STRiDE

IN-DEPTH SITUATIONAL ANALYSIS:

DESK-REVIEW TOPIC GUIDE

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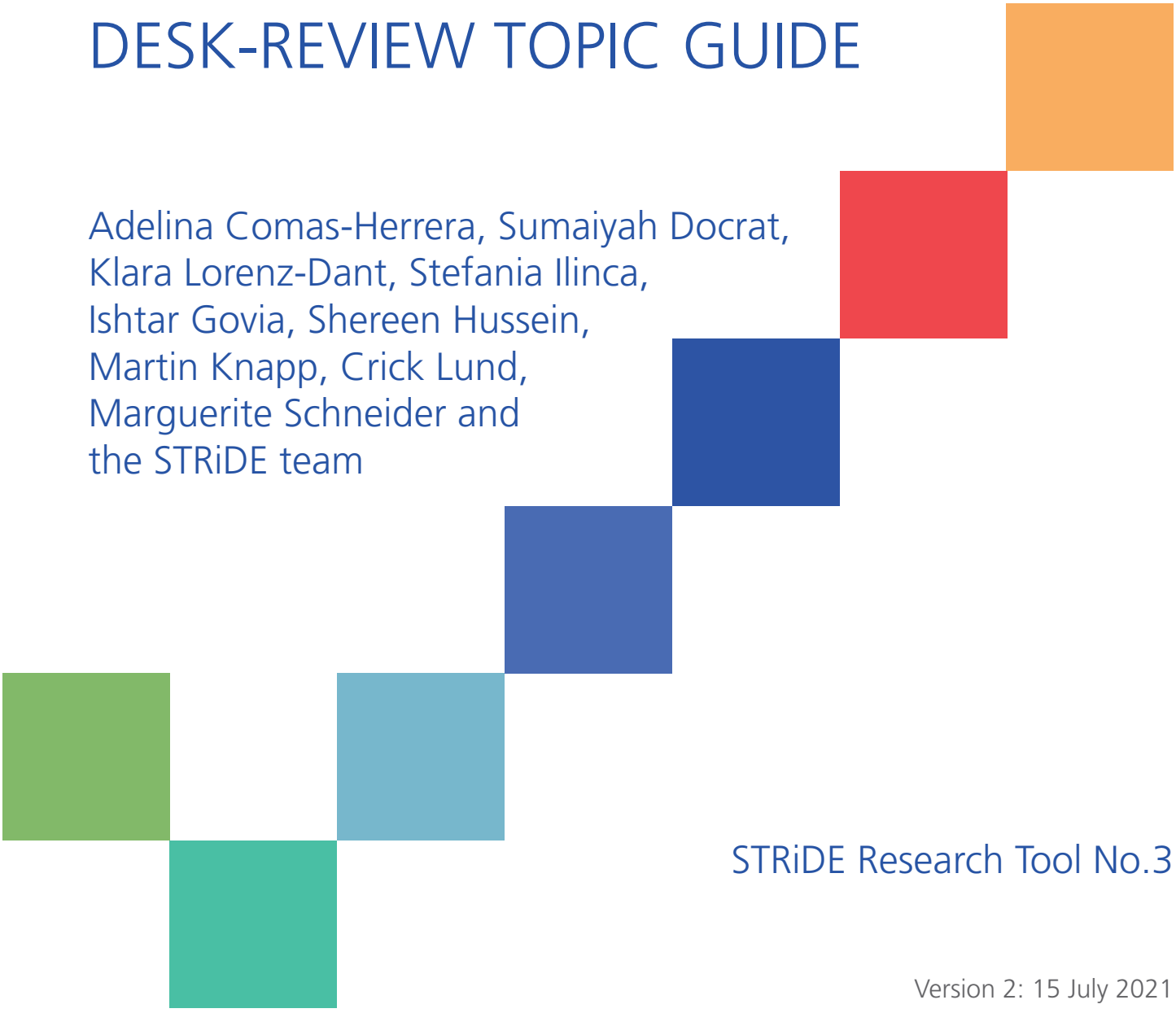

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The authors would like to acknowledge the use of the World Health Organization Global Dementia Observatory (GDO) Reference Guide, which was incorporated into this manual to facilitate collaboration between the STRiDE project and the GDO's focal points in each country. All GDO questions are acknowledged through colour coding.

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INTRODUCTION

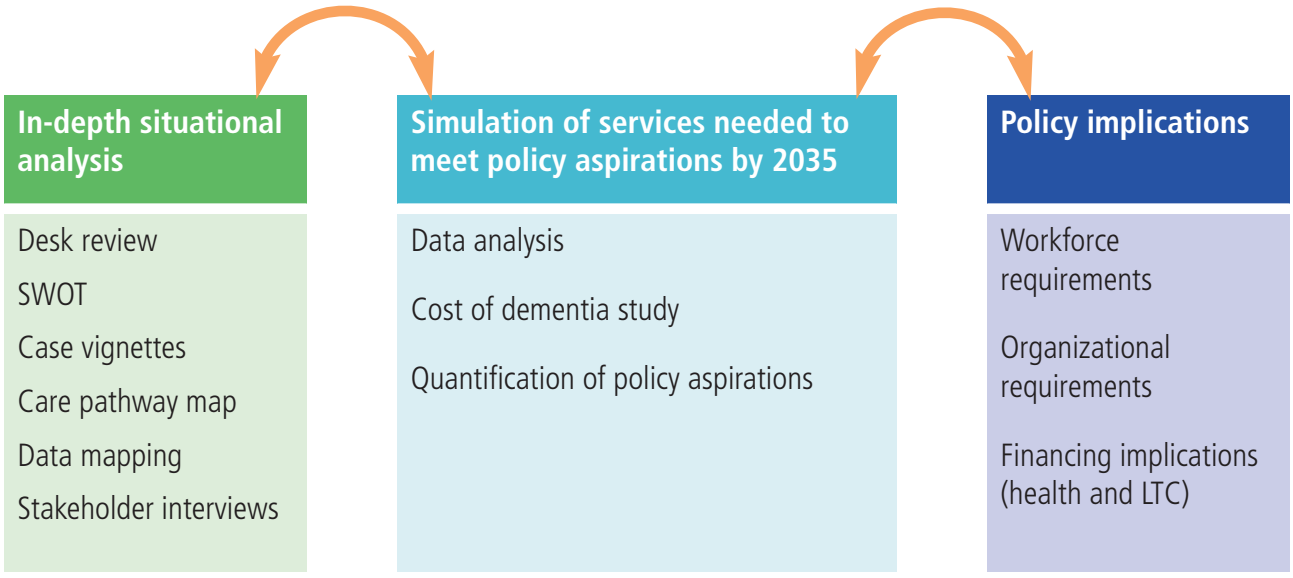
STRIDE'S SITUATIONAL ANALYSIS OF THE DEMENTIA CARE LANDSCAPE

This document provides the topic guide for a desk-based review as part of an in-depth situational analysis of the dementia care landscape. It has been developed as part of the Strengthening responses to dementia in developing countries (STRiDE) project.[1]

The situational analysis is part of STRiDE's Work Package 7 (WP7), which involves the development of a set of research-based tools to inform national dementia policy, which are summarized in Figure 1. The tools aim to provide a diagnostic of the current situation, analyse the opportunities and barriers to improvement, and to quantify the resources needed to deliver improved care, treatment and support for people living with dementia. The tools for WP7 include the following:

1. An in-depth situational analysis of the dementia care landscape.
2. A study of the costs of dementia to society (including health, long-term care and unpaid care costs).
3. A simulation model to project future dementia care needs, services required to respond to those needs and the associated costs.
4. An assessment of the implications of the situational analysis and the model outcomes for the health and long-term care systems (in terms of financing, workforce and organisation).

Figure 1: STRiDE's research tools for policy development



1. There is more information on the STRiDE project in the project's website: https://stride-dementia.org

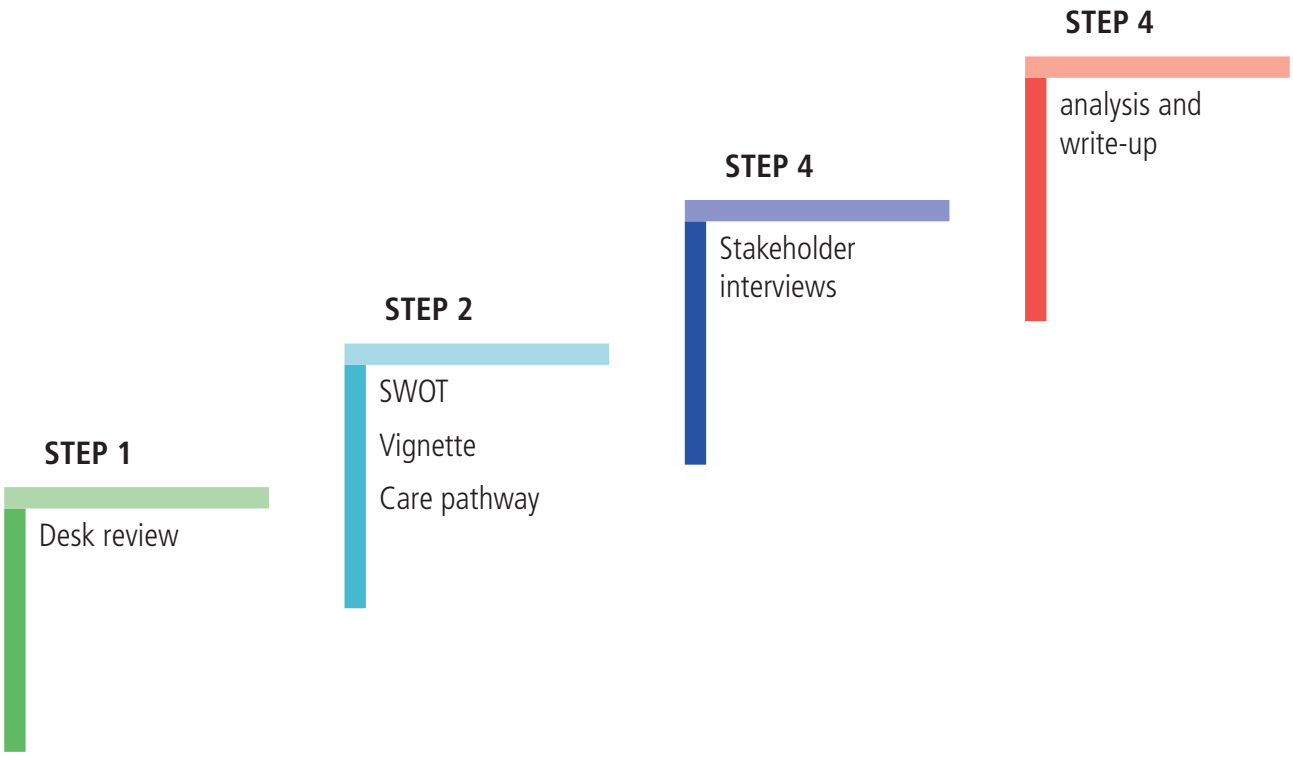
WHAT IS A SITUATIONAL ANALYSIS?

Situational analyses are used to assess the current state of affairs in order to be able to understand the multiple interacting factors that need to be considered for the design and updating of policies, strategies and plans, and also for the implementation of interventions (Murphy et al., 2019; Schmets, Rajan, & Kadandale, 2016; World Health Organization, 2018b). The World Health Organization (WHO) recommends carrying out situational analyses as part of their guide towards a National Dementia Plan (World Health Organization, 2018b). Situational analyses have also been used for health system strengthening programmes (WHO 2016) and in mental health projects[2] such as the PRogramme for Improving Mental health carE (PRIME) and Emerging mental health systems in low and middle-income countries (Emerald).

The STRiDE situational analysis methodology has built on the tools used in the Emerald project (Mugisha et al., 2017) and PRIME (Hanlon et al., 2014) and it incorporates questions from the WHO's Global Dementia Observatory (World Health Organization, 2018a).

The STRiDE situational analysis is carried out in four steps, as outlined in Figure 2. This document is the topic guide for the first step, the desk review.[3] This is followed by a Strengths, Weaknesses, Opportunities and Threats analysis (SWOT).

Figure 2: The four steps involved in carrying out the in-depth situational analysis



2. See Murphy et al 2019 for scoping review on the use of situational analysis in global mental health.

3. This guide also contains a few questions that will build on the information gathered for the situational analysis and that will be helpful to prepare for parts 2 and 3 of WP7 (the study of costs of dementia and the simulation model).

In order to address substantial information and data gaps identified during the completion of the desk reviews in the STRiDE project, we used case vignettes and graphical representations of care pathways as a way to gather expert knowledge from the STRiDE members and advisors in each of countries. Separate guidance documents have been prepared for each of these activities, as well as for interviewing stakeholders to complete and validate the situational analysis.[4]

Although not essential, it is recommended to carry out this in-depth situational analysis after a Theory of Change workshop along the lines of that carried out in the STRiDE project, see (Breuer et al., 2021 and Breuer, Comas–Herrera, Docrat, Freeman, Schneider and the STRiDE team, 2019).

The objectives of each step in the in-depth situational analysis process are outlined below:

STEP 1: Desk review

The STRiDE Situational Analysis Desk Review Topic guide (this document) has been prepared as a series of questions to be answered narratively to gather the information needed to describe the current dementia care, treatment and support situation within your country. This will be used to enable the identification of potential strengths, weaknesses, opportunities and threats to future dementia care, treatment and support. The contextual and system information and data also feeds into another part of STRiDE's WP 7, informing the estimation of the cost of dementia in each country and the development of a simulation model of future dementia care needs and resources needed to meet those needs.

Research teams who complete all the questions of the STRiDE Situational Analysis Desk Review will be able to contribute their findings to a searchable web-based database (currently under development), following a peer-review process.[5] The aim of the database is to provide access to contextual information in relation to the dementia care situation in both the original STRiDE project countries and other countries that have used the same research tools subsequently. The questionnaire also includes data to inform the WHO GDO database.

STEP 2: SWOT, case vignettes and care pathways mapping[6]

Using the findings from the desk review, we will conduct an initial Strengths, Weaknesses, Opportunities and Threats (SWOT) analysis on the provision of dementia care in each of the countries. This initial SWOT analysis helps to identify questions for the stakeholder interviews. Please refer to the guidance document for further information on the analytical process.

Next, the STRiDE case vignettes will be populated, as well as their graphical representation as care pathways.

4. The STRiDE project research tools that are complete and publicly available can be accessed through: https://stride-dementia.org/library/guidance-and-resources

5. For more information, please email Stride.Dementia@lse.ac.uk

6. Guidance on how to do a SWOT analysis and complete the STRiDE case vignettes and care pathways will be shared through https://stride-dementia.org/library/guidance-and-resources

STEP 3: Stakeholder interviews[7]

Following the desk review, the initial SWOT analysis, the case vignettes and the care pathways mapping, the next step involves conducting in-depth interviews[8] with experts to obtain feedback on emerging findings and gain a deeper understanding of priority areas and the process of reform. The number of interviews will be determined at country-level based on the availability of key informants but will generally comprise around six experts by experience (people living with dementia and family carers) and 10 policy stakeholders.

In each country we will develop a topic guide in order to:

- Obtain feedback on emerging findings (from the desk-review) for meeting the future needs for dementia care, treatment and support and implications of implementing/ scaling-up an evidence-informed care pathway.
- Identify what the priority areas for development (short, medium and long-term goals) and aspirations of the country are in terms of the care, treatment and support that should be available to people living with dementia and their carers.
- Gain a deeper understanding of the process for reform, generally and specifically for dementia care, with respect to key stakeholders, structures and processes involved in public health, social care/development, public finance and the political economy in each country, as well what are realistic time frames.

Step 4: Situational analysis write-up

Following the interviews, we will update the initial SWOT analysis, case vignettes and care pathways map, bringing together all the information collected during the desk-based review and the interviews. This will form the situational analysis and can be published as country-specific papers that:

- Analyse how current dementia care, treatment and support contexts compare to the aspirations of the country in terms of the care, treatment and support that should be available to people with dementia and their carers.
- Consider the barriers that the current care and financing systems are posing at present, and the reform opportunities to improve dementia care, putting dementia care in the wider context of reforms of health and social care financing.

For an example of publications of similar situational analyses in another study, please see Chisholm et al. (2019) and Docrat et al. (2019).

In the STRiDE project we also use the evidence collected in each of the countries to develop policy recommendations and other non-academic outputs.

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7. Guidance on how to conduct and analyse stakeholder interviews for the STRiDE situational analysis will be shared through https://stride-dementia.org/library/guidance-and-resources

8. Please note that ethical approval will be required for the interviews of experts by experience (people with dementia and family carers) in most countries. Most of the interviews will be carried out by telephone or video-conference. The interviews and how to analyse them will be covered by a separate guidance document.

9. For a 'public' long-term care system we mean a system that is designed, regulated and monitored by the state (or other sub-national government level). For example, in some countries (Singapore and Germany) the state sets out the 'rules' of a long-term care insurance system, but the actual insurers and care providers are in the private sector.

CARRYING OUT THE STRIDE SITUATIONAL ANALYSIS DESK REVIEW

As outlined above, the desk review is based on a detailed topic guide. This situational analysis desk-review topic guide has been developed in order to better understand the context, barriers and opportunities for improving dementia care, treatment and support in each of the STRiDE countries.

It is important to highlight that, in addition to STRiDE specific questions, this topic guide includes questions that have been purposively and directly drawn from the World Health Organization Global Dementia Observatory Reference Guide 2018 (World Health Organization, 2018a) which provides the monitoring mechanism for the global action plan on the public health response to dementia (2017–25). All questions or components in this document that have been sourced from The Global Dementia Observatory (GDO) Reference Guide are listed in purple text. The rationale for including the GDO questions in this topic guide is to facilitate collaboration between the STRiDE project and the GDO's focal points in each country and avoid duplicating efforts.

OVERVIEW OF THE DESK REVIEW TOPIC GUIDE

The topic guide is organized as follows:

Topic guide section	Content
Part 1 Overall country context	This section aims to generate a comprehensive picture of your country, by describing the overall population and demographic characteristics, the epidemiological, social and economic situation, the political situation and an overview of the social protection system.
Part 2 Overall health system context	This section aims to generate a comprehensive picture of your country's health system, by describing its organization, workforce and financing. At this stage, the focus should not be on dementia-specific health systems aspects; the focus should be on describing the overall health system.
Part 3 Overview of the long-term care system context	This section aims to generate a comprehensive picture of your country's long-term care system, describing the balance between formal and informal care, the role of the public system, its organisation, workforce and financing. It will also seek to understand the boundaries between health and social care. At this stage, the focus should not be on dementia-specific long-term care system aspects; the focus should be on describing the overall long-term care system.

Topic guide section	Content
Part 4 Dementia policy context	This section aims to generate a comprehensive picture of your country's policies, strategies and plans for dementia and seeks to explore the broader policy processes.
Part 5 Dementia awareness and stigma	This section seeks to generate a comprehensive understanding of the cultural and societal perceptions of dementia in your country.
Part 6 Epidemiology and information systems for dementia	This section seeks to summarize the current knowledge about epidemiology of dementia, and the information systems that are in place in your country to monitor dementia care services.
Part 7 The dementia care system	This section aims to generate a comprehensive picture of your country's health and long-term care services for people living with dementia. Specifically, this section seeks to understand the availability of specific cadres of long-term care workers, the availability of health and long-term care facilities and the availability of anti-dementia medication, psychosocial interventions and care products. In addition, this section seeks to understand how care systems for dementia are organized and resourced.
Part 8 Unpaid care and other informal care for dementia	This section seeks to unpack the support arrangements and extent of unpaid care and other informal care for dementia in your country.
Part 9 Social protection for people with dementia	This section seeks to document whether social protection mechanisms are in place for people living with dementia and their carers
Part 10 Dementia research	This section considers funding and capacity for dementia research.
Part 11 Data mapping	This table aims to map the data sources for different aspects of the dementia care system, focussing on variables that will be needed for the cost of dementia study and simulation models

COMPLETION OF THE DESK REVIEW TOPIC GUIDE

In response to the experience of carrying out the STRiDE situational analysis desk review in seven countries, we have compiled a guide with resources on literature searching and writing to accompany this guide, expanding the material in this section (Lorenz-Dant et al., 2020). Figure 3 describes the structured literature reviewing process to be used for each topic area.

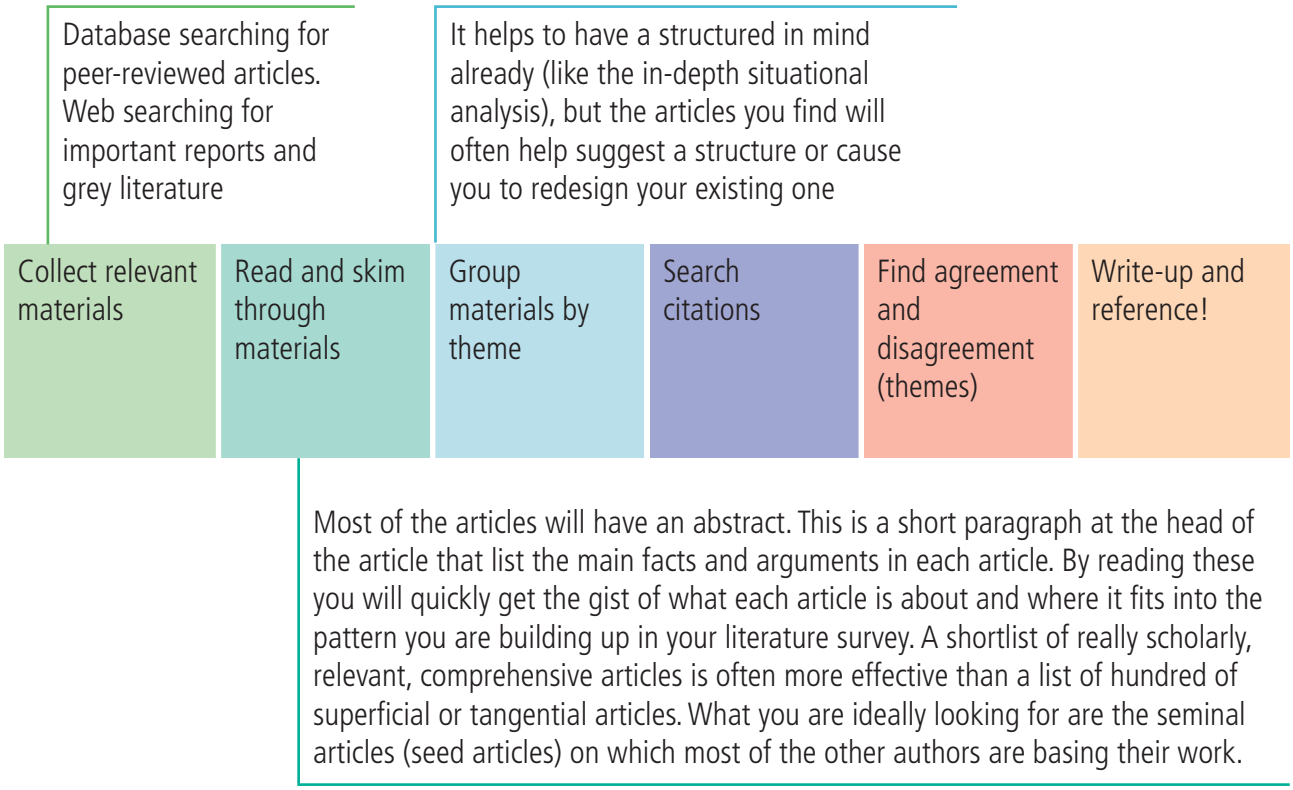
In order to ensure completeness, this guide should be completed in two steps. The first step consists of working each section of this situational analysis desk review topic guide and responding to each question narratively and/or quantitatively. In the second step, the answers will be edited and formatted as a report.

If the team completing this would like to contribute their responses to the Global Dementia Observatory Reference Guide, it may be helpful to mark those questions out to facilitate this process (in this guide the GDO questions are in purple text).

It is very important to ensure that all references and sources are appropriately referenced, using citation management software as agreed by the STRiDE project (i.e, Mendeley). The STRiDE writing guide has a section on literature referencing (Lorenz-Dant et al., 2020).

For many of the questions there may be no information available, it is a good idea to note this and to also keep a record of the sources consulted and references of the documents that did not contain useful information. The fact that there is no information about some sections is a finding in itself, as it indicates lack of previous research and of policy focus in certain areas.

Figure 3: Literature review process



TIPS FOR WORKING ON THE DESK REVIEW DOCUMENT

- Please avoid using words and abbreviations such as 'PLWD' or 'PWD' or 'the elderly', 'the demented' that are sometimes used when referring to people living with dementia. In STRiDE we seek to use dementia-friendly language, referring instead to people living with dementia, people with dementia or older people. Please have a look at this guide on dementia-friendly language for further information.

- When drafting responses to the different questions in the topic guide it is a good idea to avoid using statements such as 'recent data' or 'recent information' without adding the year of the data. The precision of adding the year will provide the reader with clarity about the timeliness of the information. Please remember, the year in which the document cited was published does not necessarily reflect the year of data collection.

- When evidence is not available for some questions, we suggest stating no evidence found as of (date) under the respective question.

- Reporting of percentages and numbers:

  Please write out the number in text if it is less than 10:
  … nine per cent of the population...
  … three regions...

  Please state the number in text if you are referring to a decimal figure for numbers that are 10 or over:
  … 4.2 per cent of the population…
  ... 14 per cent of the population…
  … 45 cities…
  … per 100,000 population…

  Please note that, in English, decimal numbers are noted as follows: 4.2%, while numbers over one thousand use comma separators: 1,000 … 10,000... 100,000

- As part of the desk review, you might want to refer to specific programmes, policies or institutions. In your answer, please use the English translation of the programme/ institution name followed by its full name (and abbreviation where appropriate) in the appropriate language of the country:
  … The Ministry of Health in Germany (Bundesministerium für Gesundheit (BMG))…

- You may decide that you would like to use some abbreviations in the text. Please ensure that the full name is spelled out followed by the abbreviation in brackets, before using the abbreviation alone. You may also want to add a list of acronyms to the document:
  … The National Health Service (NHS) in England... The NHS provides…

- You may decide to illustrate your argument with tables or graphics. Please ensure that you provide a brief title of each table or graphic as well as an exact reference of where you sourced this evidence from (see Part 2 for detailed information). Please also ensure that you describe/mention the table or graphic in the text so that it is clear why this additional information has been added.

Please find further information and guidance in the STRiDE guide to conducting academic literature searches (Lorenz-Dant et al., 2020).

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ANNEX 1: THE STRIDE SITUATIONAL ANALYSIS DESK REVIEW TOPIC GUIDE

This document provides the topic guide questions together with resources that may be helpful in responding to the different sections. This document mostly contains links to resources that provide information for several countries; however, we may also indicate country specific resources. These resources offer a starting point for the identification of relevant material but are by no means exhaustive.

At the end of the guide there is a glossary with definitions of many of the concepts that appear in the guide.

Please refer to STRiDE Research Tool 2 on literature searches to find additional information on how to approach identifying information useful for the completion of this desk review (Lorenz-Dant et al., 2020).

PART 1: OVERALL COUNTRY CONTEXT

1.1 Population and Demographic Characteristics

Please note: you may want to use tables as part of the answers to some of these questions, when there are different estimates available (for example for the size of the older population), please explain why they are different and seek expert advice on which sources are more reliable or up to date.

Total population size and structure	The United Nations population estimates and projections: contains useful resources of demographics (demographic projections, fertility). Most information is reported by region rather, but country information is also available. Link: https://population.un.org/wpp/Publications
	The World Population Prospects 2017: provides a wide array of demographic indicators. Link: https://population.un.org/wpp/DataQuery
Key geographical/ demographic characteristics e.g, population density, urbanisation, whether country formed of islands, etc.	CIA World Factbook: provides on information on the history, people, government, economy, energy, geography, communications, transportation, military, and transnational issues for 267 world entities. Link: www.cia.gov/library/publications/the-world-factbook

Key languages, ethnic groups and other diverse groups	Please use the classification of ethnic groups used by the National Office of Statistics in the respective country and provide a brief overview. Please use this same classification when you refer to ethnic groups as part of other questions in this document. Following the initial description, you may want to use inverted commas (i.e., 'white'…) to indicate that you recognise the potential implications of using classifications by ethnic groups. This question aims to identify groups that may be disadvantaged and that may be important to pay attention to when considering inequalities, if in your country it may be that belonging to particular religious groups, or migration status are more relevant than ethnicity, in that case, please include this in the answer.
	CIA World Factbook: provides on information on the history, people, government, economy, energy, geography, communications, transportation, military, and transnational issues for 267 world entities. Link: www.cia.gov/library/publications/the-world-factbook
Population projections and growth rate	The United Nations population estimates and projections: contains useful resources of demographics (demographic projections, fertility). Most information is reported by region rather, but country information is also available. Link: https://population.un.org/wpp/Publications
	The World Population Prospects 2017: provides a wide array of demographic indicators. Link: https://population.un.org/wpp/DataQuery
Ageing and life expectancy	Please make sure you include: percentage of population aged 65 and over; life expectancy at birth by gender; life expectancy at age X (for example, at age 65); median age of the population, total fertility rate
	UNFPA & Help Age International report, Ageing in the Twenty-First Century: A Celebration and a Challenge: provides an overview of issues and useful information of countries in Africa, Europe, Latin America and the Caribbean, Asia and the Pacific and Western Asia. Link: www.unfpa.org/sites/default/files/pub-pdf/Ageing%20report.pdf
	WHO Global Health Observatory data: this database includes more than 1000 indicators (mortality, morbidity and other health-related indicators organized to monitor progress towards the Sustainable Development Goals) for the 194 Member States of the WHO. Indicators on life expectancy can be found at: Link: www.who.int/gho/mortality_burden_disease/life_tables/en

Migration within country and international	CIA World Factbook: provides on information on the history, people, government, economy, energy, geography, communications, transportation, military, and transnational issues for 267 world entities. Link: www.cia.gov/library/publications/the-world-factbook
	International Organization for Migration: provides information on migration for many countries. Link: www.iom.int/countries

1.2 Epidemiological Situation

Please note: This section is not about dementia, but about key epidemiological characteristics of the country. Dementia epidemiology is covered in Part 6. This section seeks to provide an overview of key health concerns and priorities in the country, it does not need to be answered in too much detail.

Prevalence and burden of significant non-communicable diseases (NCDs) or conditions if available, please provide by age and gender groups	Global Health Observatory data: this website offers data on health-related outcomes related to the Sustainable Development Goals. The website contains epidemiological information on a variety of communicable and non-communicable diseases. This information is available by country Link: www.who.int/gho/en
	The WHO regional offices: the website directs you first to the regional office, from there you can access epidemiological information by country (data is linked to GHO data, see link www.who.int/gho/en) Link: www.who.int/about/regions/en
	The Global Burden of Disease project: provides country specific data on life expectancy, mortality, main causes of death, premature death and morbidity as well as on health expenditure Link: www.healthdata.org/results/country-profiles
	Disability-free life expectancy: Prina AM, Wu Y-T & Kralj C. (2019) Dependence- and disability-free life expectancy across eight low- and middle-income countries: a 10/66 study. Journal of Aging and Health. Link: https://doi.org/10.1177/0898264319825767

Prevalence or burden of injury and violence if available, please provide by age and gender groups, as well as cause of injury and violence (e.g., car accidents, natural disasters)	The World Health Organization: The WHO provides information on violence and injury. Link: www.who.int/violence_injury_prevention/key_facts/en

1.3 Economic and Social Situation

Please note: This section is only meant to provide context, so you do not need to provide a lot of detail.

Strength of the economy GDP per capita (nominal or PPP), growth rates, World Bank country categorization	The World Bank: publishes a list of countries by whether they are low, middle or high income: Link: https://datahelpdesk.worldbank.org/knowledgebase/articles/906519
	CIA World Factbook: provides on information on the history, people, government, economy, energy, geography, communications, transportation, military, and transnational issues for 267 world entities. Link: www.cia.gov/library/publications/the-world-factbook
Composition of the economy main productive sectors, etc.	CIA World Factbook: provides on information on the history, people, government, economy, energy, geography, communications, transportation, military, and transnational issues for 267 world entities. Link: www.cia.gov/library/publications/the-world-factbook
Debt public sector and personal debt among the population	CIA World Factbook: provides on information on the history, people, government, economy, energy, geography, communications, transportation, military, and transnational issues for 267 world entities. Link: www.cia.gov/library/publications/the-world-factbook

Poverty and inequality absolute, relative and spatial	The World Bank: publishes a list of countries by whether they are low, middle or high income. Link: https://datahelpdesk.worldbank.org/knowledgebase/articles/906519
	The World Bank: further provides information on countries' GINI index, a well-established measure for equality/inequality within a country.) Link: https://data.worldbank.org/indicator/SI.POV.GINI
	The United Nations Development Programme: provides information on countries' Human Development Index and their rank. Link: http://hdr.undp.org/en/countries/profiles/IND
	The United Nations WIID database: hosts information on inequality in different countries. The database can be downloaded. Link: hwww.wider.unu.edu/project/wiid-world-income-inequality-database
	CIA World Factbook: provides on information on the history, people, government, economy, energy, geography, communications, transportation, military, and transnational issues for 267 world entities. Link: www.cia.gov/library/publications/the-world-factbook
	LAC Equity Lab: is a comprehensive source of the latest data on poverty, inequality, and shared prosperity in the Latin America and the Caribbean region. Includes some data and materials on indigenous populations and gender inequality in access to education, health and social services. Link: www.worldbank.org/en/topic/poverty/lac-equity-lab1
	SEDLAC: this database includes statistics on poverty and other distributional and social variables from all Latin American and some Caribbean countries, based on microdata from household surveys. Link: www.cedlas.econo.unlp.edu.ar/wp/en/estadisticas/sedlac
	UN Economic Commission for Latin America and the Caribbean: has developed information systems on statistical data (CEPALSTAT) and a tool that can produce thematic maps based on local, regional and national databases (REDATAM). Link: www.cepal.org/en/datos-y-estadisticas
	UN Economic Commission for South Asia and the Pacific: The ESCAP databased provides statistical information on country and regional indicators, such as the SDGs, for countries that are part of the UN Economic Commission for South Asia and the Pacific. Link: www.unescap.org/stat/data

Environmental and infrastructural aspects risks of hurricanes, earthquakes, floods, electricity/water shortages, etc.	CIA World Factbook: provides on information on the history, people, government, economy, energy, geography, communications, transportation, military, and transnational issues for 267 world entities. Link: www.cia.gov/library/publications/the-world-factbook
Employment and unemployment rates please include employment rate by age and gender	CIA World Factbook: provides on information on the history, people, government, economy, energy, geography, communications, transportation, military, and transnational issues for 267 world entities. Link: www.cia.gov/library/publications/the-world-factbook
	International Labour Organization: Key Indicators of the Labour Market (KILM) is a collection of 18 key indicators of the labour market, ranging from employment and variables relating to employment (status, sector, hours, etc.), the lack of work, the conditions of work (wages, compensation costs, working poverty, etc.) and the characteristics of jobseekers, (education, labour productivity). Link: www.ilo.org/empelm/pubs/WCMS_114060/lang--en/index.htm
Prevalence of the informal economy	International Labour Organization: Key Indicators of the Labour Market (KILM) includes a collection of indicators on informal employment (by gender and sector). Link: www.ilo.org/empelm/pubs/WCMS_114060/lang--en/index.htm
Education system overview please include literacy rate by age and gender	Education at a Glance: The OECD provides an overview of education indicators for its member countries as well as for Argentina, Brazil, China, Colombia, Costa Rica, India, Indonesia, the Russian Federation, Saud Arabia and South Africa. Link: www.oecd.org/education/education-at-a-glance
	The World Bank: provides information on education by country. Link: http://databank.worldbank.org/data/reports.aspx?source=Education-Statistics:-Education-Attainment
	UNESCO – UIS: this website offers statistical information on education indicators. Link: http://data.uis.unesco.org
	World Inequality Database on Education: provides an overview of indicators influencing education, such as wealth or ethnicity, by country. Link: www.education-inequalities.org

1.4 Social Protection

Please note: This section is only meant to provide context, so you do not need to provide a lot of detail.

Social protection schemes can include direct welfare programmes (conditional and unconditional cash transfers, disability grants, old-age grants, dependency grants, school feeding programmes, food aid, state pensions), which may or may not focus on targeting vulnerable groups.

Social protection schemes	Brief overview of schemes implemented by the government.
	Brief overview of schemes implemented by development partners or international organisations.
	For schemes implemented in your country, please add proportion (%) of households covered.

1.5 Political Situation

Please note: This section is only meant to provide context, so you do not need to provide a lot of detail.

Background	The political system and background.
History	Brief history of the country (e.g., previously colonised by X, independence at Y date).
Elections	The timing and description of any upcoming major elections.
Corruption	Transparency International: hosts the corruption perception index. Link: www.transparency.org/country
Stability please use World Bank political stability indicators	The World Bank: hosts the Worldwide Governance Indicators (WGI) project. Among these indicators you can find information on political stability and absence of violence for every country. Link: http://info.worldbank.org/governance/WGI/#home

PART 2: OVERALL HEALTH SYSTEM CONTEXT

Please note: In this section we do not aim to collect vast amounts of information. We encourage the teams to provide a thorough but relatively brief summary of each of the key points, and then refer the reader to documents where more information can be obtained. For example, in South Africa the Health Systems Trust provides an annual review of the national health system, which can be cited for more detail.

Please provide a broad overview of how health care is provided in your country, discussing, for example, the government level at which it is organized, the degree of coverage of public/insurance systems, etc.

2.1 Health System Organisation

The public health system

The size of the public sector, a description of the services provided and the proportion of the population that makes use of the public health system.

Please provide information on public and private health expenditure as part of GDP (with estimates of previous years where this data is available) and on availability and affordability of primary, specialist and hospital care services.

Health Systems at a Glance: the OECD provides an overview of health indicators for its member countries.

Link: www.oecd.org/health/health-systems/health-at-a-glance-19991312.htm

Reader on health systems policy analysis in Low- and Middle-Income countries: information on health policy analysis and reflections on health policy processes in low- and middle-income countries as well as some country specific examples.

Link: www.who.int/alliance-hpsr/resources/publications/Alliance-HPA-Reader-web.pdf

Health Systems in Transition profiles: for some of the countries there may be comprehensive reports based on these profiles, for example:

Indonesia: The Republic of Indonesia Health System Review: www.searo.who.int/entity/asia_pacific_observatory/publications/hits/Indonesia_HIT/en

India: https://international.commonwealthfund.org/countries

The Americas: PAHO has articles providing an overview of the health system of the member countries.

Jamaica: www.paho.org/salud-en-las-americas-2017/?p=2457

Mexico: OECD Reviews of Health Systems: Mexico 2016

OECD provide reviews on a number of countries (e.g., Lithuania, Kazakhstan, Peru, Costa Rica, Denmark, Latvia, Colombia, Russian Federation, Switzerland, Turkey, Finland, Mexico, Korea): www.oecd.org/els/health-systems/reviews-health-systems.htm

WHO produced a report for Asia: 'Resilient and people-centred health systems': http://apps.who.int/iris/bitstream/handle/10665/276045/9789290226932-eng.PDF?sequence=5&isAllowed=y

The private health sector	The size of the private sector, a description of the services provided through the private health system (if applicable) and the proportion of the population that make use of the private health system. Please also provide information on availability and affordability of primary, specialist and hospital care services.
Access	How are health services accessed? Does primary care access act as a gatekeeper system for access to secondary and tertiary care? Is access to health services universal? What are potential barriers? Are there specific geographical areas or population groups for which access to health care is problematic?

2.2 Health System Financing

How is the health system financed? Please explain both for the private and public health system if applicable	You may find it interesting to compare the two indicators below
	The World Bank: provides information on health expenditure as percentage of GDP. Link: https://data.worldbank.org/indicator/SH.XPD.CHEX.GD.ZS
	WHO Global Health Expenditure Database: Link: https://apps.who.int/nha/database
Coverage	What proportion of the population is not covered by health insurance (private or public)?
Out-of-pocket expenditure	Is there any data on the proportion of the population that incurs out-of-pocket expenditure when purchasing health care services, the amounts of out-of-pocket expenditure on health services and on the numbers of people incurring catastrophic levels of out-of-pocket expenditure? Please also add information on impoverishment due to health care costs (e.g., proportion of population pushed below the poverty line by healthcare cost, proportion of population spending more than 25% as well as indicators of household expenditure/consumption on out-of-pocket healthcare costs)
	Catastrophic health expenditure: Wagstaff A, Flores G, Hsu J, et al. (2018) Progress on catastrophic health spending in 133 countries: a retrospective observational study. The Lancet Global Health, 6(2): E169–E179. Link: www.thelancet.com/journals/langlo/article/PIIS2214-109X(17)30429-1/fulltext

Out-of-pocket expenditure (continued)	World Bank Health Equity and Financial Protection Indicators: HEFPI includes data series on impoverishment due to out-of-pocket expenditure on health care. Details on indicators and coverage at: https://datacatalog.worldbank.org/dataset/hefpi Link (data access): https://databank.worldbank.org/home.aspx
	World Bank – Universal Health Coverage Global Monitoring Data: this dataset contains the underlying data used to produce the 2017 joint WB-WHO global monitoring report in universal health coverage 'Tracking universal health coverage: 2017 global monitoring report'. It includes information on service coverage and on financial protection indicators at country, regional and global level. Link: https://datacatalog.worldbank.org/dataset/universal-health-coverage-global-monitoring-data-2017
Public funding	Are there any planned changes to the financing strategies or financing mechanisms to fund the health system (e.g., plans for social health insurance, payroll taxes etc.)?
	Who is responsible for deciding how much funding is available for health care in your country?
	What is the process for deciding how much funding is available for health service provision? (e.g., timing of budget processes and cycles).
	Who sets the priorities for funding?
Budget allocation	How are health budgets allocated and dispersed, across levels of the health system? Do health budgets get dispersed through geographical areas?
	How are health budgets allocated and dispersed, across program areas?
Private health care insurance	What proportion of the population purchases private health care insurance?
	Are private health insurance markets regulated?
Remittances	Do remittances play an important role in the financing of health care in your country? [Please note: remittances here refer to private payments that friends or relatives send from abroad to cover private healthcare expenditure]
International donations	Does your country receive a significant amount of donations (of time, skills or equipment) from other countries or individuals located outside of the country to support the healthcare system?

2.3 Health System Workforce

Size and structure of the workforce	Number of doctors, nurses, social workers, neurologists, geriatricians per 100,000 population, if possible/applicable broken down by public and private sector
	The World Bank: provides information on the number of physicians and other members of the health care workforce per 1,000 people. Link: https://data.worldbank.org/indicator/SH.MED.PHYS.ZS
	WHO: provides data and reports on members of the health workforce. Link: www.who.int/health-topics/health-workforce#tab=tab_1 Link: www.who.int/healthsystems/topics/workforce/en
	OECD: provides data and policy reports on the health workforce Link: www.oecd.org/els/health-systems/workforce.htm
Trends	Are there any patterns (i.e., in terms of job roles, organisations, geographical locations, etc.) of health staff vacancies (or with high turnover rate) that have been identified in the health system?
Migration	Does migration (within and between countries) play a role in the availability of health care workers? What are the migration patterns?

PART 3: OVERVIEW OF THE LONG-TERM CARE SYSTEM CONTEXT

Please provide an overview of how long-term care (including care in the community and care provided by family and other carers) is provided in your country, discussing, for example, the extent to which there is an organized system and the extent to which the country relies on informal/unpaid care.

Please note: In this section we do not aim to collect vast amounts of information. We encourage the teams to provide a thorough but relatively brief summary of each of the key points, and then refer the reader to documents where more information can be obtained.

WHAT IS LONG-TERM CARE?

If you are not familiar with long-term care (what is understood by LTC and the key types of services, activities and benefits that it covers) we recommend, as a starting point, reading the OECD 'Help Wanted?' report:

> Definition of LTC: "A range of services required by persons with a reduced degree of functional capacity, physical or cognitive, and who are consequently dependent for an extended period on help with basic activities of daily living. This 'personal care' component is frequently provided in combination with help with basic medical services such as 'nursing care', as well as prevention, rehabilitation or services of palliative care."

Colombo F. et al. (2011) Help Wanted? Providing and Paying for Long-Term Care. OECD Health Policy Studies, OECD Publishing. Paris: OECD (p11)

3.1 Long-term care system organisation

Overview

Health Systems in Transition (series): provides a comprehensive overview of the health system for the country under study, with a chapter on long-term care.

A full list of countries reviewed and access to the reports can be found here: www.euro.who.int/en/about-us/partners/observatory/publications/health-system-reviews-hits/full-list-of-country-hits

WHO: also provides a report on LTC in Sub-Saharan Africa: www.who.int/publications/i/item/9789241513388

Coverage and access	Does your country have a public long-term care system? If so, please provide a description of its coverage: is it universal (i.e., everyone who needs care is covered, irrespective of income, professional group, etc.), or residual (the public system only covers those without means to pay for their own care or without family support, or it only covers specific parts of the population)? What are potential barriers to access?
	International Labour Organization: review of long-term care protection in 46 countries (Algeria, Argentina, Australia, Austria, Belgium, Brazil, Canada, Chile, China, Colombia, Czech Republic, Denmark, Estonia, Finland, France, Germany, Ghana, Greece, Hungary, Iceland, India, Indonesia, Ireland, Israel, Italy, Japan, Korea, Luxembourg, Mexico, Netherlands, New Zealand, Nigeria, Norway, Poland, Portugal, Russia, Slovak Republic, Slovenia, South Africa, Spain, Sweden Switzerland, Thailand, Turkey, United Kingdom, United States) Link: www.social-protection.org/gimi/RessourcePDF.action?ressource.ressourceId=53175
General reading on long-term care concepts (resources may or may not contain country-specific information)	International Labour Organization: review of long-term care protection in 46 countries (Algeria, Argentina, Australia, Austria, Belgium, Brazil, Canada, Chile, China, Colombia, Czech Republic, Denmark, Estonia, Finland, France, Germany, Ghana, Greece, Hungary, Iceland, India, Indonesia, Ireland, Israel, Italy, Japan, Korea, Luxembourg, Mexico, Netherlands, New Zealand, Nigeria, Norway, Poland, Portugal, Russia, Slovak Republic, Slovenia, South Africa, Spain, Sweden Switzerland, Thailand, Turkey, United Kingdom, United States) Link: www.social-protection.org/gimi/RessourcePDF.action?ressource.ressourceId=53175
	OECD: Colombo F. et al. (2011) Help Wanted? Providing and Paying for Long-Term Care. This book discusses issues related to long-term care, such as family care, long-term care workforce, long-term care insurance and other financing arrangements. Link: www.oecd.org/els/health-systems/help-wanted-9789264097759-en.htm
	WHO: The World Report on Ageing and Health was published in 2015 and focuses on concepts of ageing and the importance on healthy ageing. Link: https://apps.who.int/iris/handle/10665/186463
	International Encyclopaedia of Public Health: Long term care, organisation and financing, Freeman E, Knapp M & Somani A. Heggenhougen K & Quah S (eds.) 2006. Elsevier, New York, USA.
	WHO: report on LTC systems in Sub-Saharan Africa: www.who.int/publications/i/item/9789241513388

Public long-term care system	Description of the long-term care services provided through the public long-term care system and the proportion of the population that makes use of the public long-term care system. If available, please provide indications of the size of public sector (i.e., numbers of people covered, volume of services, expenditure, etc). If your system also offers cash benefits, please describe those too. Please consider any types of long-term care services/services for older people/services for people with special needs. Long-term care services can be offered in residential facilities (e.g., nursing homes, institutions for disabled or dependent individuals), in the community (e.g., day-care centres, community centres) or in the home of the older person (e.g., home maintenance, personal care, meals on wheels)
Private long-term care sector (if applicable)	Description of the services provided through the private long-term care sector and the proportion (and characteristics) of the population that make use of the private long-term care services. If available, please provide indications of the size of the private sector. Please consider any types of long-term care services/services for older people/services for people with special needs. Please note, if possible, whether these services are provided and financed privately, or whether they are privately provided and financed publicly (at least in part).
Volunatry long-term care sector (if applicable)	Description of services for people with long-term care needs provided by the voluntary sector (i.e., religious groups, charities). For example, these services may include care homes, day centres, volunteers who visit people with care needs in their own homes and offer support, etc.

3.2 Long-term Care System Financing

If your country has a public[9] long-term care system, please answer:	How is the public long-term care system financed?
	Who is responsible for deciding how much funding is available for long-term care in your country?
	What is the process for deciding how much funding is available for long-term care service provision (e.g., timing of budget processes and cycles)?
	Who sets the priorities for funding?
	How are long-term care budgets allocated and dispersed, across levels of the long-term care system? Do budgets get dispersed through geographical areas?
	How are long-term care budgets allocated and dispersed, across program areas?

9. For a 'public' long-term care system we mean a system that is designed, regulated and monitored by the state (or other sub-national government level). For example, in some countries (Singapore and Germany) the state sets the 'rules' for a long-term care insurance system, but the insurers and care providers are in the private sector.

	Are some aspects of long-term care[10] covered by the country's main health financing mechanisms (for example by the insurance schemes)?
Private insurance	Are there private long-term care insurance products available in your country? If so, what proportion of the population purchases private long-term care insurance? Are private insurance markets regulated?
Out-of-pocket expenses	Is there any data on the proportion of the population that incurs out-of-pocket expenditure when purchasing long-term care services, the amounts of out-of-pocket expenditure on LTC and on the numbers of people incurring catastrophic levels of out-of-pocket expenditure?
Remittances	Do remittances play an important role in the financing of long-term care in your country? [Please note: remittances here refer to private payments that friends or relatives send from abroad to cover private long-term care expenditure]
Reforms	Are there any planned changes (reforms) to the organisation and financing of the long-term care system?

3.3 Long-term Care Workforce (including unpaid/informal workers)

Please Include all types of workers who provide care, including family carers who provide mostly unpaid care and Informal care workers such as live-In domestic staff who provide care as part of their duties (see glossary for definitions).

Size and structure of the workforce	Include information on gender if possible and considering all types of workforce, including those unpaid or informally employed.
Training and qualification	Are there recognized professional training and qualification systems for the long-term care workforce?
Regulation	Is there a regulatory body? Or do formal care workers belong to any professional body? Are there any guidelines published by any government agencies (regarding workforce training, staff/user ratio, quality monitoring, compliance etc.)?
Trends	Are there any patterns of staff vacancies (or with high turnover rate) that have been identified in the long-term care system?
Migration	Does migration (within and between countries) play a role in the availability of long-term care workers? What are the migration patterns?

10. For example, nursing and/or home help for people living who have functional dependency, rehabilitation services, day care, care homes, etc.

Conditions	What is the organisation and working conditions of the long-term care workforce?
Volunteers	Is there a clear role for volunteers within this workforce and how is this organised (shadowing paid staff, offered training etc.)?
Unpaid and informal carers	Is there any training available to unpaid and informal carers or any form of support?

PART 4: DEMENTIA POLICY CONTEXT

Please note: We are interested in policies on all levels. Please include national policies where available, but we would also like to know about regional policies where they exist and have a specific focus on dementia.

4.1 Governance

For the questions from the Global Dementia Observatory (GDO), please also refer to the GDO reference guide available at: https://apps.who.int/iris/bitstream/handle/10665/272669/WHO-MSD-MER-18.1-eng.pdf?ua=1

(a) Is dementia included within the portfolio of one or more ministries in the national government? (GDO 1x1)

(b) Which government sector is primarily responsible for Dementia? (e.g., Ministries of Health, Social Welfare…)

(c) In which branch is dementia primarily included: Health, Ageing, Social services, Mental health, NCDs? (GDO 1x1x1)

(d) Is there a dementia-specific representative within the national government? (GDO 1x2)

4.2 Dementia Policies and Plans

Dementia-specific policies and plans	WHO Dementia plan guide: this tool aims to support countries in preparing, developing and implementing a dementia plan. Link: www.who.int/mental_health/neurology/dementia/policy_guidance/en Alzheimer's Disease International (ADI): provides a lot of resources on National Dementia Plans in their website, including existing dementia plans of their member countries and subnational plans of regions within these countries. Link: www.alz.co.uk/dementia-plans

Dementia-specific policies and plans (continued)

(a) Is there a dementia-specific national document (policy or plan) either in place or under development? (GDO 2x1)

(b) When was this document updated? (GDO 2x1x1)

(c) Have any resources been committed to its' implementation? If so, please also specify the amount that has been committed. (GDO 2x1x2)

(d) Are there any targets or milestones for monitoring implementation included? What do these encompass? (GDO 2x1x3)

(e) What are the key goals/ aims of the dementia policy/plan?

(a) How are people living with dementia and their care needs presented and represented in this context? Are families/carers involved in the development of the policies and plans?

(f) How are policies and plans operationalized? Do they include (in addition to specific targets, indicators and timelines):

i. Resources/budgets attached to specific targets/indicators?

ii. Any consequences for implementing or not implementing (e.g., are there legal consequences for not providing protection against abuse of older adults)?

Example: would there be legal consequences (i.e., fines) if a policy was not adhered to in practice by healthcare providers?

Other policies and plans that include dementia

WHO Mindbank: contains a number of resources on mental health by country, including national policies on mental health, non-communicable diseases and older persons.

Link: www.who.int/mental_health/mindbank/en

(a) Is dementia integrated into or covered by a different national plan (such as a mental health plan)? (GDO 2x2)

(b) Please specify which area of dementia is covered. (GDO 2x2x1)

(c) Are there dementia-specific documents operationalized at subnational levels? If so, please also specify the number of sub-national areas that have operationalized dementia-specific documents. (GDO 2x3)

[Sub-national levels refers to any level lower than national level. Depending on country context this could be state-, territorial-, provincial-, regional-, city-level or others.]

(d) How is dementia framed in this context?

This question refers to language used in the policy. For example, is dementia described as a non-communicable disease or a mental illness or a scientific challenge? Are there any patterns of language when referring to people with dementia and their carers?

4.3 Characteristics of Policies and Plans for Dementia

The questions in this section have been designed to be answered in a brief way, but feel free to provide examples, particularly in the questions asking "how".

WHO Dementia plan guide: this tool aims to support countries in preparing, developing and implementing a dementia plan.

Link: www.who.int/mental_health/neurology/dementia/policy_guidance/en

Alzheimer's Disease International (ADI): provides a lot of resources on National Dementia Plans in their website, including existing dementia plans of their member countries and subnational plans of regions within these countries.

Link: www.alz.co.uk/dementia-plans

(a) Do the plans and/or policies outlined above include/follow/ensure they are in line with:

i. Human rights-based approach (GDO 2x4)

ii. Equity

iii. Empowerment

iv. Multisectoral collaboration

v. Universal Health Coverage

(b) (How) does the policy reflect aspects of the sustainable development goals?

(c) (How) are people with dementia and their family (unpaid) carers recognised in the policy document?

(d) (How) is the risk of mistreatment and abuse of people with dementia incorporated into the policy?

(e) (How) does the policy encourage person-centred care?

i. Are people with dementia supported in maintaining an active role in the community?

ii. Are people with dementia encouraged to/ supported in maintaining self-management where possible?

iii. Are the preferences of people with dementia encouraged to be considered in care practice and decision making?

(f) (How) are aspects of care quality assurance incorporated into the policy document?

(g) (How) are health and long-term care workforce represented in the policy document?

(h) (Who) are the key actors described in the policy document? Are their roles defined?

11. You can find out more information about the Sustainable Development Goals here: www.un.org/sustainabledevelopment/sustainable-development-goals

(i) (How) does the policy document support integrated care?

(j) (How) does the policy outline the interface between other aspects of care (e.g., general health care for older adults, mental health care etc)?

(k) Does the policy document recognise potential barriers to access? Does the document suggest solutions to overcome identified barriers?

This question refers to barriers in access to services. Are there perhaps specific population groups that find it harder to get appropriate care? (i.e., people in rural areas, people in the informal economy…)

(l) (How) does the policy incorporate equity? (e.g., in access to care (availability, provision, costs), workforce rights, carer rights & protection

(m) (How) does the policy incorporate aspects of prevention and risk reduction? (e.g., link to public health initiatives, community initiatives)

(n) (How) does the policy address aspects of sustainability? (e.g., financing, political and social commitment)

(o) If there is a policy already, who were the stakeholders involved in developing the policy? What is their role in enacting their policy? How is this monitored ((what) are there tangible outcomes)?

(p) How are targets/ milestones monitored? Is there evidence of achievements?

(q) Are there named (key) stakeholders in the policy document? If yes, who are they and what is their role?

(r) What are the expectations of the different stakeholders who participated in developing this policy?

4.4 Areas for Action Included in Policies and Plans for Dementia

You may also want to comment on the degree of implementation of the actions that have been included in the policies and plans.

(a) Please describe the areas for action that are included in any policies or plans for dementia in your country according to the following seven categories (GDO 2x5):

i. Dementia awareness, stigma reduction and dementia-friendly communities

ii. Dementia prevention and risk reduction

iii. Timely dementia diagnosis, post-diagnostic supports and care

iv. Workforce training on dementia

v. Support for dementia carers and families

vi. Improved monitoring or information systems for dementia

vii. Dementia research and innovation

4.5 Legislation

You may also want to comment on the degree of implementation of the actions that have been included in the policies and plans.

(a) Is there dementia-specific legislation in your country either at the national or sub-national level? (GDO 3x1)

(b) Are there provisions in other laws related to, or that apply to, protecting the rights of people with dementia? If so, please describe these laws and indicate whether they comply with international human rights standards according to the following criteria (GDO 3x2 and 3x3):

i. Provisions exist which promote supported decision-making, the ability for people with dementia (or all persons) to nominate a trusted person or network of persons for discussing issues and making decisions.

ii. Provisions exist which provide for procedures to enable people with dementia (or all persons) to protect their rights (safeguards against exploitation, violence or abuse) and to file appeals and complaints to an independent legal body.

iii. Provisions exist which promote the transition of dementia care to community-based services.

iv. Provisions exist which provide for regular inspections of human rights conditions (safeguards against exploitation, violence or abuse) and/or care quality by an independent body in facilities where people with dementia reside.

v. Provisions exist which aim to end coercive practices, including seclusion and mechanical/ physical/ chemical restraints for people with dementia (or all persons).

(c) Is there specific legislation pertaining to the following (GDO 3x4):

i. Advance care directives

ii. Provisions which aim to end discrimination against people with dementia (including in the workplace)

iii. Provisions which aim to end discrimination against family carers

Additional STRiDE questions

(d) Are there provisions to protect the rights of family and other unpaid carers?

(e) Does the legal system in [country] place the responsibility of older parents directly on their offspring (either in the law or specifically in various policies)?

(f) How is curatorship/power of attorney obtained? Is curatorship/power of attorney awarded on a temporary basis only?

4.6 Clinical Guidelines, Standards and Protocols for Dementia

	(a) Are there standards, guidelines or protocols for dementia? (GDO 4x1)
	(b) Are they national or subnational standards/ guidelines/ protocols? (GDO 4x1x1)
	(c) Are they approved by government? (GDO 4x1x2)
	(d) What areas are covered by standards, guidelines and protocols? (GDO 4x2) i. Prevention and risk reduction of dementia ii. Diagnosis of dementia iii. Management of dementia (including treatment, medication management, non-cognitive symptoms and comorbidities) iv. Other post-diagnostic supports of people with dementia. If yes, please respond below: v. Advance care directives, power of attorney or guardianship vi. Palliative and end-of-life care vii. Care in nursing and residential care facilities viii. Care in hospitals
Additional STRiDE questions	(e) Who developed the guidelines, and when were they developed?
	(f) What are the expectations of different stakeholders in relation to the guidelines?
	(g) Besides clinical standards or guidelines, is the use of traditional medicine and healers to manage or treat dementia common? i. If yes, what is commonly used? ii. How are medicines or practices communicated and accessed?

4.7 Dementia Care Coordination

(a) Is there a mechanism to coordinate care across sectors in government for people with dementia? Examples of care coordination models include integrated care pathways, care networks, multidisciplinary or interdisciplinary teams and case management. (GDO 5x1)

(b) Which of the following sectors are included in the coordinated planning and resourcing of care for people with dementia across the continuum of care? (GDO 5x1x1)

i. Health
ii. Social
iii. Education
iv. Employment
v. Justice
vi. Housing
vii. Civil Society
viii. Transport
ix. Private sector
x. Other?

(c) Is the coordinated planning and resourcing of care for people with dementia implemented at the national or sub-national level, or both? (GDO 5x1x2)

(d) Do formal agreements and/or joint plans exist across sectors in government for people with dementia? (GDO 5x1x3)

(e) What are the components of care coordination? (NB: this is not a comprehensive list) (GDO 5x2x1)

i. Multi or interdisciplinary teams
ii. Task shifting/sharing
iii. Responsive referral protocols or pathways
iv. Continuity of information
v. Provider continuity
vi. Community-based approach
vii. Other?

(f) Is care coordination between multiple governmental sectors occurring at Primary, secondary or tertiary level care? (GDO 5x2x2)

Additional STRiDE question

(g) How are the different aspects of care coordination (covered in the section above) organised? For example, if task sharing is being pursued, who trains whom, who supervises whom?

4.8 The Policy Process

	(a) What changes in policy in relation to dementia are expected in the next five years? (b) Is there evidence of ongoing developments that indicate a change in policy or financing for dementia in the future? (c) By whom and by what process are they driven by? What are the motivations? (d) Are the expected policy changes, likely to result in any of the following: i. A new or a revised National Dementia Plan? ii. Dementia being included in another National Plan or policy, such as ageing, or NCDs? iii. Do you expect any policy changes, perhaps in relation to wider health services reform, or long-term care or social protection, which may result in increased availability of care, treatment and support?
Please provide your interpretation following the completion of previous parts of this desk review	(e) Can new clinical guidelines covering dementia be expected? (f) Who are the key stakeholders who can bring about a policy change in relation to dementia in your country (if possible, please provide names and position)?

PART 5: DEMENTIA AWARENESS AND STIGMA

Useful resources on dementia awareness and stigma

United Nations Enable Disabilities: country-level CRPD state and shadow reports may provide information on this generally for disability but may include information on ageing and dementia.

Link: www.un.org/development/desa/disabilities

World Alzheimer Report 2019: contains findings from a survey on attitudes to dementia (including awareness and knowledge), there are separate figures for different countries)

Link: www.alz.co.uk/research/WorldAlzheimerReport2019.pdf

Disability-focused organisations within government or NGOs may have information on accessibility programmes.

(a) Was at least one functioning dementia public awareness campaign to improve understanding and reduce stigma and discrimination carried out during the past year in your country? (GDO 13x1)

(b) Please describe all known public awareness campaigns for dementia and specify for each: the name of the campaign, the delivery channel (i.e., tv, radio, print etc), the audience, funding (government/public or NGO) and the area of implementation (i.e., national, sub-national, or a specific area)? (GDO 13x2)

(c) What population groups outside the health and long-term care sector receive training and education in dementia? (GDO 15x1 and 15x2)

i. Volunteers
ii. Police and fire services
iii. First responders / paramedics
iv. Judges, solicitors, notaries
v. Community/city workers (e.g., public transport staff, librarians)
vi. School children
vii. Bankers, financial service staff
viii. Retail and hospitality staff (e.g., restaurants, grocery stores)

(d) Please describe the cultural/societal perceptions of dementia (including gender factors) in your country.

Please check the results of the survey carried out as part of the World Alzheimer Report 2019 as it may have data on perceptions of dementia in your country www.alz.co.uk/research/WorldAlzheimerReport2019.pdf

Additional STRiDE question

(e) Is there any evidence of current or changing perceptions of dementia in your country? If so, what is motivating these changes?

(f) What factors predominantly affect perceptions about dementia in your country: individual, family, community, society, government

(g) What aspects does the training you described under question (c) cover?

(h) In question (a) you provided information on dementia public awareness campaigns. Have these (or earlier) campaigns been evaluated? Is there evidence of impact?

i. Are there initiatives to improve the accessibility of the physical and social environment, including people with dementia? If so, which of these dimensions do they cover? (GDO 14.1 &14.2)

ii. Accessibility of public spaces and buildings

iii. Accessibility of public transportation vehicles

iv. Assistance with home modification

v. Assistive technology to compensate for loss of capacity

vi. Availability of community places where older people can meet

vii. Availability of social opportunities as well as accessible information on leisure and social activities

Where available, please include local, regional or national initiatives targeting older people, people with disabilities or other groups if these initiatives may also be accessible for people with dementia.

PART 6: EPIDEMIOLOGY OF AND INFORMATION SYSTEMS FOR DEMENTIA

Information systems for dementia

(a) Is the number of people with dementia routinely monitored in your country? (GDO 16x1)

i. By the Ministry/Department of Health?

ii. By the Ministry/Department of Social Development/other?

iii. By research-led institutions?

iv. By non-governmental organizations?

(b) For each source, please describe what indicators are gathered, and what year the most recent estimates are available for. If no data is routinely monitored, please also mention this.

(c) For each source, please outline what data sources are used to routinely monitor people living with dementia in your country (Clinical records/ household surveys/ administrative data/ facility surveys or records/ other?) (GDO 16x1x1)

(d) For each source, please specify if the estimates are available electronically? (GDO 16x1x2)

Information systems for dementia (continued)	(e) For each source, please specify if the estimates can be disaggregated by gender, geographical area or by type of dementia. (GDO 16x1x3)
Epidemiology of dementia	If there is no recent/reliable data from your country: Alzheimer's Disease International (ADI): World Alzheimer Report 2015 provides information on dementia prevalence, incidence and costs on a number of countries. Link: https://www.alz.co.uk/research/world-report-2015
	(a) What is the estimated prevalence and incidence of dementia and the source of these estimates? (GDO 21 & 22) (b) Please outline the total deaths and Years of Life Lost (YLL) due to dementia and the source of these estimates. (GDO 23 &24) (c) Please outline the total Years lived with disability (YLDs) due to dementia and the source of these estimates. (GDO 25) (d) Is the prevalence of dementia more pronounced in any specific geographical areas? (e) What is the average age of onset? (f) What is the average number of years people live with dementia? (g) Is there evidence for difference in incidence/prevalence by gender and for different ethnic groups? (h) What is the average number of years lived by people who have with dementia? (i) Are there relevant sub-groups of specific dementias (e.g., HIV-dementia)? What is their prevalence/ incidence? (j) Is there evidence of associations between dementia and poverty in your country? (k) Is there a campaign to reduce the risk of dementia in your country? (GDO 13.3) Please provide details. (l) What risk factors have been associated with dementia in your country?

Epidemiology of dementia (continued)

(m) Dementia is associated with a number of preventable risk factors.[12,13] Can you provide information on (please include age, sex, ethnicity and other relevant stratifier when available):

i. The proportion of people with primary education?[2]

ii. The proportion of people with secondary education?[2]

The World Bank: provides information on education by country.

Link: http://databank.worldbank.org/data/reports.aspx?source=Education-Statistics:-Education-Attainment

The OECD: offers data on educational attainment by country.

Link: https://data.oecd.org/eduatt/adult-education-level.htm#indicator-chart

iii. The proportion of the population living with high blood pressure (hypertension)? (GDO 33)

iv. The proportion of the population considered to be obese? (GDO 31)

v. The proportion of the population experiencing hearing loss?

vi. The proportion of the population that smokes? (GDO 29)

vii. The proportion of the population living with depression? (GDO 35)

viii. The proportion of the population that is physically inactive? (GDO 28)

ix. The proportion of the population living with diabetes? (GDO 32)

x. Amount of alcohol consumed per capita (15+) (GDO 30)

xi. The proportion of the population with high cholesterol (GDO 34)

Global Health Observatory: data on health-related outcomes related to Sustainable Development Goals. It contains epidemiological information on a variety of communicable and non-communicable diseases. Information is available by country.

Link: www.who.int/gho/en

The Global Burden of Disease Project: provides country-specific data on life expectancy, mortality, main causes of death, premature death and morbidity as well as on health expenditure.

Link: www.healthdata.org/results/country-profiles

Countries may also want to refer to regional data where no country specific data is available. WHO provide regional overviews:

Link: www.who.int/immunization/monitoring_surveillance/data/regions/en

You will have provided some of this information in earlier parts of this desk review. You may choose to repeat this information in brief and/or to cross-reference the appropriate parts.

12. Preventable risk factors as identified by Livingston et al. (2017) "Dementia prevention, intervention, and care" The Lancet Commissions, 390, pp.2673–2734.

13. Preventable risk factors as identified by Read et al. (2017) The effect of midlife risk factors on dementia in older age, London: Public Health England.

PART 7: THE DEMENTIA CARE SYSTEM

7.1 Overview of the Dementia Care System

(a) Where and how do people get a diagnostic assessment for dementia? Please describe what would be the "typical" path to access a diagnostic assessment.

(b) What is the percentage of people with dementia that have received a diagnostic assessment? (GDO 7x1)

(c) Please provide the number of people who received a diagnostic assessment in the most recent year for which data are available (GDO 7x2)

(d) Are there differences in diagnostic assessment according to geographical areas (rural/urban) and also according to other socio-economic factors?

(e) Which health or long-term care providers are responsible for coordinating the care of people with dementia?

(f) Are there dedicated services supporting people with dementia (e.g., mental health, dementia specific) after a diagnostic of dementia?

(g) What are the links between primary care services, specialist care services and community/ institutional care services supporting people with dementia?

i. How are these links initiated/ maintained?

ii. Are there protocols/bills (laws)/ policies that outline who carries responsibility or is this depending on local practice/ individuals?

(h) Do people with dementia experience out-of-pocket expense to access diagnosis or care?

(i) How do people with dementia access long-term care?

(j) What is the estimated cost of dementia in your country? Please report all the studies available, reporting whether they include costs from a societal perspective (that is, including medical care, long-term care (or social care), and unpaid care), or just from the formal care or public sector perspective. (GDO 27)

World Alzheimer Report 2015:
Link: https://www.alz.co.uk/research/WorldAlzheimerReport2015.pdf

The worldwide costs of dementia 2015 and comparisons with 2010:
Link: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5232417/

Estimates for India: Rao GN, Bharath S. Cost of dementia care in India: delusion or reality? Indian J Public Health. 2013;57(2):71–7.

7.2 Dementia Care System Organisation

Community-based services for dementia

(a) Does your country provide health and long-term care services to support people with dementia in community-based settings? (GDO 8x1)

(b) Do you have any of the following (if yes, please provide details) (GDO 8x2)

i. Diagnostic services (in primary care)

ii. Assessment & management of behavioural and psychological symptoms of dementia

iii. Psychosocial services and rehabilitation

iv. Activities of daily living support services

v. Palliative and end-of-life care services

vi. Social & financial protection and benefit

(c) Are these community-based services available in certain areas only? e.g., capital city only; capital and main cities; capital, main cities and rural areas (GDO 8x3)

(d) Are these services provided by the public sector, the private sector or both? (GDO 8x4)

(e) If available, the number of people who received community-based care (most recent estimate). If these estimates are not available, please state this. (GDO 8x5)

(f) Is there a mechanism to co-ordinate care, treatment and support for people with dementia such as a care manager or dementia advisor, particularly across health and long-term care? (GDO 5x1)

(g) Are family and other unpaid carers recognised/registered as part of dementia diagnostic services?

(h) In question b(ii) you provided information on assessment and management of behavioural and psychological symptoms. What kind of interventions are available to people with dementia or their informal carers? (e.g., pharmaceutical, behavioural)

(i) Are there any other social interventions available for people with dementia in community-based settings? What kind of interventions are available?

(j) In questions c you provided information on the provision of community-based services. Could you provide some information on potential regional diversity?

(k) Are home care services available? Are there differences in availability by location? What kind of services are provided in people's homes?

(l) Is access to care restricted through eligibility criteria? What are these criteria?

Non-governmental Organizations (NGOs)

(a) Is there at least one national nongovernmental dementia association such as an Alzheimer Association/Society? (GDO 11x1)

(b) If so, please indicate if they have (1) a national office; (2) sub-national offices or (3) both. (GDO 11x2)

(c) Are the majority of staff (>50%) volunteers or salaried? (GDO 11x2x3)

(d) What dementia-specific activities and/or services does the association provide? (GDO 11x2x4)

(e) Are any of their activities funded by the government? (GDO 11x2x5)

(f) Has the association been involved in any policy development related to dementia? (GDO 11x2x6)

(g) Where are services provided by NGOs available? (nationally, regionally, locally). Please describe the variability in availability and accessibility (across regions, rural/urban)

(h) Are there any costs associated with accessing services provided by NGOs for people living with dementia and their carers/families?

(i) How many people with dementia and their carers are served by NGOs? Please provide information on their profile e.g., do they tend to be more educated, living in urban areas, etc.

7.3 Dementia Care System Workforce

(a) For each type of LTC workforce category, please specify the total number (absolute) in your country, please specify the year these estimates were updated (GDO 6x1)

i. Neurologists

ii. Geriatricians/ Psychogeriatricians

(b) For each type of health and social workforce category, please indicate whether basic competencies on dementia are included in either undergraduate or graduate curricula training, residency programmes, continuing education programmes, specialist certification or clinical practice training (GDO 6x2)

i. Physicians/medical doctors

ii. Specialist medical doctors

iii. Psychologists

iv. Rehabilitation professionals/workers

v. Nurses

vi. Pharmaceutical personnel

vii. Social workers

viii. Personal support workers

(c) How are education and training programmes for members of the long-term care workforce delivered and assessed?

(d) Is training/education available for 'untrained' paid workers (e.g., live-in carers)? Who provides that training?

(e) For question b you provided information on the training for members of the health and long-term care workforce. Are there other professionals that receive dementia training? (e.g., Clinical psychologists, occupational therapists, physiotherapists, receptionists)

7.4 Health and Long-term Care Facilities

(a) Are the following types of health and long-term care facilities available in your country? (GDO 9)

i. Residential long-term care facilities

ii. Hospice centres

iii. Adult day centres

iv. Outpatient (community) social centres

(b) Please specify the total number of residential long-term care facilities in your country i.e., long-term nursing care facilities and other residential long-term care facilities. If available, please also specify the total number of beds across all long-term residential facilities in your country.

(c) How many people with dementia are living in residential long-term facilities in your country (ideally for a one-year period)?

(d) Do hospitals in your country have any dementia-specific beds? If yes, please try to find the number of beds available either at national or sub-national levels.

(e) Do hospitals in your country have any geriatric-specific beds? If yes, please try to find the number of beds available either at national or sub-national levels.

(f) Do hospitals in your country track dementia-related admissions? If so, please indicate the total number of dementia-related admissions and specify the date this was reported.

(g) Of the different types of health and long-term care facilities listed above, where such facilities are available, how many such facilities are available?

(h) What services are provided in (community) social centres?

(i) Do these facilities offer dementia specific programmes/interventions? What kind of interventions are provided?

(j) Question c above investigated the number of residential long-term facilities. Do mental health hospitals/institutions play a role in the provision of residential dementia care?

7.5 Antidementia Medication and Care Products

(a) Are any antidementia medications approved by your National Medicines Regulatory Authority? Please specify. (GDO 10)

(b) Are any of these medications available as generics?

(c) Are any of the following care products, equipment and technologies available for free or partially subsidised for those with dementia in your country?

i. Adult hygiene products (e.g., diapers, disposable cloths, underpads)

ii. Assistive technology (e.g., walking frames, wheelchairs, spectacles, hearing aids)

iii. Housing adjustments (e.g., ramps, grab bars, smoke detectors)

(d) Are any of the aforementioned medications available for free or partially subsidised?

(e) Are non-pharmacological interventions, such as Cognitive Stimulation Therapy available for people with dementia? Are such interventions evidence based?

(f) Does technology play a role in dementia care? (e.g., GPS tracking)

(g) What are the costs of the main antidementia medications in your countries: donepezil, galantamine, rivastigmine and memantine? If possible provide cost per dose.

PART 8: UNPAID CARE AND OTHER INFORMAL CARE FOR DEMENTIA

Please refer to the Glossary for a definition of unpaid care.

8.1 Informal Care Workers

(a) To what extent are informal care workers used to care for people with dementia in your country?

(b) Please describe the employment conditions and any safeguarding concerns related to informal care workers for dementia in your country.

(c) Please describe the socio-demographic characteristics of informal carers in your country

(d) Does migration (within and between countries) play a role in the availability of informal care workers? What are the migration patterns?

(e) Do you have information on the socio-economic status of informal care workers?

(f) What is the average income of an informal care worker?

8.2 Family/Unpaid Care

(a) What support is available for family/unpaid carers in your country? (GDO 12x2)

i. Social protection (i.e., care support grants; paid/unpaid leave; tax credits)

ii. Payments (cash transfers)

iii. Training and education

iv. Psychosocial support for carers

v. Respite services for carers where they can take time away from their caring role to engage in other activities of choice.

vi. Information on legal rights

(b) Please describe the kind of social protection (i.e., care support grants, paid/unpaid leave, tax credits, cash benefits or other) available for family/unpaid carers in your country.

(c) What are the social norms and traditions of family care in your country? Are there gender roles associated with family care in your country?

(d) Please describe the documented impacts on the caregiver of provision of unpaid care to people with dementia

i. Health impact

ii. Employment, education and other impacts

iii. Impact on social protection

(e) Does your country have any employment policies for unpaid/family carers?

(f) In question d(i) you described the health impact of unpaid carers. Is there evidence for aspects of both physical and mental health?

(g) In question a) you provided information on support for family/unpaid carers. Who are the key providers?

(h) Does social media or other technologies (e.g., GPS tracking) play a role in caring for a person with dementia?

PART 9: SOCIAL PROTECTION FOR PEOPLE WITH DEMENTIA

(a) Please describe whether any of the following social protection mechanisms are available for those living with dementia in your country, for example:

i. Disability Grant(s); Pensions; Old Age Grants; any other form of cash benefits

ii. Employment protection,

iii. Carers' benefit, (including in-kind and financial benefits)

iv. Paid or unpaid leave,

v. Credited social contributions,

vi. Tax allowances,

vii. Duty rebates,

viii. Discount transportation fares,

ix. Free companion fares,

x. Others

PART 10. DEMENTIA RESEARCH

(a) Is there a published government policy, statement or document detailing the government's plan or programme for dementia research? If yes, is it national or sub-national, and when was it published? (GDO 17x1)

(b) Has your government been allocating money specifically for dementia research in the last fiscal year? If so, how much was allocated to basic, clinical/translational and implementation, social and economic research? (GDO 18x2)

(c) Are people with dementia involved in the research development process? (GDO 19x1)

(d) Are there any other sources of funding for dementia research in your country (even if these are from other countries?)

(e) Are there any capacity building initiatives for dementia research? For example: fellowships/scholarships or networks for building early career researchers in dementia?

(f) Have there been any scoping reviews of dementia research in your country in order to identify research gaps? If so, please highlight the key findings.

PART 11: DATA MAPPING

This phase of work will require all countries to identify datasets that can potentially be used for when we build the simulation models of the dementia care system later in WP7. We need to identify all the datasets that include people with dementia and their carers (and where it is possible to identify whether they have dementia).

The data we (ideally) need for the models is listed in the table below, we have also included an example from the Mexican rapid situational analysis, in case that is helpful. As you work through the different sections of the topic guide, please add information on data sources to the table.

	Data is collected, reported and publicly accessible (may be subject to permission)	Existing data available at:
Prevalence of dementia		
Co-morbidities/other disabilities		
Quality of life		
Use of medications		
Use/cost of health and long-term care services		
Receipt of unpaid care		
Provision of unpaid care		
Impact of providing care on unpaid carers		
Receipt of pensions, disability benefits, other cash payments		
Dementia services' availability, types of providers and access information (any cost indicators)		
Dementia workforce (size, profile, organisational structures, any trends)		

Example from Mexico

	Data is collected, reported and publicly accessible (may be subject to permission)	Existing data available at:
Prevalence of dementia	No data from medical records or diagnosis. Data available from population studies.	From population studies: MHAS: www.mhasweb.org ENSANUT: https://ensanut.insp.mx https://www.alz.co.uk/1066/
Co-morbidities/other disabilities	Data on co-morbidity and disability collected by MoH and the National Institute of Statistics. Data reported and publicly available.	From official statistics: MoH Information System: www.dgis.salud.gob.mx/contenidos/sinais/subsistema1.html From population studies: MHAS: www.mhasweb.org ENSANUT: https://ensanut.insp.mx International studies: IHME Global Burden of Disease: www.healthdata.org/gbd/data-visualizations
Quality of life	No systematic collection of QoL data. Data from research studies and specific groups of the population	
Use of medications	As no national programme for dementia is in place, data on medications is not collected routinely. No knowledge at national level on the use of medications, their side effects, results, etc.	
Use/cost of health and long-term care services	There are no health care programmes for dementia and no long-term care policies are in place in Mexico.	
Receipt of unpaid care	No specific data on receipt of unpaid care at national level. Mexico was part of the 10/66 INDEP study that has information on unpaid care of dependent older people.	INDEP study: http://gtr.ukri.org/projects?ref=ES/I034331/1

Provision of unpaid care\	No specific data on receipt of unpaid care at national level. Mexico was part of the 10/66 INDEP study that has information on unpaid care of dependent older people.	INDEP study: http://gtr.ukri.org/projects?ref=ES/I034331/1
Impact of providing care on unpaid carers	No specific data on receipt of unpaid care at national level. Mexico was part of the 10/66 INDEP study that has information on unpaid care of dependent older people.	INDEP study: http://gtr.ukri.org/projects?ref=ES/I034331/1
Receipt of pensions, disability benefits, other cash payments	No specific data for people with dementia. National Institute of Statistics and several national surveys collect this data for the general population on receipt of pensions, source of the pension and other cash payments from public social programmes or non-contributory pensions. There are no disability benefits in place in Mexico.	For general population through national surveys or official programmes data: INEGI: www.inegi.org.mx National Household Income and Expenditure Survey: www.beta.inegi.org.mx/proyectos/enchogares/regulares/enigh/tradicional/2014 National Employment and Social Security Survey: www.beta.inegi.org.mx/proyectos/enchogares/modulos/eness/2013 From national older adult surveys: MHAS: www.mhasweb.org ENSANUT: https://ensanut.insp.mx
Dementia services' availability, types of providers and access information (any cost indicators)	There is no publicly available data as no formal health care services for dementia are available. Most people that do get timely diagnosis and treatment are in the private sector and no reporting of data is in place.	
Dementia workforce (size, profile, organisational structures, any trends)	No specific dementia workforce as there are no national or state level dementia programmes in place.	

ANNEX 2: GLOSSARY

PART 1: DESCRIBING CARERS

	PAID Receives a wage	**UNPAID** Does not receive a wage
FORMAL has contract and/or social security (for caring)	Employed directly by person/family, or through an agency… but also in Germany family carers can receive "wage" and social insurance	Volunteers may have contracts
INFORMAL no contract, no social security	Paid (usually cash) to provide care: from migrant live-in workers to family members who are paid as "compensation"	Usually family carers, but also friends and neighbours

PART 2: FULL GLOSSARY

TERM	DEFINITION	REFERENCE
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.	GDO Reference Guide, 2018
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.	GDO Reference Guide, 2018
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.	GDO Reference Guide, 2018
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.	GDO Reference Guide, 2018
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.	GDO Reference Guide, 2018

TERM	DEFINITION	REFERENCE
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.	GDO Reference Guide, 2018
BPSD management	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.	GDO Reference Guide, 2018
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.	GDO Reference Guide, 2018
Care home	A residential facility that provides accommodation and offers a range of care and support services. Care homes may provide a limited number of services to support low dependency or may provide a wide range of services to cater for the continuum from low to high dependency care.	WHO Glossary of Terms for Community HC and Services for Older Persons 2004
Care setting	The place where users of care services live, such as nursing homes, assisted living facilities/sheltered housing or private homes.	OECD 2011 Help Wanted
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.	GDO Reference Guide, 2018

TERM	DEFINITION	REFERENCE
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.	GDO Reference Guide, 2018
Case management	A targeted, community-based and proactive approach to care that involves case-finding, assessment, care planning and care coordination to integrate services around the needs of people with long-term conditions.	WHO 2015b
Case management	A collaborative process of planning services to meet an individual's health needs through communication with the individual and their service providers and coordination of resources	GDO Reference Guide, 2018
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.	
Catastrophic long-term care expenditure	Out-of-pocket payments for paid services that exceed a given fraction of total household expenditure.	N/A
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.	GDO Reference Guide, 2018
Community-based approach	Care networks that integrate social and health systems and provide quality care and evidence-based interventions within the community.	GDO Reference Guide, 2018

TERM	DEFINITION	REFERENCE
Community health worker	Individuals who provide health education, referral and follow up, case management, and basic preventive health care and home- visiting services to specific communities. They provide support and assistance to individuals and families in navigating the health and social services system.	WHO Guidelines ICOPE 2017
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).	GDO Reference Guide, 2018
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.	GDO Reference Guide, 2018

TERM	DEFINITION	REFERENCE
(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.	GDO Reference Guide, 2018
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.	GDO Reference Guide, 2018
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.	GDO Reference Guide, 2018

TERM	DEFINITION	REFERENCE
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.	GDO Reference Guide, 2018
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.	GDO Reference Guide, 2018
Demography	The study of populations, especially with reference to size and density, fertility, mortality, growth, age distribution, migration and vital statistics, and the interaction of all of these with social and economic conditions.	WHO Glossary of Terms for Community HC and Services for Older Persons 2004
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.	GDO Reference Guide, 2018
Domestic help	Help with instrumental activities of daily living including help with housework, meals, shopping and transportation. They can also be referred to as "domestic care or home help".	OECD 2011 Help Wanted
Effective/effectiveness	The degree to which a treatment plan, programme or project has achieved its purpose within the limits set for reaching its objective. For example, an expression of the desired effect of a programme, service or institution in reducing a health problem or improving an unsatisfactory health situation.	WHO Glossary of Terms for Community HC and Services for Older Persons 2004

TERM	DEFINITION	REFERENCE
Electronic medical and social care 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.	GDO Reference Guide, 2018
Epidemiology	The study of the various factors influencing the occurrence, distribution, prevention and control of disease, injury and other health-related events in a defined population. Epidemiology utilizes biology, clinical medicine, and statistics in an effort to understand the etiology (causes) and course of illness and/or disease. The ultimate goal of the epidemiologist is, not merely to identify underlying causes of a disease, but to apply findings to disease prevention and health promotion.	WHO Glossary of Terms for Community HC and Services for Older Persons 2004
Equity of care	Fair treatment of needs, regarding both the distribution of services and allocation of resources.	WHO Glossary of Terms for Community HC and Services for Older Persons 2004
Focal point (for dementia, national)	The person responsible for long-term care in a Ministry of Health (or equivalent) or national institute.	GDO Reference Guide, 2018
Formal care/services	Includes all care services that are provided in the context of formal employment regulations, such as through contracted services, by contracted paid care workers, declared to social security systems.	OECD 2011 Help Wanted
Framework	Provides a set of guiding principles for the provision of evidence-based health services.	GDO Reference Guide, 2018
Functional ability	The health-related attributes that enable people to be and to do what they value.	GDO Reference Guide, 2018
Functional ability and intrinsic capacity	Functional ability refers to the attributes that enable people to be and to do what they have reason to value. It is determined by individuals' intrinsic capacity (the combination of all their physical and mental – including psychosocial – capacities), the environments they inhabit and the interaction between the individual and these environments.	WHO Series LTC, Sub-Saharan Africa 2017

TERM	DEFINITION	REFERENCE
Geriatrics	The branch of medicine specializing in the health and illnesses of older age and their appropriate care and services.	GDO Reference Guide, 2018
Health care	Services provided to individuals or communities by health service providers for the purpose of promoting, maintaining, monitoring or restoring health.	WHO Glossary of Terms for Community HC and Services for Older Persons 2004
Health care facility	Facilities that provide health services, including include mobile clinics, pharmacies, laboratories, specialty clinics, and private and faith-based establishments.	GDO Reference Guide, 2018
Health inequality	Differences in health status occurring among individuals or groups or, more formally, the total inter-individual variation in health for a population, which often considers differences in socioeconomic status or other demographic characteristics.	WHO 2015 Report on Ageing and Health
Health inequity	Differences in health that are unnecessary, avoidable, unfair and unjust.	WHO 2015 Report on Ageing and Health
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.	GDO Reference Guide, 2018
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.	GDO Reference Guide, 2018
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.	GDO Reference Guide, 2018

TERM	DEFINITION	REFERENCE
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.	GDO Reference Guide, 2018
Home modifications/ adjustments	Conversions or adaptations made to the permanent physical features of the home environment to improve safety, physical accessibility and comfort.	GDO Reference Guide, 2018
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.	GDO Reference Guide, 2018
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).	GDO Reference Guide, 2018

TERM	DEFINITION	REFERENCE
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.	GDO Reference Guide, 2018
Impoverishing long-term care costs	Overall costs shouldered by families, including both out-of-pocket payments for paid services and the opportunity costs of providing unpaid care, putting households below, or further below, the poverty line.	N/A
Indicator or performance measure	Methods or instruments to estimate or monitor the extent to which the actions of an individual practitioner or whole programme conform to practice standards of quality or allow comparisons between services.	WHO Glossary of Terms for Community HC and Services for Older Persons 2004
Informal care worker	Paid care workers who have not received formal training in care delivery and are do not have a formal contract of employment.	N/A
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.	GDO Reference Guide, 2018
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.	GDO Reference Guide, 2018

TERM	DEFINITION	REFERENCE
Integrated health services	Integrated health services are managed and delivered in a way that ensures people receive a continuum of services including health promotion, disease prevention, diagnosis, treatment, disease management, rehabilitation and palliative care at different levels and sites within the health system, and that care is provided according to their needs throughout their life course	WHO 2015 Report on Ageing and Health
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.	GDO Reference Guide, 2018
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[14] 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.	GDO Reference Guide, 2018
Legislation	A law or set of laws, which have been enacted by the governing bodies in a country. For the purposes 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.	GDO Reference Guide, 2018
Long-term care (LTC)	The activities undertaken by others to ensure that people with or at risk of a significant ongoing loss of intrinsic capacity can maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity.	WHO 2015 Report on Ageing and Health

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

TERM	DEFINITION	REFERENCE
LTC systems	Long-term care systems are national systems that ensure integrated long-term care that is appropriate, affordable, accessible and upholds the rights of older people and caregivers alike. Depending on the national context, funding and care may be provided by some combination of families, civil society, the private sector and/ or the public sector.	WHO Series LTC, Sub-Saharan Africa 2017
LTC benefit	Any benefit in-kind (goods, commodities or services), cash or a combination of both for persons who, over an extended period of time, on account of care dependence, require considerable assistance from another person or persons to carry out essential daily activities, including to support their personal autonomy. This includes benefits granted to or for the person providing such assistance.	OECD 2011 Help Wanted Report
LTC recipient (or care recipient)	People receiving long-term care in institutions or at home, including recipients of cash benefits.	OECD 2011 Help Wanted Report
LTC workforce	Individuals who provide care to long-term care recipients.	OECD 2011 Help Wanted Report
Multisectoral	Involving agencies and organizations from the different sectors of society including governments, nongovernment organizations, private for-profit sector, and civil society.	GDO Reference Guide, 2018
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.	GDO Reference Guide, 2018
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.	GDO Reference Guide, 2018
Nurse	A health professional having completed formal training in nursing at a recognized, university-level school for a diploma or degree in nursing.	GDO Reference Guide, 2018

TERM	DEFINITION	REFERENCE
Nursing care	Nursing encompasses autonomous and collaborative care of individuals of all ages, families, groups and communities, sick or well and in all settings. Nursing includes the promotion of health, prevention of illness, and the care of ill, disabled and dying people. Advocacy, promotion of a safe environment, research, participation in shaping health policy and in patient and health systems management, and education are also key nursing roles.	International Council of Nurses (www.icn.ch/who-we-are/icn-definition-of-nursing)
Opportunity costs	The concept of opportunity cost is commonly used in economics; it is measured by reference to the opportunities foregone at the time an asset or resource is used, as distinct from the costs incurred at some time in the past to acquire the asset, or the payments which could be realised by an alternative use of a resource (e.g., the use of labour in a voluntary capacity being valued at the wages which could have been earned in a paid job.	OECD Glossary of Statistical Terms (https://goo.gl/BcNVRw)
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.	GDO Reference Guide, 2018
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.	GDO Reference Guide, 2018
Out-of-pocket (OOP) payment	Direct payment made to long-term care providers by individuals (or their families) at the time-of-service use, i.e., excluding prepayment for long-term care services – for example in the form of taxes or specific insurance premiums or contributions – and, where possible, net of any reimbursements to the individual who made the payment.	N/A
Out-of-pocket (OOP) payment	Payments for goods or services that include (i) direct payments, such as payments for goods or services that are not covered by any form of insurance; (ii) cost sharing – that is a provision of health insurance or third-party payment that requires the individual who is covered to pay part of the cost of the health care received; and (iii) informal payments, such as unofficial payments for goods and services, that should be fully funded from pooled revenue.	WHO 2015 Report on Ageing and Health

TERM	DEFINITION	REFERENCE
Out-of-pocket (OOP) payment	A fee paid by the consumer of health services directly to the provider at the time of delivery.	WHO Glossary of Terms for Community HC and Services for Older Persons 2004
	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;	GDO Reference Guide, 2018
Palliative care/End-of-life care (continued)	• will enhance quality of life, and may also positively influence the course of illness; It 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.	
Paid versus unpaid care	Caregivers can be grouped into two broad categories: those who are paid for their work and those who are not. Paid caregivers may include professionals and paraprofessionals or family members who receive compensation for the long-term care services they provide to relatives.	WHO Series LTC, Sub-Saharan Africa 2017

TERM	DEFINITION	REFERENCE
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.	GDO Reference Guide, 2018
People-centred care	An approach to care that consciously adopts individuals', carers', families' and communities' perspectives as participants in, and beneficiaries of, trusted health systems that respond to their needs and preferences in humane and holistic ways. People-centred care also requires that people have the education and support they need to make decisions and participate in their own care. It is organized around the health needs and expectations of people rather than diseases.	N/A
Personal Care	Support with activities of daily living, including bathing, dressing, eating, getting in and out of bed or chair, moving around and using the bathroom.	Adapted from OECD 2011 Help Wanted Report
Person-centred care	Care approaches and practices that see the person as a whole with many levels of needs and goals, with these needs coming from their own personal social determinants of health.	N/A
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.	GDO Reference Guide, 2018

TERM	DEFINITION	REFERENCE
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.	GDO Reference Guide, 2018
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; data reported in household survey data.	GDO Reference Guide, 2018
Pharmaceutical personnel	Includes pharmacists, pharmaceutical assistants, pharmaceutical technicians and related occupations. They perform a variety of tasks associated with dispensing medicinal products.	GDO Reference Guide, 2018
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.	GDO Reference Guide, 2018

TERM	DEFINITION	REFERENCE
Plan/action plan	A dementia plan details the strategies and activities to 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.	GDO Reference Guide, 2018
Primary care	Term 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.	GDO Reference Guide, 2018
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.	GDO Reference Guide, 2018

TERM	DEFINITION	REFERENCE
Private LTC insurance	Distinguished from public coverage programmes by their funding through voluntary non-income related premia, as opposed to taxes or compulsory social security payroll contributions. Typically, private insurers promote and sell the products on the market.	OECD 2011 Help Wanted Report
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.	GDO Reference Guide, 2018
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.	GDO Reference Guide, 2018
Psychosocial interventions	Interventions that address the ongoing psychological and social needs of people with dementia, their carers, partners, and families. The scope of interventions can include: psychoeducation (asking people assessed with dementia whether they wish to know the diagnosis and with whom it should be shared), managing behavioural and psychological symptoms (identify potential triggers, considering environmental adaptation, encouraging 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	GDO Reference Guide, 2018
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.	GDO Reference Guide, 2018

TERM	DEFINITION	REFERENCE
Quality of care	A health system that makes improvements in six areas: 1. Effective – delivering health care that is adherent to an evidence base and results in improved health outcomes for individuals and communities, based on need; 2. Efficient – delivering health care in a manner which maximizes resource use and avoids waste; 3. Accessible - delivering health care that is timely, geographically reasonable, and provided in a setting where skills and resources are appropriate to medical need; 4. Acceptable/patient-centred – delivering health care which takes into account the preferences and aspirations of individual service users and the cultures of their communities; 5. Equitable – delivering health care which does not vary in quality because of personal characteristics such as gender, race, ethnicity, geographical location, or socioeconomic status; 6. Safe – delivering health care. which minimizes risks and harm to service users.	GDO Reference Guide, 2018
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.	GDO Reference Guide, 2018
Reimbursement	1. The process by which health care providers receive payment for their services. Because of the nature of the health care environment, providers are often reimbursed by third parties who insure and represent patients/clients. 2. The process whereby patients/clients receive payment for services used, most often through health insurance.	WHO Glossary of Terms for Community HC and Services for Older Persons 2004
Reimbursement policy	Provides for a reimbursement, in whole or part, of eligible LTC expenses incurred.	GDO Reference Guide, 2018

TERM	DEFINITION	REFERENCE
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).	GDO Reference Guide, 2018
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.	GDO Reference Guide, 2018
Responsive referral protocols and pathways	Outline clear indications for referrals and responsibilities of each healthcare professional and department involved.	GDO Reference Guide, 2018
Restraints (mechanical, physical or chemical)	The use of a mechanical device or medication to voluntarily prevent a person from moving his or her body.	GDO Reference Guide, 2018
Risk Pooling	The practice of bringing several risks together for insurance purposes in order to balance the consequences of the realization of each individual risk.	N/A
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.	GDO Reference Guide, 2018

TERM	DEFINITION	REFERENCE
Secondary care	Specialist care provided on an ambulatory or inpatient basis, usually following a referral from primary care.	GDO Reference Guide, 2018
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.	GDO Reference Guide, 2018
Social care	Assistance with activities of daily living (such as personal care, maintaining the home); synonym is home and community care.	GDO Reference Guide, 2018
Social insurance	Social insurance schemes are schemes in which social contributions are paid by employees or others, or by employers on behalf of their employees, in order to secure entitlement to social insurance benefits, in the current or subsequent periods, for the employees or other contributors, their dependants or survivors.	OECD Glossary of Statistical Terms
Social media	Web-based technologies to communicate between organizations, communities, and individuals. Common examples include Facebook and Twitter.	GDO Reference Guide, 2018
Social protection	Programmes to reduce deprivation that arises from conditions such as poverty, unemployment, old age and disability.	WHO 2015 Report on Ageing and Health
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.	GDO Reference Guide, 2018

TERM	DEFINITION	REFERENCE
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.	GDO Reference Guide, 2018
Stakeholder	Refers to an individual, group of individuals or an organization that has an interest in the organization and delivery of health care.	GDO Reference Guide, 2018
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.	GDO Reference Guide, 2018
Strategy	A long-term plan designed to achieve a particular goal.	GDO Reference Guide, 2018
Strategizing	Designing plans and policies to achieve a particular goal	WHO Strategizing National Health in the 21st Century: a Handbook
Subnational	Refers to individual states, territories, provinces, or regions within a country.	GDO Reference Guide, 2018
Supported decision making	A model supported by the UN Convention on the Rights of Persons with Disabilities,[15] 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.	GDO Reference Guide, 2018

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

TERM	DEFINITION	REFERENCE
Sustainable development	A process of development that meets the needs of the present generation without compromising the ability of future generations to meet their own needs.	WHO Glossary of Terms for Community HC and Services for Older Persons 2004
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.	GDO Reference Guide, 2018
Taxes	Taxes are compulsory, unrequited payments, in cash or in kind, made by institutional units to government units. They are described as unrequited because the government provides nothing in return to the individual unit making the payment, although governments may use the funds raised in taxes to provide goods or services to other units, either individually or collectively, or to the community as a whole.	OECD Glossary of Statistical Terms
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.	GDO Reference Guide, 2018
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.	GDO Reference Guide, 2018
Unit or department (national dementia)	A unit or department with responsibility for dementia in a Ministry of Health (or equivalent) or national institute.	GDO Reference Guide, 2018

TERM	DEFINITION	REFERENCE
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: www.who.int/mediacentre/factsheets/fs395/en	GDO Reference Guide, 2018
Universal long-term care coverage	All people receiving the care services they need and of sufficient quality to be effective while at the same time ensuring that the use of these services does not expose the user, or their household, to financial hardship.	N/A
Unpaid/family carer	Family members and others (usually friends or neighbours) who provide care without receiving payment.	N/A