death (years). Results will be reported by WHO at global, regional and national level.

Indicator 26: disability adjusted life years (DALYs) due to dementia	
Rationale	Systematic, routine population-level monitoring of dementia indicators provide the data needed to guide evidence-based actions to improve services and to measure progress.
Definition	A composite measure of disease burden calculated as the sum of Years Lived with Disability (YLD) and Years of Life Lost (YLL), thereby summarizing the effects of dementia on both the quantity (premature mortality) and quality of life (disability).
Method of estimation	**Centrally-conducted**. Briefly, population surveys are used to assess the disability weights of dementia by severity. Results will be reported by WHO at global, regional and national level.

Indicator 27: total estimated economic costs	
Rationale	Systematic, routine population-level monitoring of dementia indicators provide the data needed to guide evidence-based actions to improve services and to measure progress.
Definition	- Direct medical costs of dementia (within the healthcare sector) - Direct social costs of dementia (paid and professional home care, and residential and nursing home care) - Informal care costs of dementia (unpaid)
Method of estimation	**Centrally-conducted**. Briefly, costs are estimated at the country level (using literature searches for cost-of-illness studies) and then aggregated in various combinations to summarize worldwide cost and cost by WHO region. For each country there is a cost per person (per capita) estimate, which is then multiplied by the number of people estimated to be living with dementia in that country. The per capita costs are divided into three cost subcategories: direct medical costs, direct social care costs (paid and professional home care, and residential and nursing home care) and costs of informal (unpaid) care. The base option for costing informal care reflects an opportunity cost approach, valuing hours of informal care by the average wage for each country. Where data are unavailable for regions/countries, extrapolations of economic conditions from other regions are carried out, adjusting for gross domestic product per person. Results will be reported by WHO at global, regional and national levels.

SUBDOMAIN 3.4: RISK FACTORS

Growing evidence suggests that dementia shares several modifiable risk factors with other NCDs. These risk factors include physical inactivity, obesity, tobacco use, harmful use of alcohol, diabetes mellitus and mid-life hypertension. In addition, other potentially modifiable risk factors are more specific to dementia and include social isolation, low educational attainment, cognitive inactivity and mid-life depression.

Reducing individual- and population-level exposure to these potentially modifiable risk factors, beginning in childhood and extending throughout life, can improve the capacity of individuals and populations to make healthier choices and follow lifestyle patterns that foster good health.

This subdomain links to action area 3 in the global action plan on the public health response to dementia 2017-2025.

Data for indicators included herein are being collected routinely as part of either WHO's *Country capacity surveys* (CCS) for monitoring of the Noncommunicable Diseases Action Plan, or through WHO's *Mental health atlas* for monitoring of the Comprehensive Mental Health Action Plan 2013-2020.

Details on the indicators being collected for monitoring of the Noncommunicable Diseases Action Plan are linked to this document.[1]

Indicator 28: insufficient physical exercise		
Rationale	Insufficient physical exercise is associated with an increased risk of dementia	
Method of estimation	Self-report	
Data source	Population-based surveys Surveillance systems	
Data type representation	Percent	
Data collected elsewhere	Global Health Observatory	
Comments/notes	Age, sex, other relevant socio-demographic stratifiers where available	
Definition	Percent of defined population attaining less than 150 minutes of moderate-intensity physical activity per week, or less than 75 minutes of vigorous-intensity physical activity per week, or equivalent.	
Measurement:	Prevalence of insufficient physical activity among adults aged 18+ years (age-standardized and crude estimates)	Percentage

Indicator 29: tobacco use	
Rationale	Tobacco use is associated with an increased risk of dementia
Method of estimation	A statistical model based on a Bayesian negative binomial meta-regression was used to derive modelled crude estimates for four indicators of tobacco smoking (current and daily tobacco smoking as well as current and daily cigarette smoking) for countries, for men and women separately
Data source	Population-based surveys

[1] Available at: http://www.who.int/nmh/ncd-tools/indicators/GMF_Indicator_Definitions_FinalNOV2014.pdf?ua=1

	Surveillance systems	
Data type representation	Percent	
Data collected elsewhere	Global Health Observatory	
Comments/notes	Age, sex, other relevant socio-demographic stratifiers where available	
Definition	Prevalence of current smoking of any tobacco product by persons aged 15 years and above, resulting from analysis of the full set of adult tobacco use surveys (or surveys which asks tobacco use questions) completed by countries since 1990. "Tobacco smoking" includes cigarettes, cigars, pipes or any other smoked tobacco products. "Current smoking" includes both daily and non-daily or occasional smoking.	
Measurement:	Prevalence of smoking any tobacco product among persons aged >= 15 years	Percentage

Indicator 30: harmful use of alcohol		
Rationale	Harmful use of alcohol is associated with an increased risk of dementia	
Method of estimation	Is calculated as the sum of beverage-specific alcohol consumption of pure alcohol (beer, wine, spirits, other) from different sources.	
Data source	Government statistics	
Data type representation	Rate	
Data collected elsewhere	Global Health Observatory	
Definition	Recorded APC is defined as the recorded amount of alcohol consumed per capita (15+ years) over a calendar year in a country, in litres of pure alcohol. The indicator only takes into account the consumption which is recorded from production, import, export, and sales data often via taxation. Numerator: The amount of recorded alcohol consumed per capita (15+ years) during a calendar year, in litres of pure alcohol. Denominator: Midyear resident population (15+ years) for the same calendar year, UN World Population Prospects, medium variant	
Measurement:	Alcohol, recorded per capita (15+ years) consumption (in litres of pure alcohol)	Number

Indicator 31: obesity	
Rationale	Midlife obesity is associated with an increased risk of dementia
Method of estimation	Worldwide trends in body-mass index, underweight, overweight, and obesity from 1975 to 2016: a pooled analysis of 2416 population-based measurement studies with 128.9 million participants
Data source	Population based surveys
Data type representation	Percent
Data collected elsewhere	Global Health Observatory
Comments/notes	Age, sex, other relevant socio-demographic stratifiers where available
Definition	Percentage of defined population with a body mass index (BMI) of 30 kg/m2 or higher.

Measurement:	Prevalence of obesity among adults, BMI ≥ 30 (age-standardized estimate) (Percentage)	Percentage

Indicator 32: diabetes mellitus		
Rationale	Diabetes mellitus is associated with an increased risk of dementia	
Method of estimation	Worldwide trends in diabetes since 1980: a pooled analysis of 751 population-based studies with 4.4 million participants	
Data source	Population-based surveys	
Data type representation	Percent	
Data collected elsewhere	Global Health Observatory	
Comments/notes	Age, sex, other relevant socio-demographic stratifiers where available	
Definition	Percent of defined population with fasting glucose ≥126 mg/dl (7.0 mmol/l) or history of diagnosis with diabetes or use of insulin or oral hypoglycaemic drugs.	
Measurement:	Raised fasting blood glucose >=8.0 mmol/L or on medication (age-standardized estimate)	Percentage

Indicator 33: hypertension		
Rationale	Hypertension is associated with an increased risk of dementia	
Method of estimation	Worldwide trends in blood pressure from 1975 to 2015: a pooled analysis of 1479 population-based measurement studies with 19.1 million participants.	
Data source	Population-based surveys	
Data type representation	Percent	
Data collected elsewhere	Global Health Observatory	
Comments/notes	Age, Sex, other relevant socio-demographic stratifiers where available	
Definition	Percentage of defined population with raised blood pressure (systolic blood pressure ≥ 140 OR diastolic blood pressure ≥ 90).	
Measurement	Raised blood pressure (SBP>=140 OR DBP>=90) (age-standardized estimate)	Percentage

Indicator 34: high cholesterol	
Rationale	Hyperlipidaemia is associated with an increased risk of dementia
Method of estimation	National, regional, and global trends in serum total cholesterol since 1980: systematic analysis of health examination surveys and epidemiological studies with 321 country-years and 3.0 million participants.
Data source	Population-based surveys; surveillance systems
Data type representation	Percent
Data collected elsewhere	Global Health Observatory
Comments/notes	Age, sex, other relevant socio-demographic stratifiers where available
Definition	Percentage of defined population with total cholesterol ⩾ 190 mg/dl (5.0 mmol/l).

Measurement:	Raised total cholesterol (>= 5.0 mmol/L) (age-standardized estimate)	Percentage

Indicator 35: depression		
Rationale	Depression is associated with an increased risk of dementia	
Data source	Mental health atlas; WHO Global Health Estimates[1]	
Data type representation	Percent	
Data collected elsewhere	Global Health Estimates	
Comments/notes	Stratified by age and sex	
Definition	Percentage of persons with depressive disorder (major depressive disorder/depressive episode or dysthymia) in the last year	
Measurement	Prevalence of depressive disorder	Percentage

[1] For WHO Global Health Estimates, see:
http://www.who.int/mental_health/management/depression/prevalence_global_health_estimates/en/

GLOSSARY

TERM	DEFINITION
Activities of daily living (ADLs)	The basic activities necessary for daily life, such as bathing or showering, dressing, eating, getting in and out of bed or chairs, using the toilet, and getting around inside the home.
Admissions (number of)	The annual number of admissions is the sum of all admissions (for all conditions) to the facility within that year. In the GDO, this number is a duplicated count. In other words, if one user is admitted twice, it is counted as two admissions.
Advance care directive	A mechanism by which competent individuals express their wishes so that, should circumstances arise in which they no longer are able to make decisions regarding medical treatment, their preferences are respected. Advance care directives are made by writing living wills or granting power of attorney to another individual.
Assistive technology	Any device designed, made or adapted to help a person perform a particular task; products may be generally available or specially designed for people with specific losses of capacity. Assistive health technology is a subset of assistive technologies, the primary purpose of which is to maintain or improve an individual's functioning and well-being.
Beds (number of)	**Hospital dementia-specific beds** Total beds in hospital dedicated to people with dementia. Often accompanied by staff trained in the care and management of dementia and environmental adaptations specific to dementia. **Hospital geriatric-specific beds** Total hospital beds specialized to accommodate the needs of older patients (65+) can be separate from the general population in the hospital. Often involves being managed by a specialized inpatient geriatric staff team. **Residential long-term care beds** (OECD definition) Total beds in all residential long-term care facilities Inclusion criteria: - Long-term nursing care facilities - Other residential long-term care facilities Exclusion criteria: - Beds in hospitals dedicated to long-term care - Beds in residential settings such as adapted housing that can be considered as people's home.
Behavioural and Psychological Symptoms of Dementia (BPSD)	BPSD or neuropsychiatric symptoms are a heterogeneous group of non-cognitive symptoms and behaviours that may occur in individuals with dementia. They include symptoms such as agitation, aberrant motor behaviour, anxiety, elation, irritability, depression, apathy, disinhibition, delusions, hallucinations, and sleep or appetite changes.
BPSD management	Management of BPSD or neuropsychiatric symptoms include the following: – Identifying and treating underlying physical health problems that may affect behaviour (pain, infections, etc.);

	– Considering environmental modifications, such as appropriate seating, safe wandering areas, and signs or factors which may precede, trigger or enhance problem behaviours and trying to see if they can be modified; – Considering soothing, calming or distracting strategies, such as suggesting the person does activities they enjoy especially when they are feeling agitated.
Carer/caregiver	A person who provides care and support to a person with dementia; such support may include: – Helping with self-care, household tasks, mobility, social participation and meaningful activities; – Offering information, advice and emotional support, as well as engaging in advocacy, providing support for decision-making and peer support, and helping with advance care planning; – Offering respite services; – Engaging in activities to foster intrinsic capacity. Carers/caregivers may include relatives or extended family members as well as close friends, neighbours and paid lay persons or volunteers.
Carer training	Educational training and interventions to support caring for the person with dementia – such as care techniques, nonverbal communication, and patient–carer relationship development.
Case management	A continuous process of planning, arranging and coordinating multiple health-care services across time, place and discipline for patients with high-risk conditions or complex needs, in order to ensure appropriate care and optimum quality, as well as to contain costs, usually through the use of care coordinators, case managers or dementia advisers. The fundamental difference between case management and disease management is that case management focuses more on individual patients and their families than on the population of patients with a certain disease.
Care network	A network that formally links health professionals across facilities/disciplines to share good practice, increase the efficiency and effectiveness of medical services for patients, and improve coordination of care to ensure that patients receive the right care in the right place at the right time.
Clinical practice recommendations/ guidelines	Statements that include recommendations intended to optimize patient care, informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options. Provide guidance on clinical elements such as diagnosis, assessment and treatment, as well as quality long-term care. They should also include guidance on any legal and ethical issues that could compromise quality care.
Community-based approach	Care networks that integrate social and health systems and provide quality care and evidence-based interventions within the community.
Continuity of (long-term health and social) care	Continuity of care between different care providers is crucial from the first symptoms of dementia until the end of life and across all settings (e.g. at home, in the community, in assisted-living facilities, nursing homes, hospitals and hospices). It is a term used to indicate one or more of the following attributes of care: – The provision of services that are coordinated across levels of care (e.g. primary care and referral facilities, across settings and providers); – The provision of care throughout the life cycle;

	– Care that continues uninterrupted until the resolution of an episode of disease or risk; – The degree to which a series of discrete health care events are experienced by people as coherent and interconnected over time and are consistent with their health needs and preferences. **Continuity of information:** For example, continuous flow of information from community to acute care as a person with dementia is admitted to a hospital, as well as from acute care back to the community (e.g. in the form of effective discharge planning). Continuity of information is best achieved by a single information system, or by shared access to medical records and highly effective communication. **Provider continuity:** Seeing the same professional each time, with the opportunity to establish a therapeutic, trusting relationship (a role often filled by the primary care physician, a care worker, or case manager).
Continuing Professional Development (CPD)/ Continuing Education	CPD refers to formal educational activities conducted after graduation (i.e. pre-service education) to maintain, improve and adapt the knowledge, skills, attitudes and practices of health professionals, so that they can continue to provide care/services safely and effectively.
(Adult) Day Centre	A facility that typically provides care for users during the day. The facilities are generally: i. available to groups of users at the same time (rather than delivering services to individuals one at a time), ii. expect users to stay at the facilities beyond the periods during which they have face-to-face contact with staff (i.e. the service is not simply based on users coming for appointments with staff and then leaving immediately after the appointment) and iii. involve attendances that last half or one full day. It allows families to have a regular break from their caregiving responsibilities and enables them to maintain their employment. Care workers may provide education, support groups and counselling for families. They also offer a broad package of services for people with dementia, such as transportation to and from the centre; activities such as painting, cooking, gardening, reading the newspaper, and daily exercise; and help with personal care.
Dementia	Dementia is a syndrome due to disease of the brain – usually of a chronic or progressive nature – in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer's disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain (motor neurone diseases; Prion disease (Prion); Parkinson's disease (PD) and PD-related disorders; Huntington's disease; Spinocerebellar ataxia; Spinal muscular atrophy). ICD 9: 290, 330-331; ICD9 BTO: B222, B210; ICD 10: F01, F02, F03, G30 - G31.

Dementia awareness campaigns	An organized effort to give the public more information about dementia, its risk factors and prevention, causes, types, early signs and symptoms, treatment options, and available support services.
Dementia core competencies	Diagnosis, comorbidities, assessment and management of behavioural and psychological symptoms (i.e. BPSD), risk reduction, palliative care, assessment and treatment of carer distress.
Dementia diagnostic services (in primary care)	Entities/Centres/Facilities that have the capacity to assess presenting symptoms to provide a diagnosis and exclude a potentially treatable illness or reversible cause of the dementia. Initial diagnostic services include assessment of memory and cognitive functioning using simple tests/locally validated tools and interviewing a key informant who knows the person well. Other services can include physical examination, baseline investigations (blood tests, imaging etc.) and possible referral for secondary services if symptoms are severe or difficult to manage. Diagnosis may be given in primary, secondary or tertiary level.
Disability	Disability is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations.
Electronic patient medical records	Contains all personal health information belonging to an individual; is entered and accessed electronically by healthcare providers over the person's lifetime; and extends beyond acute inpatient situations including all ambulatory care settings at which the patient receives care. Ideally it should reflect the entire health history of an individual across his or her lifetime including data from multiple providers from a variety of healthcare settings.
Focal point (for dementia, national)	The person responsible for dementia in a Ministry of Health (or equivalent) or national institute.
Framework	Provides a set of guiding principles for the provision of evidence-based health services.
Functional ability	The health-related attributes that enable people to be and to do what they value.
Geriatrics	The branch of medicine specializing in the health and illnesses of older age and their appropriate care and services.
Health care facility	Facilities that provide health services, including include mobile clinics, pharmacies, laboratories, specialty clinics, and private and faith-based establishments.
Health professionals	Health professionals study, advise on or provide preventive, curative, rehabilitative and promotional health services based on an extensive body of theoretical and factual knowledge in diagnosis and treatment of disease and other health problems. They may conduct research on human disorders and illnesses and ways of treating them, and supervise other health workers.
Health service	Any service (i.e. not limited to medical or clinical services) aimed at contributing to improved health or to the diagnosis, treatment and rehabilitation of sick people.
Health system	Refers to (i) all the activities whose primary purpose is to promote, restore and/or maintain health; (ii) the people, institutions and resources, arranged

	together in accordance with established policies to improve the health of the population they serve, while responding to people's legitimate expectations and protecting them against the cost of ill-health through a variety of activities whose primary intent is to improve health.
Home care (provided by community and home care providers)	Also sometimes referred to as "independent social welfare associations" or "community and home care providers". Typically include services such as routine personal care, support and assistance with activities of daily living to persons who are in need of such care due to effects of ageing, illness, injury, or other physical or mental condition in private homes and other independent residential settings. They assist clients with personal, physical mobility and therapeutic care needs, usually as per care plans established by a health professional.
Home modifications/ adjustments	Conversions or adaptations made to the permanent physical features of the home environment to improve safety, physical accessibility and comfort.
Hospice	Hospices are locations where end-of-life care is provided by health professionals and volunteers in tertiary care facilities or in community health centres. They give medical, psychological and spiritual support. The goal of the care is to help people who are dying have peace, comfort and dignity. The caregivers try to control pain and other symptoms so a person can remain as alert and comfortable as possible. Hospice programmes also provide services to support a patient's family.
Hospital	Comprise licensed establishments primarily engaged in providing medical, diagnostic and treatment services that include physician, nursing, and other health services to inpatients and the specialised accommodation services required by inpatients. Hospitals provide inpatient health services, many of which can be delivered only by using specialised facilities and professional knowledge as well as advanced medical technology and equipment, which form a significant and integral part of the provision process. Although the principal activity is the provision of inpatient medical care they may also provide day care, outpatient and home health care services as secondary activities. The tasks of hospitals may vary by country and are usually defined by legal requirements. (OECD definition)
Human rights of people with dementia	Action related to the following issues to ensure the protection of a person's human rights: least restrictive care, informed consent to treatment, confidentiality, avoidance of restraint and seclusion when possible, voluntary and involuntary admission and treatment procedures, discharge procedures, complaints and appeals processes, protection from abuse by staff, and protection of user property. In the context of dementia, this means human rights for people with dementia include a comprehensive approach including the full spectrum of civil, political, economic, social and cultural rights.
Inpatient care	Inpatient care is composed of general hospitals; geriatric and psychiatric hospitals; dementia-specific and non-specific psychiatric, geriatric or other wards in hospitals used for long-term institutional care of people with dementia; palliative care units; as well as residential care facilities.
Integrated action plan	A concerted approach to addressing a multiplicity of issues within a chronic disease prevention and health promotion framework, targeting the major risk factors common to the chronic disease, including the integration of primary, secondary and tertiary prevention, health promotion and disease prevention programmes across sectors and disciplines.

Integrated pathway	An agreed and explicit route an individual takes through health and social care services. Agreements between the various providers involved will typically cover the type of care and treatment, which professional will be involved and their level of skills, and where treatment or care will take place. The fundamental principle is to apply a structured and organised approach to the planning, resourcing and delivery of continuing care.
Legal capacity	Legal capacity is what a human being can do within the framework of the legal system. It is a construct, which has no objective reality but is a relation every legal system creates between its subjects and itself. Legal capacity gives the right to access the civil and juridical system and the legal independence to speak on one's own behalf. The UN Convention on the Rights of Persons with Disabilities[1] recognizes that people with disabilities, including mental disabilities, have the right to exercise their legal capacity and make decisions and choices on all aspects of their lives, on an equal basis with others.
Legislation	A law or set of laws, which have been enacted by the governing bodies in a country. For the purpose of this document, legislation refers to legal provisions that are either specific to dementia or are applied to people with dementia. They typically focus on issues such as civil and human rights protection of people with dementia, treatment facilities, personnel, professional training and service structure.
Multisectoral	Involving agencies and organizations from the different sectors of society including governments, nongovernment organizations, private for-profit sector, and civil society.
Noncommunicable diseases (NCDs)	Are not passed from person to person. They are of long duration and generally slow progression. The four main types of NCDs are cardiovascular diseases (such as heart attack and stroke), cancers, chronic respiratory diseases (such as chronic obstructed pulmonary disease or asthma) and diabetes.
Nongovernmental organization (NGO)	NGOs are created and operated to contribute to the public's benefit. The ways that NGOs can pursue that goal vary widely. NGOs usually work on a not-for-profit basis. They can be organised on a local, national or international level. Task-oriented and driven by people with a common interest, they perform a variety of service and humanitarian functions. Examples include charities, missions, faith-based organisations, consumer organisations, etc.
Nurse	A health professional having completed formal training in nursing at a recognized, university-level school for a diploma or degree in nursing.
Operational	A policy, strategy or plan of action, which is being used and implemented in the country, and has resources and funding available to implement it.
Outpatient facilities	Facilities that focus on the management of clinical and social care on an outpatient basis. Composed of hospital outpatient departments, primary health care and community-based health care facilities, including day centres.

[1] Convention on the Rights of Persons with Disabilities [A/RES/61/106]. New York: United Nations Division for Social Policy and Development Disability; 2007 (https://www.un.org/development/desa/disabilities/resources/general-assembly/convention-on-the-rights-of-persons-with-disabilities-ares61106.html, 26 October 2017).

Palliative care/End-of-life care	Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care: - provides relief from pain and other distressing symptoms; - affirms life and regards dying as a normal process; - intends neither to hasten nor postpone death; - integrates the psychological and spiritual aspects of patient care; - offers a support system to help patients live as actively as possible until death; - offers a support system to help the family cope during the patient's illness and in their own bereavement; - uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated; - will enhance quality of life, and may also positively influence the course of illness; - is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.
Patient Registries	Patient registries, sometimes called disease registries, can be broadly defined as systems of ongoing registration of all cases of a particular disease or a health condition in a population. They provide epidemiological data, support clinical best practice and facilitate research. At the most basic level, a patient registry is a data collection tool or database, which contains information about patients' medical conditions and/or treatments.
Person-centred care	Refers to care that is focused and organized around the health needs and expectations of people and communities rather than on diseases. Person-centred care extends the concept of patient-centred care to individuals, families, communities and society. Whereas *patient*-centred care is commonly understood as focusing on the individual seeking care, i.e. the patient, *person*-centred care encompasses these clinical encounters and also includes attention to the health of persons in their communities and their crucial role in shaping health policy and health services.
Persons with dementia (total number)	Number of persons with a diagnosis of dementia for the most recent calendar year. Examples of methods of calculating this include: – a diagnosis of dementia (PDx or SDx fields) during a hospital admission; – prescription for dementia drugs (donepezil hydrochloride; galantamine; memantine hydrochloride; rivastigmine); – a diagnosis of dementia recorded on their primary care record; – a dedicated dementia register, an insurance register, or other register-type dataset; – data recorded by the long-term care institution showing that they have a diagnosis of dementia; – reported in household survey data.

Personal support worker	Provides routine care, support and assistance with activities of daily living to persons who are in need of such care due to effects of ageing, illness, injury, or other physical or mental condition in private homes and other independent residential settings. They assist clients with personal, physical mobility and therapeutic care needs, usually as per care plans established by a health professional. Also known as nurse aides, personal care workers, nurse assistant, home/health care aide, auxiliary nurse, patient care technician, geriatric aide/assistant, psychiatric aide or nurse technologist.
Pharmaceutical personnel	Includes pharmacists, pharmaceutical assistants, pharmaceutical technicians and related occupations. They perform a variety of tasks associated with dispensing medicinal products.
Policy	An official statement by a government or health authority providing the overall direction for dementia by defining a vision, values, principles, objectives, and by establishing a broad model of action to achieve that vision.
Plan/action plan	A dementia plan details the strategies and activities that will be implemented to realise the vision and achieve the objectives of the dementia policy. The plan also specifies a budget and timeframe for each strategy and activity, and delineates the expected outputs, targets and indicators that can be used to assess whether the implementation of the plan has been successful.
Primary care	The term primary care is often used interchangeably with first level of care generally provided in the local community. Professionals tend to be generalists, dealing with a broad range of psychological, physical and social problems. It is part of a health services system that assures person-focused care over time to a defined population, accessibility to facilitate receipt of care when it is first needed, comprehensiveness of care in the sense that only rare or unusual manifestations of ill health are referred elsewhere, and coordination of care such that all facets of care (wherever received) are integrated. It is the provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community.
Protocol	A document with the aim of guiding decisions and criteria regarding diagnosis, management, and treatment in specific areas of healthcare. These can include statements with recommendations intended to optimize patient care, that are informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options
Primary care doctor (or generalist medical practitioners)	A general practitioner, family doctor, or other non-specialised medical doctor working in a primary health care clinic. **Generalist medical doctors** (including family and primary care doctors) diagnose, treat and prevent illness, disease, injury, and other physical and mental impairments and maintain general health in humans through application of the principles and procedures of modern medicine. They plan, supervise and evaluate the implementation of care and treatment plans by other health care providers. They do not limit their practice to certain disease categories or methods of treatment, and may assume responsibility for the provision of continuing and comprehensive medical care to individuals, families and communities.
Psychiatrist	A medical doctor who has had at least two years of post-graduate training in psychiatry at a recognized teaching institution. This period may include training in any subspecialty of psychiatry.

Psychosocial interventions	Psychosocial support interventions address the ongoing psychological and social needs of people with dementia, their carers, partners, and families. The scope of interventions can include: psychoeducation (ask people assessed with dementia whether they wish to know the diagnosis and with whom it should be shared), manage behavioural and psychological symptoms (identify potential triggers, consider environmental adaptation, encourage calming strategies), promoting function in activities of daily living, community life and interventions to improve cognitive function and provide carer support. For further information refer to (WHO's mhGAP): http://apps.who.int/iris/bitstream/10665/250239/1/9789241549790-eng.pdf?ua=1
Public health services	Public health services are targeted at the population as a whole and funded by the government. These include, among others, health situation analysis, health surveillance, health promotion, prevention services, infectious disease control, environmental protection and sanitation, disaster preparedness and response, and occupational health.
Quality of care	A health system that makes improvements in six areas: - effective - delivering health care that is adherent to an evidence base and results in improved health outcomes for individuals and communities, based on need; - efficient - delivering health care in a manner which maximizes resource use and avoids waste; - accessible - delivering health care that is timely, geographically reasonable, and provided in a setting where skills and resources are appropriate to medical need; Acceptable/patient-centred - delivering health care which takes into account the preferences and aspirations of individual service users and the cultures of their communities; - equitable - delivering health care which does not vary in quality because of personal characteristics such as gender, race, ethnicity, geographical location, or socioeconomic status; - safe - delivering health care. which minimizes risks and harm to service users.
Rehabilitation	A set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments. Services include rehabilitation medicine, therapy and assistive technology.
Residential care (nursing home or long-term care) facility	Comprise establishments primarily engaged in providing residential long-term care that combines nursing, supervisory or other types of care as required by the residents. In these establishments, a significant part of the process and the care provided is a mix of health and social services, with the health services being largely at the level of nursing care, in combination with personal care services. The medical components of care are, however, much less intensive than those provided in hospitals (OECD definition).
Respite care	Mostly occurs in older people's homes, but can also be provided at day centres or residential facilities. Respite for the care recipient involves participation in enjoyable activities that are meaningful and appropriate and which provide opportunities for social engagement, companionship and stimulation. Respite care also provides them with support to live in the community for as long as possible and is delivered in a dignified and respectful way. For the care provider

	it is time away from the caring role to engage in other activities of choice, knowing the care recipient is happy and receiving quality care. This contributes to the ultimate aims of supporting ageing in place for all people, including people with dementia, ensuring that they receive high-quality care, and reducing the likelihood of health problems for carers.
Responsive referral protocols and pathways	Responsive referral protocols or pathways, outline clear indications for referrals and responsibilities of each healthcare professional and department involved.
Restraints (mechanical, physical or chemical)	Restraint means the use of a mechanical device or medication to voluntarily prevent a person from moving his or her body.
Seclusion	Refers to the voluntary placement of an individual alone in a locked room or secured area from which he or she is physically prevented from leaving. 'Alternatives to seclusion' include prompt assessment and rapid intervention in potential crises; using problem-solving methods and/or stress management techniques such as breathing exercises.
Secondary care	Specialist care provided on an ambulatory or inpatient basis, usually following a referral from primary care.
Social & financial protection benefits	Financial transfers received by households for the purpose of providing for a range of needs due to circumstances or events such as housing, education, family circumstances or sickness, retirement and unemployment. This also includes economic and/or social benefits provided by the government (such as paid or unpaid leave, credited social contributions, or price subsidies such as tax allowances, duty rebates, discount transportation fares, and free companion fares) to support people with dementia and their carers.
Social care	Assistance with activities of daily living (such as personal care, maintaining the home); synonym is home and community care.
Social worker	A professional having completed a formal training in social work at a recognised, university-level school for a diploma or degree in social work. The GDO asks only for information related to social workers working in relevant fields (such as geriatrics, mental health, neurology) and potentially providing treatment or care for individuals with dementia.
Social media	Web-based technologies to communicate between organizations, communities, and individuals. Common examples include Facebook and Twitter.
Specialist medical doctor	Specialists who diagnose, treat and prevent illness, disease, injury and other physical and mental impairments using specialised testing, diagnostic, medical, surgical, physical and psychiatric techniques, through application of the principles and procedures of modern medicine. They specialise in certain disease categories, types of patient or methods of treatment. For the purpose of the GDO, "specialist medical doctor" refers to the following groups of physicians: geriatricians, psychogeriatricians, old-age psychiatrists as well as psychiatrists and neurologists who can diagnose dementia and provide treatment for individuals with dementia.
Stakeholder	Refers to an individual, group of individuals or an organization that has an interest in the organization and delivery of health care.

Standard	A standard is an established, accepted and evidence-based technical specification or basis for comparison. National standards provide a set of principles that form the foundation upon which care can be based and progress measured. They generally do not need to be adapted to the local context.
Strategy	A long-term plan designed to achieve a particular goal.
Subnational	Refers to individual states, territories, provinces, or regions within a country.
Supported decision making	A model supported by the UN Convention on the Rights of Persons with Disabilities,[1] which enables people with mental disabilities to nominate a trusted person or network of people with whom they can consult and discuss issues affecting them, including making decisions.
Task shifting	Task shifting is defined as delegating selected tasks to existing or new health professional cadres with either less training or more narrowly-focused training.
Team	**Interdisciplinary team** Consists of members who work together interdependently to develop goals and a common treatment plan, although they maintain distinct professional responsibilities and individual assignments. In contrast to multidisciplinary teams, leadership functions are shared. **Multidisciplinary team** Consists of members of different disciplines, sometimes from one or more organizations, involved in the same task (assessing people, setting goals and making care recommendations) and working alongside each other, but functioning independently. The highest-ranking team member traditionally leads these teams, which may include: physicians, nurses, community health workers, allied health professionals (such as physiotherapists, occupational therapists, dieticians, psychologists, social workers, podiatrists), health educators - such as diabetes educators - providing promotion and prevention clinics and other activities.
Tertiary care	The provision of highly specialized services in ambulatory and hospital settings or in a facility that has personnel and facilities for advanced medical investigation and treatment.
Unit or department (national dementia)	A unit or department with responsibility for dementia in a Ministry of Health (or equivalent) or national institute.
Universal health coverage	Universal health coverage means that all people receive the health services they need without suffering financial hardship when paying for them. The full spectrum of essential, quality health services should be covered, including health promotion, prevention and treatment, rehabilitation and palliative care. For more information see the WHO factsheet on Universal Health Coverage: http://www.who.int/mediacentre/factsheets/fs395/en/

[1] Convention on the Rights of Persons with Disabilities [A/RES/61/106]. New York: United Nations Division for Social Policy and Development Disability; 2007 (https://www.un.org/development/desa/disabilities/resources/general-assembly/convention-on-the-rights-of-persons-with-disabilities-ares61106.html, 26 October 2017).

Annex 1:

Terms applicable to the provision of data to WHO by Member State

Data are the basis for all sound public health actions and the benefits of data-sharing are widely recognized, including scientific and public health benefits. Whenever possible, the World Health Organization (WHO) wishes to promote the sharing of health data, including but not restricted to surveillance and epidemiological data.

As used in this data collection tool, the term "Data provider" means a duly authorized representative of the governmental body with authority to release health data of the country to WHO (i.e. the Ministry of Health or other responsible governmental authority). The recipient of this data collection tool is responsible for ensuring that he/she is the Data provider, or for providing this data collection tool to the Data provider.

In this connection, and without prejudice to information sharing and publication pursuant to legally binding instruments, by providing data to WHO, the Data provider:

- confirms that all data to be supplied to WHO (including but not limited to the types listed in Table 1) hereunder have been collected in accordance with applicable national laws, including data protection laws aimed at protecting the confidentiality of identifiable persons;
- agrees that WHO shall be entitled, subject always to measures to ensure the ethical and secure use of the data, and subject always to an appropriate acknowledgement of the country:
    - to publish the data, stripped of any personal identifiers (such data without personal identifiers being hereinafter referred to as “the Data”) and make the Data available to any interested party on request (to the extent they have not, or not yet, been published by WHO) on terms that allow non-commercial, not-for-profit use of the Data for public health purposes (provided always that publication of the Data shall remain under the control of WHO);
    - to use, compile, aggregate, evaluate and analyse the Data and publish and disseminate the results thereof in conjunction with WHO’s work and in accordance with the Organization’s policies and practices.

Except where data-sharing and publication are required under legally binding instruments (International Health Regulations (2005), WHO Nomenclature Regulations 1967, etc.), the Data provider may in respect of certain data opt out of (any part of) the above, by notifying WHO thereof in writing at the following address, provided that any such notification shall clearly identify the data in question and clearly indicate the scope of the opt-out (in reference to the above), and provided that specific reasons shall be given for the opt-out.

Director Strategy, Policy and information (SPI)
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Table 1. List types of data provided to WHO (non-exhaustive)

Data types	Examples
WHO-supported household surveys	WHO Strategic Advisory Group of Experts (SAGE) on Immunization, WHO STEPwise approach to surveillance (STEPS), World Health Survey
Unit record mortality data	(Not currently collected by WHO headquarters, but by the WHO Regional Office for the Americas/Pan American Health Organization)
Aggregated mortality data	WHO Mortality Database
Aggregated health facility data	DHIS 2.0 data (not currently collected by WHO headquarters, but hospital data are collected by the WHO Regional Office for Europe)
Case-based health facility data	WHO Global Burn Registry data [1]
Health expenditure data	WHO Global Health Expenditure Database (National Health Account indicators)
Health facility surveys	Availability of medicines and diagnostics
Health research data (other than clinical trials)[2] [3]	Case–control investigations, prospective cohort studies
Key informant surveys	Existence of national road traffic laws
National survey reports	Prevalence of hypertension or tobacco use
Disease surveillance data	HIV prevalence in pregnant women or tuberculosis treatment outcomes
Surveillance of notifiable diseases	Total number of cases of plague

Legend
[1] Note: Case-based health facility data collection such as that in the WHO Global Burn Registry does not require WHO Member State approval.
[2] The world health report 2013: research for universal coverage. Geneva: World Health Organization; 2013 (http://apps.who.int/iris/bitstream/10665/85761/2/9789240690837_eng.pdf, accessed 21 February 2018).
[3] WHO statement on public disclosure of clinical trial results, Geneva: World Health Organization; 2015 (http://www.who.int/ictrp/results/en/, accessed 21 February 2018).