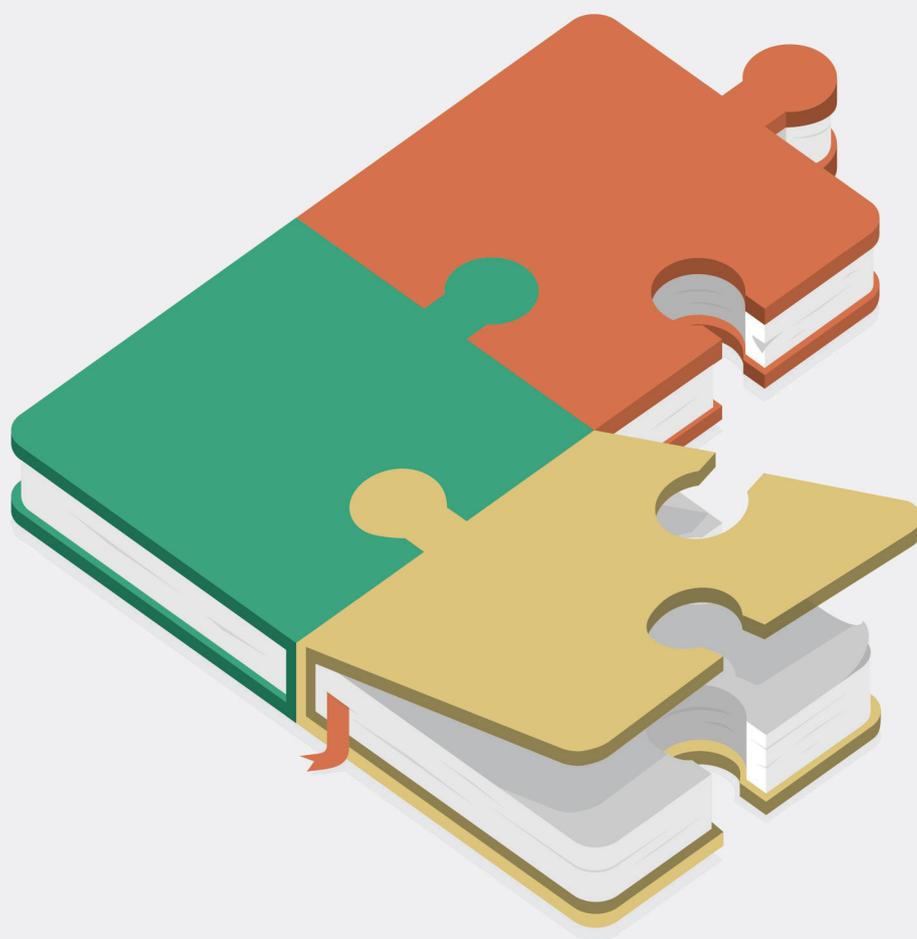


Towards a dementia plan: a WHO guide



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Abbreviations

DALY	disability-adjusted life year
CRPD	Convention on the Rights of Persons with Disabilities (United Nations)
GDO	Global Dementia Observatory
HIS	health information system
ICD	International Classification of Diseases
LMICs	low- and middle-income countries
M&E	monitoring and evaluation
NaFAD	National Framework for Action on Dementia 2015–2019 (Australia)
NCDs	noncommunicable diseases
NGO	nongovernmental organization
PD	Parkinson's disease
PHC	primary health care
SDG	Sustainable Development Goal
UHC	universal health coverage
UN	United Nations
WHO	World Health Organization
YLD	years lived with disability
YLL	years of life lost

Executive summary

Fifty million people worldwide currently live with dementia, a condition that causes significant psychological burden as well as social and financial distress to those living with it, their carers and families. A comprehensive, multisectoral public policy response aimed at addressing the needs of people with dementia, their carers and families is needed to improve quality of life, enhance equitable access to services and reduce stigma and social isolation. This guide assists WHO Member States in formulating this response, through a multi-phased, stepwise approach.

The guide is divided into five sections. Section 1 provides an overview of global trends in dementia, including projected prevalence and costs, as well as the international community's response to date. Section 2 defines the term "dementia plan", including what is meant by stand-alone versus integrated dementia plans, and highlights the rationale for developing a policy response to dementia. Section 3 summarizes the guide's purpose, approach and primary target audience. Section 4 outlines the importance of political leadership, governance and multisectoral collaboration as well as stakeholder engagement. These elements are considered cross-cutting across all phases and steps involved in developing and implementing a dementia plan. Section 5 presents the essential steps of creating a dementia plan, organized into three phases:

- Phase A: preparing for the dementia plan;
- Phase B: developing the dementia plan; and
- Phase C: implementing the dementia plan.

Each of the three phases is divided into a series of steps that include practical tips and lessons learned both from the literature and country experiences.

Phase A is composed of two steps: carrying out a situational analysis; and identifying priorities. A situational analysis represents a crucial first step to determining the needs and health status of people with dementia, their carers and families, key stakeholders, as well as gaps and opportunities in service delivery, existing resources and policies. Grounded in the situational analysis, priority setting is critical to identifying which issues take precedence over others based on evidence-based criteria and broad, multisectoral stakeholder engagement.

Phase B builds on the evidence gathered in Phase A to define the scope of the dementia plan. It organizes identified priorities into a cohesive, strategic framework to guide the development of the dementia plan. Phase B includes a series of three steps: developing a strategic framework for the dementia plan; determining resource implications; and obtaining stakeholder and political approval. It is necessary to identify what the dementia plan can and cannot achieve, based on each country's distinct political, cultural and socioeconomic context. The strategic framework highlights the rationale for the dementia plan and identifies its overall strategic direction. Both stakeholder and political approval are essential to ensuring government leadership, stakeholder ownership and accountability in transitioning from planning to implementation.

Grounded in the objectives, action areas and resources identified in Phase B, Phase C provides the foundation for operationalizing the dementia plan. Phase C involves three steps: developing an operational work plan; allocating the budget; and monitoring and evaluating (M&E). A concrete operational work plan links strategic priorities and objectives to dementia interventions, delineates resources required and highlights stakeholders' roles and responsibilities across sectors. Budget allocation involves costing resources across sectors, by comparing required resources with earmarked funding for dementia. Monitoring and evaluation is essential to determining the impact of the plan on people with dementia, their carers and families, and ensuring that it is implemented as intended.

The guide closes with concluding remarks, a glossary of terms and a series of tools and aids in the annexes. Developing and implementing a comprehensive, multisectoral dementia plan that effectively addresses the needs of people with dementia requires leveraging the capacity of various sectors and multiple stakeholders. A successful dementia plan will closely involve stakeholders throughout all phases of the process, particularly people with dementia, their carers and families.

1. Introduction

Global trends in dementia

Dementia describes a syndrome of cognitive impairment that affects memory, cognitive abilities and behaviour, and significantly interferes with a person's ability to perform daily activities. Alzheimer's disease is the most common form of dementia, accounting for approximately 60–70% of cases (1). While age is the strongest known risk factor, dementia does not exclusively affect older people and is not an inevitable consequence of ageing (1). The most commonly recognized risk factors are mid-life hypertension, low educational attainment, diabetes mellitus and tobacco use (1,2). Other risk factors include physical inactivity, obesity, unbalanced diets, and harmful use of alcohol as well as mid-life depression, social isolation and cognitive inactivity (1,2).

Almost 9.9 million people develop dementia each year, the majority (63%) of whom reside in low- and middle-income countries (LMICs) (2,3). Dementia currently affects approximately 50 million people worldwide; a number that is projected to grow to 82 million by 2030 and 152 million by 2050 (3,4). It is the second largest cause of disability for individuals aged 70 years and older, and the seventh leading cause of death (4,5). Dementia imposes an estimated economic cost of approximately US\$ 818 billion per year globally – or 1.1% of global gross domestic product (3,4). Left unaddressed, dementia could represent a significant barrier to social and economic development (6).

Improvements in population health responses have the potential to reduce the number of new cases by 10–20% (2). People with dementia have complex needs spanning the health and social sector, which require coordinated psychological, social and biomedical support. For example, housing adjustments may need to be developed to assist people with dementia with activities of daily living. They will also require specialized transportation as well as integrated care from diagnosis to the end of life. Yet, many of these needs remain unaddressed, as more than half of all people with dementia are undiagnosed and one third are discharged from hospitals with reduced functional capacity (7). Additionally, carers are 20% more likely to experience mental health issues (7).

In many countries, these issues are exacerbated by an ongoing lack of awareness and understanding surrounding dementia. The absence of legal frameworks protecting the rights of people with dementia also poses a significant challenge in ensuring equitable access to services and acceptance in society. Together, these gaps lead to stigmatization, loss of decision-making power and barriers to diagnosis and care. People with dementia, their carers and families also experience significant physical, psychosocial and financial hardship.

Global response to dementia

In May 2017, the global action plan on the public health response to dementia 2017–2025¹ was adopted by the Seventieth World Health Assembly in Geneva, Switzerland. The endorsement of the global dementia action plan represents an international commitment to improving the lives of people with dementia, their carers and families. It has close conceptual and strategic ties to other global dementia action plan adopted by the World Health Assembly, sharing a focus on multisectoral collaboration, equity, human rights, empowerment, prevention, and service integration across the care continuum. The global dementia action plan also aligns with the Shanghai Declaration on Promoting Health in the 2030 Agenda for Sustainable Development, Sustainable Development Goal 3 (good health and well-being) and the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD), applicable to people with dementia.

The global dementia action plan identifies seven action areas (see Figure 1.1):

- dementia as a public health priority
- dementia awareness and friendliness
- dementia risk reduction
- dementia diagnosis, treatment, care and support
- support for dementia carers
- information systems for dementia
- dementia research and innovation.

The first action area (dementia as a public health priority) is the focus of this guide and highlights the need for a whole-of-government, multisectoral and multistakeholder public health response to dementia, developed in close collaboration with people with dementia, their carers and other relevant stakeholders and partners.

1. Hereafter referred to as the "global dementia action plan."

Figure 1.1. The seven action areas and targets of the global dementia action plan

Dementia as a public health priority



By 2025, **75%** of countries have national policies, strategies, plans or frameworks for dementia

Dementia awareness and friendliness



By 2025, **100%** of countries have a functioning public-awareness campaign on dementia
By 2025, **50%** of countries have at least one dementia-friendly initiative

Dementia risk reduction



Risk reduction targets identified in the global action plan for prevention and control of noncommunicable diseases 2013–2020 are achieved¹

Dementia diagnosis, treatment and care



By 2025, **50%** of people with dementia are diagnosed, in at least 50% of countries

Support for dementia carers



By 2025, **75%** of countries provide support and training for carers and families

Information systems for dementia



By 2025, **50%** of countries routinely collect data on core dementia indicators

Dementia research and innovation



Global research output on dementia doubles between 2017 and 2025

1. Available at: <http://www.who.int/nmh/publications/ncd-action-plan/en/>

2. The need for a dementia plan

Dementia is a debilitating condition for which there is currently no cure. Research investments remain relatively low compared to other diseases of similar importance, such as cancer or cardiovascular disease, impeding the identification of preventive and disease-modifying treatments (8). It is therefore crucial to focus on what can be done to improve the lives of people with dementia, their carers and families.

People with dementia have complex needs that are multisectoral in nature. Recognizing and addressing these needs requires coordinated efforts across all levels of government – local, regional and national – and public sectors. Creating a dementia plan is an opportunity to collaborate closely with relevant stakeholders, most importantly those living with dementia, their carers and families. Formulating a dementia plan not only signals political commitment to identifying and addressing dementia as a public health priority, but also provides the opportunity to identify system inefficiencies, rationalize service delivery and optimize the use of available resources (8,9).

Definition of a dementia plan

A **dementia plan** recognizes the value of older people and those with dementia in society (10,11). It also asserts the need for policy change aimed at enhancing prevention, treatment and care for people with dementia and their carers through better integration of health and social sectors (i.e. long-term care).¹ A dementia plan is a written document that provides the basis for action to be jointly taken by government and nongovernmental partners (9,10).

A comprehensive dementia plan identifies a vision for the future and a strategic framework, which highlight a common set of principles and objectives that guide action. It defines and prioritizes action areas, identifies coordination responsibilities and mechanisms, and delineates targets to direct resources towards achieving objectives and measuring impact (12). Together, the main components of a dementia plan act to raise public awareness and create mutual understanding about dementia, address population needs, reduce the burden of dementia, and protect the human rights of people with dementia, their carers and families (9,13).

Stand-alone versus integrated plans

A **stand-alone dementia plan** refers to a document that is mainly focused on addressing dementia. It can be beneficial in emphasizing dementia as a key governmental priority and securing dedicated dementia resources. Careful attention should be given to aligning the dementia plan with existing mental health policies, care coordination models, programmes and services to avoid fragmentation.

1. It should be noted that different terminologies exist to denote long-term care. For the purpose of this document, long-term care refers to the necessary integration of health and social sectors in providing comprehensive prevention, treatment and care to people with dementia, as well as their carers and families throughout the course of the disease. A more comprehensive definition of long-term care can be found in the glossary.

Rather than developing a stand-alone dementia plan, some countries **integrate dementia**, i.e. include dementia as a priority, into existing national/subnational plans or legislation that address related issues such as mental health, ageing, disability or noncommunicable diseases (NCD) (see Box 1). Integrating dementia into existing plans raises political awareness surrounding dementia by aligning it to current priorities, even if dementia does not constitute a distinct national/subnational priority (9). It can also allow for a more harmonized response across the health sector and prove effective in pooling and allocating limited resources. However, the potential for fragmentation and lack of dedicated resources being allocated to dementia should be considered (9).

Other countries choose to develop a stand-alone dementia plan as well as incorporate dementia into existing plans to maximize the potential for a comprehensive, multisectoral response (see Box 1, Australia, Chile and Switzerland). It is also possible to embed dementia priorities into **non-health sector plans**, such as workplace education, poverty reduction or community safety. Finally, dementia may be streamlined into international development plans aimed at addressing global priorities, e.g. the 2030 Sustainable Development Agenda and SDGs, universal health coverage (UHC), WHO's global action plan for the prevention and control of noncommunicable diseases, or upholding international commitments such as the CRPD or the Universal Declaration of Human Rights.

Prioritizing dementia in low-resource settings: lessons learned from Togo

Almost every household in Togo has an older family member presenting symptoms of dementia. Due to a lack of awareness, people with dementia are sometimes abused and even killed. A number of community-based groups have undertaken efforts to raise awareness related to dementia. To address these issues the Government of Togo created the Ministry of Ageing and is in the process of integrating dementia as a priority condition into the national NCD plan. Annual operational plans will be developed to specifically address dementia.

Integrating dementia into an existing plan represents a resource-efficient manner of addressing the issue given limited resources. A tobacco tax may mobilize additional resources to support the implementation of the NCD plan. The government is also considering the creation of a stand-alone dementia plan to ensure dementia is prioritized. Champions are currently being identified and include opinion leaders in the areas of communication, education, policy, health care as well as traditional healers and community leaders. Champions will be invited to collaborate when identifying priorities for dementia and developing the plan.

Box 1. Integrating dementia into existing plans: country examples

SWITZERLAND*

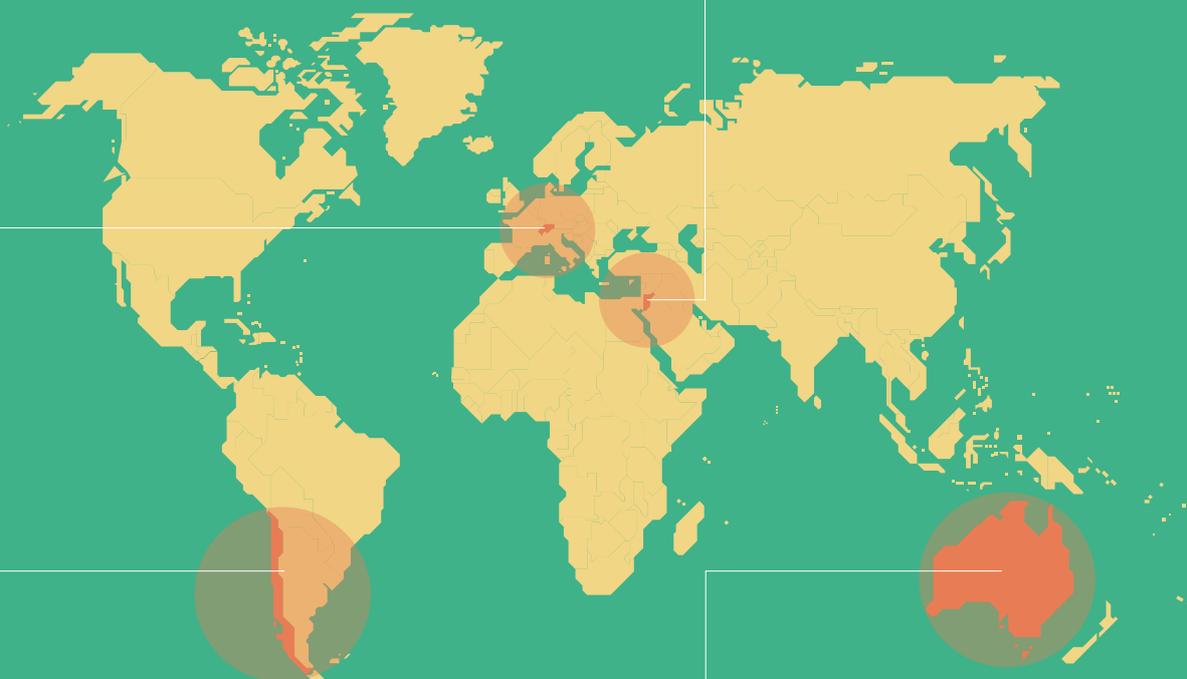
Stratégie nationale Prévention des maladies non transmissibles (stratégie MNT) 2017–2024

Mentions dementia within the context of NCD costs.

JORDAN

National Mental Health and Substance Use Action Plan 2018–2021

Lists dementia as a priority condition.



CHILE*

Plan Nacional de Salud Mental (2000)

Highlights the target population, relevant facilities and infrastructure, regulations, types of health care access, prevalence, estimated annual demand for services, relevant activities and objectives for dementia in both primary care and specialized settings.

Delineates the importance of mental health and psychiatry care networks, person-centred care, cooperation between health and social care sectors, the participation of people with dementia and their families in care, and lists activities required for each level of care.

AUSTRALIA*

The guide: accessible mental health services for people with an intellectual disability (2014)

Refers to dementia within the context of intellectual disability and mental health, and the need for personalized support.

*Identifies countries that both have a stand-alone dementia plan and have incorporated dementia into other existing plans.

3. Overview of the guide

For the purpose of this guide, the terms dementia policy, strategy, plan or framework are considered equivalent and interchangeable, and are referred to as the "dementia plan". The term dementia plan was selected for its operational focus and encompasses both national and subnational strategies, unless otherwise indicated.

Purpose and approach

Towards a dementia plan: a WHO guide provides technical guidance to Member States in creating and operationalizing a dementia plan. This might involve developing a new, stand-alone dementia plan, strengthening an existing dementia plan, or integrating dementia into existing dementia-related plans.

The guide organizes the process of creating a dementia plan into three phases: preparing, developing and implementing the plan. The first phase focuses on the steps involved in gathering evidence and setting priorities. The second phase guides countries in creating a strategic framework, assessing resource needs and obtaining political and stakeholder approval. Finally, the third phase outlines the steps involved in implementing and evaluating the dementia plan.

Each of the three phases includes a series of steps (see Figure 3.1), discussed in subsequent sections. In practice, there will likely be overlap between the steps both within and across phases, with some steps occurring simultaneously and others being skipped or returned to. The process of developing a dementia plan is both iterative and dynamic, with stakeholder engagement and multisectoral collaboration occurring throughout.

The guide is closely linked to WHO's Global Dementia Observatory (GDO) and includes associated aids such as a checklist to guide the preparation, development and implementation of the dementia plan as well as stakeholder mapping and priority setting tools (see Annexes 1–3). In an effort to avoid a one-size-fits-all approach, this guide seeks to strike a balance between generic recommendations and practical, how-to, advice, reflective of individual countries' unique epidemiological, socioeconomic and political situations.

Target audience

Government representatives working within ministries concerned with dementia or dementia-related issues, including ministries of health, social welfare, housing, education, labour, finance, etc. are the primary target audience. However, the guide may also be of interest to others, including:

- nongovernmental organizations (NGOs) working in the field of health, dementia, mental health, ageing, disability, NCD issues;
- academics involved in dementia research and in the development and/or evaluation of appropriate solutions;
- private sector representatives involved in the development of health technologies for dementia, dementia health care service delivery or health care insurance;
- international organizations supporting national efforts to prevent and reduce the impact of dementia, including funding agencies, bilateral donors and/or UN agencies;
- emergency service workers;
- people with dementia, their carers and families;
- traditional healers, community leaders and representatives of community-based organizations.

Figure 3.1. A multi-phased approach to developing a dementia plan



4. The dementia plan: cross-cutting elements

Leadership, governance and multisectoral collaboration

Three elements are central to formulating a comprehensive policy response to dementia: leadership, governance and multisectoral collaboration. **Leadership** refers to the guidance and direction provided by government in preparing for, developing and implementing the dementia plan. **Governance** involves the establishment of multisectoral coordinating mechanisms – whether formal or informal, aimed at overseeing the creation and operationalization of the dementia plan. **Multisectoral collaboration** includes the engagement of, and cooperation between, multiple sectors to ensure that the dementia plan is comprehensive in scope and appropriately resourced. Together, these components provide accountability, buy-in and ownership to the process.

Leadership and governance

Government holds a leadership role in coordinating and overseeing the dementia plan. It is helpful to identify a clear “lead” entity and assign roles and responsibilities early on, so as to avoid diffusion of responsibility and duplication of labour (9,13,19–21). The lead entity may be an existing unit or functional division, e.g. for mental health, NCDs, ageing, disability, or a newly established coordinating mechanism for dementia within a ministry (or equivalent body).

A **focal point, coordinating team or secretariat** should be identified to oversee and manage the development of the plan across sectors. The focal point/coordinating team may be located within the lead entity, or across the lead entity and one or more other ministries. The focal point/coordinating team will also be responsible for engaging key experts, partners and stakeholders identified through the situational analysis in Step A.1. Countries may choose to establish a multisectoral steering committee, management board or task force responsible for making decisions on key elements of the dementia plan. Similarly, working groups focused on addressing specific content issues, such as dementia risk reduction, information systems, etc. may be convened. To avoid a health-centric perspective, some countries choose to establish a national commission or council, typically convened by the ministry of health, representing multiple sectors (e.g. education, housing, justice, environment, social welfare).

Leadership and governance: lessons learned from Norway

A working group consisting of representatives of the Norwegian Directorate of Health, National Advisory Unit on Aging and Health, Health Association and Ministry of Health and Care Services led the planning and development of a dementia plan (Dementia Plan 2020) (22). The working group's mandate provided clear guidelines related to developing the dementia plan and the distribution of roles and responsibilities during planning, implementation and evaluation. The division of labour and responsibilities was agreed upon amongst

partners, which provided predictability during the process. Academic and civil society representatives, user organizations, health care professionals as well as local and regional health authorities were invited to form the process and contribute at all stages.

The most significant challenge was the limited timeframe available to prepare the Dementia Plan 2020. Strong political leadership from the Ministry of Health and Care Services was crucial in overcoming this barrier. The ability to leverage working group members' local networks, especially to involve people with dementia, their carers and families as well as the academic community, proved to be another important success factor. Furthermore, working group members' broad and diverse expertise was crucial to shaping the strategic framework, consultation materials and the plan itself. Broad stakeholder involvement created a sense of ownership, enhanced commitment to the development and implementation of the plan and allowed for the identification of a clear, common goal for the Dementia Plan 2020.

Strong emphasis was placed on involving people with dementia, their carers and families throughout the process. In addition to dialogue meetings, a short version of the public consultation paper and the final dementia plan (easy access) were accessible to people with dementia and cognitive impairments.

Multisectoral collaboration

Multisectoral collaboration requires effectively engaging diverse public sectors, partners and levels of government, to facilitate communication and clearly delineate partners' roles and responsibilities (see Box 2) (20,23,24). Within the context of dementia, the focal point/coordinating team will play a key role in cultivating, coordinating and sustaining relationships across organizations and sectors (25). Multisectoral collaboration can help identify areas of overlap between sectors. It is particularly important that government minimizes duplication of labour, maximizes harmonization and resources between sectors and stakeholders, and adopts an equity-based and human rights-oriented lens to dementia policy-making (23,26).

Multisectoral collaboration can be formal, e.g. mobilizing resources for developing a dementia plan, or informal, such as exchanging information. It may take many forms, including coordinating meetings, working groups or integrated teams (23). For example, England's Living Well with Dementia (2009) plan was developed as a partnership between the National Health Service, local authorities and key stakeholders (10). Similarly, the Netherlands' Integrated Dementia Care (Ketenzorg Dementie, 2008–2010) plan involved dementia organizations such as Alzheimer Nederland, health and social care insurers and providers, as well as local government to improve dementia care (10).

Multisectoral collaboration can go beyond the evident inter-linkages between the health and broader social sector to include physical or regulatory ministries (e.g. environment, transport, infrastructure, housing). These partners can help improve the environment and living conditions of people with dementia, their carers and families (e.g. dementia-friendly communities). As an example, Japan's Ministry of Health, Labour and Welfare formulated the New Orange Plan (2015) to accelerate dementia measures in collaboration with 11 ministries and agencies,¹ including national financial services agencies and the Ministry of Land, Infrastructure, Transport and Tourism (27).

1. Ministry of Education, Culture, Sports, Science and Technology; Ministry of Agriculture, Forestry and Fisheries; Ministry of Economy, Trade and Industry; and Ministry of Land, Infrastructure, Transport and Tourism.

Stakeholder engagement

Developing and implementing a dementia plan does not only imply working across government sectors. It also necessitates meaningful collaboration with numerous stakeholders throughout the process. Stakeholder engagement is crucial to ensuring the dementia plan is **relevant to stakeholders' needs**, in particular, people with dementia, their carers and families. It is also an important factor in ensuring **stakeholder ownership**, which will be key when transitioning from development to implementation.

A **wide array of stakeholders** both within and beyond government should be engaged. These will include people with dementia, their carers and families, government ministries and agencies, civil society representatives, research and academic institutions as well as health and social care providers. Stakeholders may also include international organizations, private sector actors, traditional healers and community and religious leaders.

Based on available resources, stakeholder engagement may be formal or informal. For example, external advisory committees and working groups may be established as mechanisms to collaborate with experts and **people with dementia, their carers and families**. Alternatively, public consultations, focus groups or interviews may be held to obtain stakeholder feedback. Ideally, information circulated to stakeholders will be done in advance by sharing key messages in easy read formats, accessible to people with dementia. A situational analysis (see Step A.1) will help identify key stakeholders, their roles, interests and influence on the dementia plan process.

Stakeholder ownership: lessons learned from a person with dementia

People with dementia, their carers and families first became involved in the development of the Dementia Action Plan for Wales 2018–2022 when they attended a public consultation session (28). They swiftly realized the lack of public engagement, particularly with respect to people with dementia, their carers and families.

Following a discussion with the Welsh Government regarding the rights of people with dementia and the importance of involving them in policy-making processes, it was decided that additional public consultations were needed. The Welsh Government provided additional funding to hold a series of public dialogues and expert meetings across Wales. These aimed to meaningfully engage people with dementia, their carers and families as well as health and social care providers in developing the Welsh Dementia Action Plan.

People with dementia, their carers and families were engaged as key experts on dementia task groups within the Welsh Government. They also provided expertise to the Welsh Government's Cross-Party Group on Dementia, the Health, Social Care and Sport committee, and the Older Persons Commissioner. As a result, two phases of wider public consultations were held across Wales, where over 400 people with dementia, their carers and families provided input into the Welsh Dementia Action Plan.

Throughout the process, the Welsh Government listened, included and supported all the voices of stakeholders affected by dementia. Stakeholders included civil society and government representatives, health and social care providers, academics and people with dementia, their carers and families.

Through meaningful collaboration, people with dementia, their carers and families were able to make significant contributions and instigate important changes to the Welsh Dementia Action Plan. The biggest challenge related to altering assumptions concerning the experience of living with dementia and the capacity of people with dementia to effectively contribute to policy-making processes.

Meaningful stakeholder collaboration provided the opportunity to share knowledge and best practices as well as influence political decision-makers. This ultimately affected the nature of the Welsh Dementia Action Plan and the lives of people with dementia, their carers and families. The Welsh Government continues to engage people with dementia, their carers and families through an advisory group overseeing the dementia plan's operationalization.

Box 2. Examples of non-health sector roles

EDUCATION

- Dementia promotion and prevention in schools and universities, including education about dementia, its risk factors and available services and support.

FINANCE

- Funding for the implementation of a dementia plan, or dementia-related activities, including the operationalization of dementia programmes, interventions and services.

HOUSING

- Supportive housing for people with dementia.

INFRASTRUCTURE, ENVIRONMENT AND/OR MUNICIPAL AFFAIRS

- Creation of dementia- and age-friendly cities and communities.
- Improvement of social and built environments.

INTERNAL AFFAIRS

- Inclusion of people with dementia, their carers and families in civic, religious and cultural activities.

INTERNATIONAL DEVELOPMENT/AFFAIRS

- Alignment with national and international frameworks and strategies (e.g. poverty reduction, SDGs).
- Financial and operational coordination with the donor community.

JUSTICE

- Mechanisms to protect the human and civic rights and freedoms of people with dementia, their carers and families.
- Treatment and rehabilitation of people with dementia in prisons.
- Diversion of people with dementia from the judicial system.

LABOUR

- Dementia promotion and prevention in the workplace, including education about dementia, its risk factors, the impact of caring for someone with dementia, and support for carers.
- Employment insurance and anti-discriminatory policies in the workplace.

PUBLIC SAFETY

- Dementia risk reduction.
- Education about dementia, its risk factors and services for emergency service responders.

- Emergency dementia care in coordination with the health sector.

SCIENCE/RESEARCH/INNOVATION

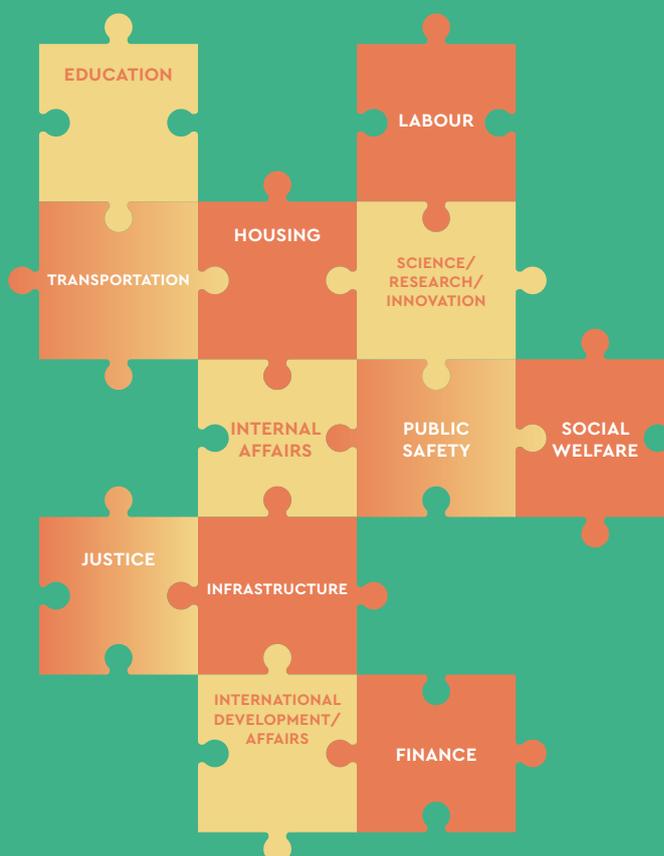
- Funding for, and regulation of, dementia research and technologies.

SOCIAL WELFARE

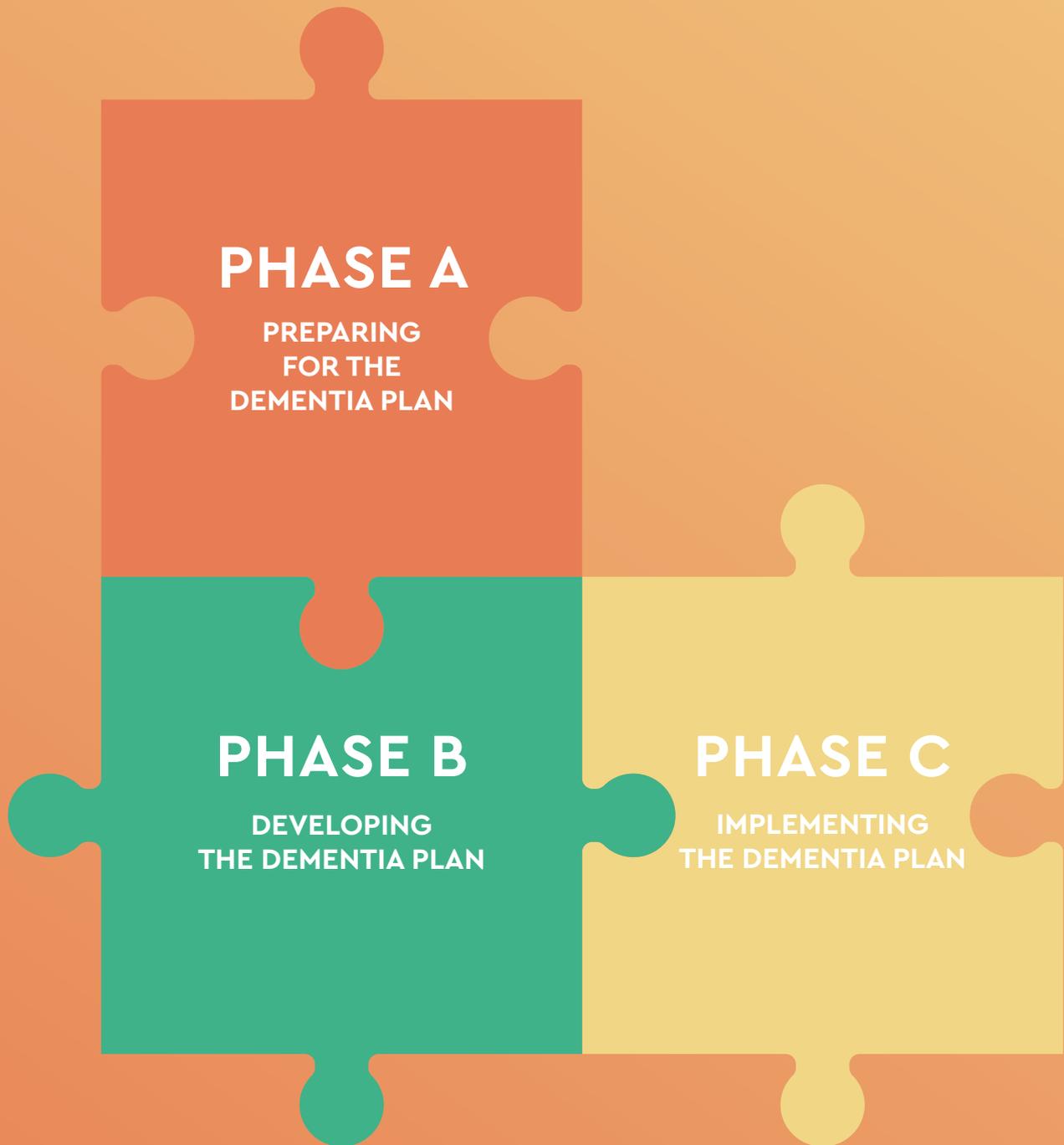
- Collective health and social insurance for people with dementia, their carers and families.
- Social benefits for people with dementia (e.g. disability benefits, household help, food services), their carers and families (e.g. social/employment insurance).
- Provision of social care and community-based social care networks.

TRANSPORTATION

- Dementia-friendly transportation systems.
- Improved transportation access to/from health and/or social care points.
- Transportation for food services.



5. The dementia plan: essential steps

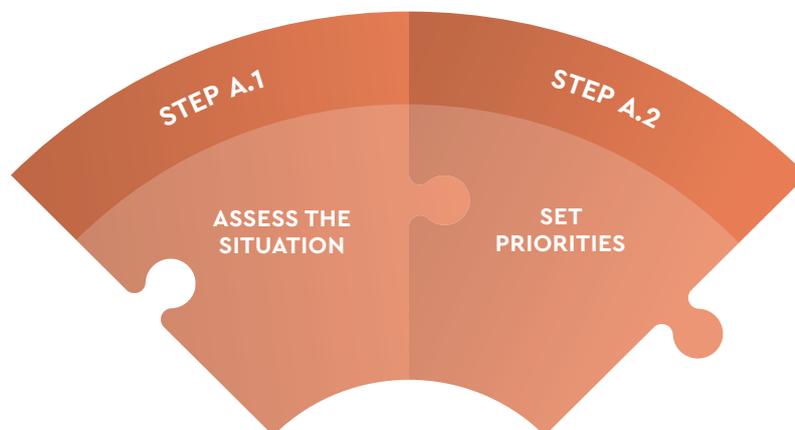


Phase A: preparing for the dementia plan



Once appropriate government leadership is established, initiating the planning process typically involves two steps: assessing needs through a situational analysis and setting priorities based on collected data (see Figure 5.1).

Figure 5.1. Steps involved in preparing for the dementia plan

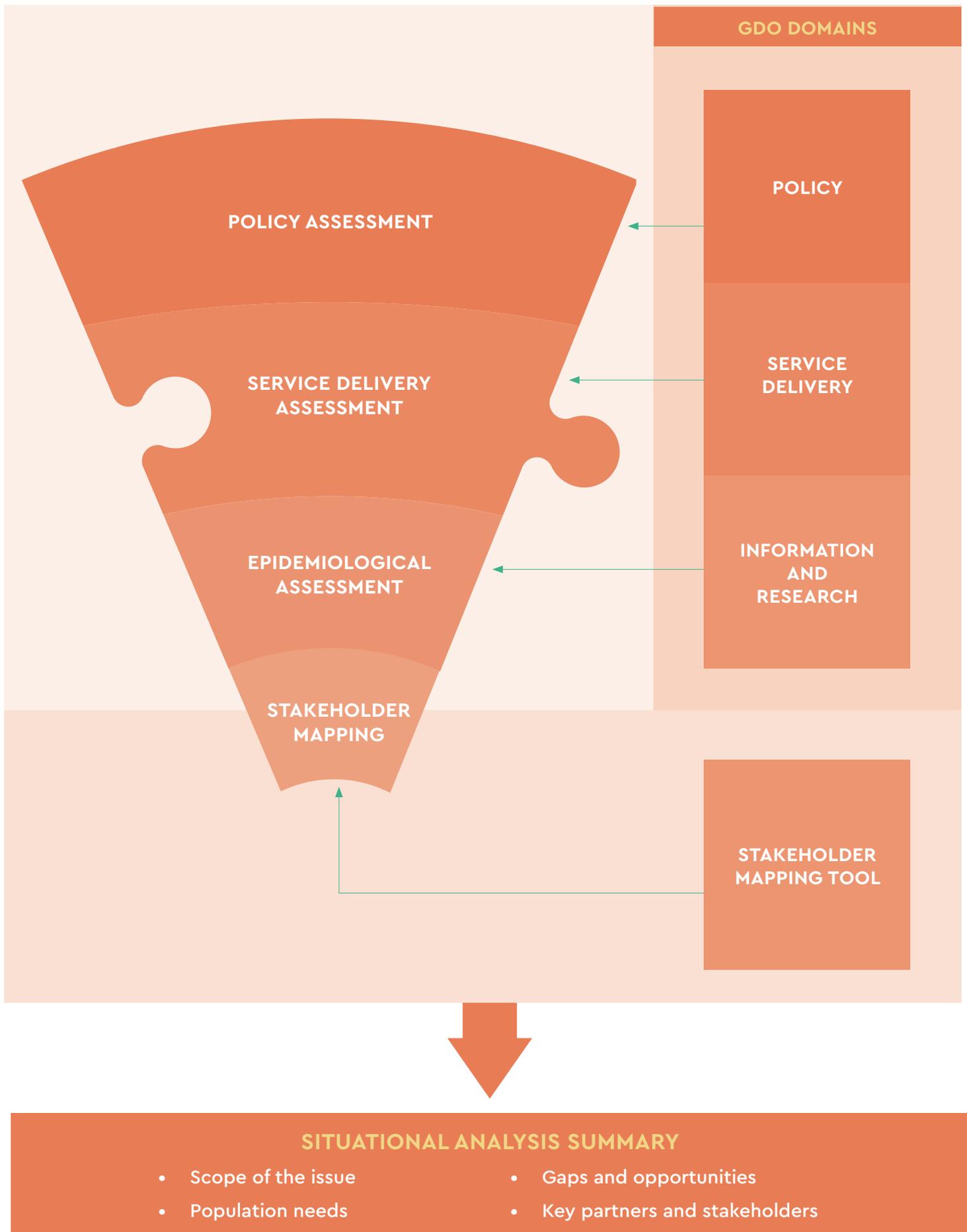


Step A.1: assess the situation

A situational analysis involves gathering and analysing information and data related to dementia to determine the scope of the issue, population needs, and key partners. It can also highlight gaps and opportunities in system capacity, the policy environment as well as existing data. Given the multisectoral scope of dementia, data will need to be gathered across multiple sectors and from various stakeholders.

The situational analysis is divided into four components: policy, service delivery, epidemiological and stakeholder assessments (see Figure 5.2). Data collected for the GDO can help gather the information required as part of the first three assessments (see Annex 4 for a list of relevant GDO domains and indicators). The stakeholder mapping tool included in Annex 2 can be used to identify relevant stakeholders, their interests and level of influence.

Figure 5.2. Situational analysis overview



Policy assessment

Beginning with a review of existing policies/legislation in the health and social sectors, the assessment can:

- highlight potential **synergies with existing policies** or legislation;
- help prioritize **which sectors and ministries** may be involved in the development and implementation of the dementia plan;
- analyse how existing legislation and/or policies may exacerbate or reduce **inequities in access to care**, e.g. socioeconomic, geographic, educational and age-related, as well as gender-based inequities (26,29).

Box 3 outlines how key elements of the policy assessment align with data collected as part of the GDO (30).

Box 3. Policy assessment: key elements and corresponding GDO indicators

- | | |
|--|------------------|
| • National ministries with portfolios focused on dementia, mental health, ageing, NCDs and/or disability | Indicator 1 |
| • Existing national and/or subnational legislation, policies, strategies, plans (including financial), and/or frameworks for dementia, mental health, ageing, NCDs and/or disability | Indicators 2–3 |
| • Existing legal provisions related to the protection of the rights of people with dementia, older people, people with cognitive impairment, mental disorders, disabilities and/or impaired mental capacity | Indicator 3 |
| • Existing national/subnational legislation pertaining to advance care directives, non-discrimination of people with dementia and/or family carers | Indicator 3 |
| • Existing government-approved, evidence-based national/subnational guidelines, protocols and standards for dementia | Indicator 4 |
| • Existing national/subnational legislation, policies, strategies, plans (including financial), frameworks, and/or models outlining coordinated planning and resourcing of continuing care for people with dementia | Indicator 5 |
| • Existing national/subnational policies, strategies, plans for, and/or investments in, dementia, mental health, ageing, NCDs and/or disability research | Indicators 17–18 |
| • Existing national/subnational legislation, policies, strategies, plans (including financial), and/or frameworks for dementia, mental health, ageing, NCDs and/or disability from other countries with similar socioeconomic, cultural, demographic and/or political contexts | N/A |

Service delivery assessment

Starting with a review of the **types of services** currently provided to people with dementia, their carers and families and how these services are organized (i.e. service pathways), the service delivery assessment will:

- identify whether resources are already being allocated to dementia services and, if so, by which sectors;
- determine current and projected **demand** for **service provision and resource gaps** as well as public perception of services;
- identify **opportunities to reduce inefficiencies**, harmonize dementia care services both within and beyond the health care sector and test new solutions;
- review how the **social determinants of health**, including socioeconomic status, age, gender, educational level and geographic location impact equitable access to programmes and services.

Box 4 outlines how key elements of the service delivery assessment align with data collected as part of the GDO (30).

Box 4. Service delivery assessment: key elements and corresponding GDO indicators

GDO subdomain 2.1: health and social care workforce

- Number and types of health and social care providers across the country Indicator 6
- Dementia training for health and social care providers Indicator 6

GDO subdomain 2.2: services, support and treatment programmes

- Diagnostic rate of dementia in the country Indicator 7
- Types, and accessibility, of community-based health and social care services provided to people with dementia Indicator 8
- Types of health and social care facilities that exist in the country Indicator 9
- Types of antedementia medicines and symptomatic drug treatments approved by the national medicines regulatory authority Indicator 10
- Types of care products (e.g. adult hygiene products), equipment (e.g. housing adjustments) or assistive technologies available to people with dementia Indicator 11
- Dementia-specific activities and services provided by NGOs dedicated to supporting and advocating for people with dementia and their carers Indicator 12
- Types, accessibility, and implementation level of services, supports or programmes available to carers of people with dementia Indicator 13

GDO subdomain 2.3: promotion of awareness and understanding

- Existence of at least one functioning dementia public awareness campaign aimed at improving understanding and reducing stigma and discrimination Indicator 13
- Existence of at least one functioning dementia risk reduction campaign Indicator 13
- Types and availability of dementia-friendly initiatives Indicator 14
- Non-health professionals and general population receiving dementia training and education Indicator 15

Epidemiological assessment

The epidemiological assessment will help gather dementia-related epidemiological data from a variety of sources.

- Countries without a formal health information system (HIS) will focus on identifying and leveraging **existing data**. In this case, information may be gathered from a variety of available sources, such as national and community surveys, death certificates, hospital or community clinic records, and/or police reports.
- Other countries may already have established a HIS that enables dementia surveillance. In this case, data related to current and projected dementia incidence, prevalence and mortality rates, risk and protective factors and total estimated economic costs can readily be extracted.
- **Social determinants of health**, including socioeconomic status, age, gender, educational level and geographic location, may also be reviewed to assess how these factors contribute to dementia prevalence and incidence.
- Research carried out by national and/or international universities or academic centres and/or institutes may also be used as part of the epidemiological assessment (9).

Box 5 outlines how key elements of the epidemiological assessment align with data collected as part of the GDO (30).

Box 5. Epidemiological assessment: key elements and corresponding GDO indicators

- Prevalence and incidence rates Indicators 21–22
- Total deaths due dementia and years of life lost (YLL) Indicators 23–24
- Disability-adjusted life years (DALYs) and years lived with disability (YLD) Indicators 25–26
- Total economic costs of dementia Indicator 27
- Prevalence of dementia risk factors Indicators 28–35

Stakeholder mapping

The stakeholder mapping assessment will help identify stakeholders affected by dementia, or dementia-related issues, who will need to be engaged during the development and implementation of the plan (see Annex 2). Specifically, it will:

- provide an understanding of the extent to which **each stakeholder group is affected by dementia**, what their viewpoints are, and how they relate to one another (12,31);
- identify stakeholders both **within and beyond government**, across ministries and sectors;
- help **determine how inequities** may exacerbate the impact of dementia on certain populations, e.g. older people, people living in remote or rural areas, women, etc. (26);
- be used to design appropriate **approaches for stakeholder engagement**, determine stakeholders' roles and responsibilities and develop a dementia plan that is beneficial to all parties.

The data collected through the four assessments can be compiled into a situational analysis summary highlighting the scope of the issue, population needs, gaps and opportunities, as well as key partners and stakeholders (see Figure 5.2). The situational analysis summary will be used as the evidence base to identify priorities as well as action areas when developing the dementia plan.

Step A.2: set priorities

Setting priorities is a crucial step, as it involves identifying the issues that will take precedence when developing and implementing the dementia plan (32). The priority setting process is determined by three core factors: available resources, evidence collected through the situational analysis and alignment with political/stakeholder priorities. Accounting for these factors will ensure that the dementia plan is **feasible** – both from a financial and human resource perspective – and that it addresses the most **pressing population needs**. It will also increase the likelihood of political **buy-in** and stakeholder **relevance**. In doing so, it can be helpful to consider the barriers and enablers that may impact these factors and the priority setting process more broadly (see Table 5.1).

Table 5.1. Barriers and enablers to developing a dementia plan

Barriers	Enablers
Stigma/lack of public awareness	<ul style="list-style-type: none"> • Country-specific advocacy and public awareness raising by civil society, academia, health and social care providers, individuals and/or communities • Public health education and prevention for dementia embedded in educational system
Lack of political will	<ul style="list-style-type: none"> • Political and social champions (e.g. Head of State, celebrities) that can drive multisectoral and cross-party approval • Consistent and reliable data, particularly related to the social and economic costs of dementia • Linkages to national and global priorities, e.g. UHC, equity, SDGs • Legislatively mandated national/subnational dementia plans and/or task force • Advocacy from civil society and WHO, including accountability through WHO monitoring

Barriers	Enablers
Lack of human and financial resources	<ul style="list-style-type: none"> • Dementia plans that include earmarked funding that is either dementia-specific or included into other budget items (e.g. mental health, NCDs, ageing) • Identification of "quick wins", i.e. short-term actions, to demonstrate impact and mobilize further funding • Multistakeholder collaboration and partnerships between government, civil society and private sector • Cross-country learning, enabled by the GDO
Lack of integration across government levels and sectors	<ul style="list-style-type: none"> • Dedicated focal point and support within government to lead multisectoral collaboration across and beyond government • Regular M&E
Lack of dementia diagnosis	<ul style="list-style-type: none"> • Train health and social care providers to diagnose dementia in a timely manner, including general practitioners, social workers and community health workers • Undertake epidemiological surveys or leverage existing research to assess baseline prevalence rates of dementia

Source: (33).

Priority-setting process

The situational analysis carried out in Step A.1 identifies the population needs and resources required to address dementia. Based on this evidence, priorities can be established in consultation with key stakeholders, across sectors. As much as possible, priorities will be identified across all seven action areas listed in the global dementia action plan (see Figure 1.1). It is recommended that countries establish priority-setting criteria, which will help clarify why particular issues should be prioritized. Assessing priorities based on criteria also allows for debate amongst stakeholders, creating transparency in the priority-setting process (13,19,29).

Priorities should be **feasible** in terms of their potential for implementation and financing. A focus should be set on selecting priorities that can be operationalized in a cost-effective manner based on **available resources** and ensure **sustainability** in terms of dementia programmes and services. Other criteria may involve assessing the burden of disease associated with dementia, whether priorities can be implemented in a cost-effective manner, are acceptable to people with dementia, their carers and families, are fair and reduce inequities, and contextual factors such as those reflected in national and global political agendas. Annex 3 provides a priority-setting tool.

The final step in the priority-setting process, involves **gaining consensus** on the proposed dementia priorities amongst stakeholders identified in Step A.1. Engaging stakeholders early on will demonstrate the government's commitment to accountability. It will also contribute to building trust by creating opportunities for joint decision-making, ultimately resulting in enhanced stakeholder buy-in, alignment and harmonization during the implementation phase (19). Key to doing so will be the **engagement of people with dementia, their carers and families**, in addition to government, civil society and private sector representatives.

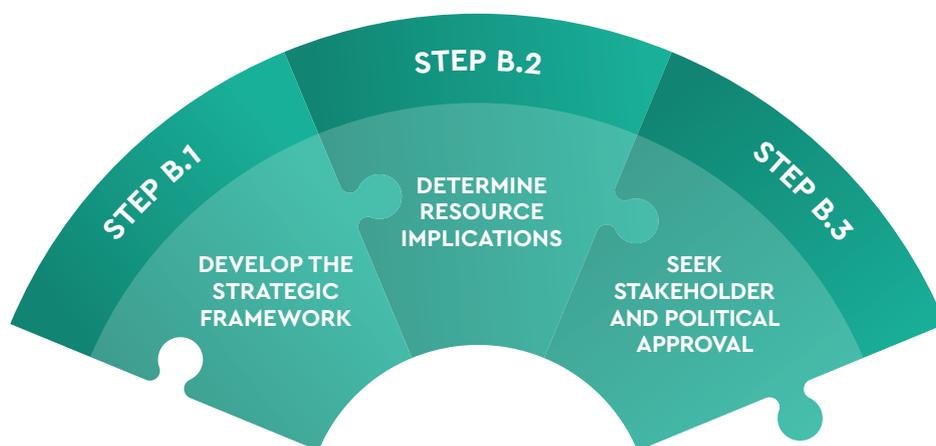
While stakeholders should be engaged throughout the priority-setting process, input may be obtained through established external advisory committees, working groups, or public dialogue and consultations. Identified priorities can also be circulated using a format accessible to people with dementia, their carers and families as well as other stakeholders. Agreed upon priorities will then be used to determine the scope of the dementia plan and establish its strategic framework (see Phase B).

Phase B: developing the dementia plan

Phase B leverages the evidence collected in Phase A to define the scope of the dementia plan and organize identified priorities into a structured, strategic framework. For the purpose of this guide, Phase B is broken down into three steps: establishing the strategic framework, determining resource implications, and seeking stakeholder and political approval (see Figure 5.3).



Figure 5.3. Steps involved in developing the dementia plan



Step B.1: develop the strategic framework

The first step in developing a dementia plan is to create the strategic, multisectoral framework. The strategic framework will define the scope of the dementia plan and highlight key elements, including: a vision, guiding principles, goals, objectives and action areas (see Figure 5.4). In addition to an evidence-based rationale, an overview of the severity and magnitude of dementia at the national or subnational level will help justify the need for the plan and why action to prevent and address dementia is required (9,13,19,32). Strategic alignment with international commitments (see Table 5.2) (e.g. the global dementia action plan, CRPD, 2030 Agenda for Sustainable Development, etc.) and subnational/national sector plans, policies and/or system reforms (e.g. national health plan, mental health and long-term care reforms, policies on workplace mental health) can help form the basis of the rationale.

Figure 5.4. Strategic framework for developing a dementia plan

STRATEGIC, MULTISECTORIAL DEMENTIA FRAMEWORK



Table 5.2. List of relevant international commitments

United Nations (1948)	Universal Declaration of Human Rights
United Nations (1966)	International Covenant on Economic, Social and Cultural Rights
United Nations (2006)	Convention on the Rights of Persons with Disabilities
United Nations (2015)	2030 Agenda for Sustainable Development and (2016) Sustainable Development Goals
WHO (2012)	Universal health coverage
WHO (2013)	Comprehensive mental health action plan 2013–2020
WHO (2013)	Global action plan for the prevention and control of noncommunicable diseases 2013–2020
WHO (2014)	Global disability action plan 2014–2021
WHO (2016)	Global strategy on human resources for health: Workforce 2030
WHO (2016)	Global strategy and plan of action on ageing and health 2016–2020
WHO (2017)	Global action on the public health response to dementia 2017–2025

Scope

The scope builds on the evidence and priorities identified in Phase A to define what the dementia plan does and does not cover. While a narrow scope may allow for faster implementation and impact – an important factor for decision-makers – a broader scope may be beneficial to embedding dementia within broader health and long-term care systems and emphasizing the mutually beneficial aspects of a combined response (e.g. between dementia and mental health more generally) (19). The scope will vary by country, based on the magnitude of the issue, stakeholder involvement, government leadership and available resources (19).

As part of the scope, it will be helpful to determine the structure of the dementia plan, which will vary by country. For example, some dementia plans may include implementation components (e.g. funding sources, outcomes and indicators) while others will integrate dementia into existing plans (e.g. mental health plans). This variation is due to a multitude of factors, including a country's history, institutions, culture, policies, political and legal systems, social structure and values, and the priority set on dementia (13). Given this variation, this guide highlights the elements that will both ideally be included in a comprehensive dementia plan and are most frequently featured in existing plans.

Vision

While the situational analysis in Step A.1 answered the question where are we now, the vision addresses the question where do we want to be, by providing a broad statement of a desired future state that will be reached after multiple years of successful implementation (9,13,19,32). The vision should be grounded in evidence identified through the situational analysis and reflect priorities set in Step A.2. It will also reflect consensus amongst partners and stakeholders. Though the vision can be aspirational in nature, it cannot be so over-prescriptive that it is biased towards any one given dementia priority, nor so idealistic that it is not realistically achievable (see Table 5.3 for examples) (13). Finally, a timeframe should accompany the vision, indicating the range of years when the plan will be effective.

Table 5.3. Examples of vision statements from existing dementia plans

Country	Vision statement
Australia	Improve the quality of life for people living with dementia and their support networks
Finland	A "memory-friendly" Finland is a society that takes the promotion of brain health and the early detection of cognitive symptoms seriously. Anyone diagnosed with a cognitive problem or dementia has access to appropriate treatment, care and rehabilitation. Patients can lead their lives with dignity, and they will not be left without support
Indonesia	Management of Alzheimer and other dementia diseases: towards healthy and productive older persons
Uruguay	Improve the quality of life of people with dementia in the country and their families
United States of America	For millions of Americans, the heartbreak of watching a loved one struggle with Alzheimer's disease is a pain they know all too well. Alzheimer's disease burdens an increasing number of our nation's elders and their families, and it is essential that we confront the challenge it poses to our public health

Sources: (27,34–39)

Guiding principles

Guiding principles for dementia will express ethical aspirations that can be operationalized through sets of activities. As much as possible, guiding principles will align with the global dementia action plan seven cross-cutting principles (see Figure 5.5). They will differ between countries, regions and organizations, as well as amongst cultural, ethnic, religious and/or social groups. Guiding principles may be discussed both within government, through established multisectoral governance mechanisms, and outside of government, through stakeholder engagement fora. Table 5.4 provides examples of guiding principles from existing country dementia plans, mapped against the global dementia action plan seven cross-cutting principles.¹

Table 5.4. Examples of guiding principles from existing dementia plans

Country	Guiding principles
Human rights of people with dementia	
Australia	<ul style="list-style-type: none"> • People with dementia are valued and respected, including their right to choice, dignity, safety (physical, emotional and psychological) and quality of life • People with dementia, their carers and families receive care and support services when needed without discrimination
Norway	<ul style="list-style-type: none"> • Openness, inclusions, dignity and respect
Switzerland	<ul style="list-style-type: none"> • Improved quality of life and dignity of people with dementia
Empowerment and engagement of people with dementia	
Australia	<ul style="list-style-type: none"> • Social participation is actively supported, and an approach that promotes enablement, wellness and inclusion is adopted • Carers and families are valued and supported, and their choices are respected
Japan	<ul style="list-style-type: none"> • To provide support to people with dementia so that they can live well, recognizing that they are not merely persons to be provided with care
Switzerland	<ul style="list-style-type: none"> • Empowerment of people with dementia, their carers and families • Respect for a person's physical and mental integrity, their autonomy and social relations
Evidence-based practice for dementia risk reduction and care	
Australia	<ul style="list-style-type: none"> • Evidence-based approaches, policies and practices are adopted for all dementia-related activities and services • Areas where the evidence base is inadequate should be prioritized for future research
Universal health and social coverage	
Australia	<ul style="list-style-type: none"> • People with dementia, their carers and families have access to competent, affordable, timely care and support services
Republic of Korea	<ul style="list-style-type: none"> • A tailored treatment and management system and policies balanced between welfare and health care

1. The guiding principles presented in Table 5.3 are provided for illustration purposes only; countries may have more than one guiding principle per crosscutting area.

Country	Guiding principles
Multisectoral collaboration on the public health response to dementia	
Slovenia	<ul style="list-style-type: none"> • Multidisciplinary approach
United States of America	<ul style="list-style-type: none"> • Support public-private partnerships
Equity	
Norway	<ul style="list-style-type: none"> • Proper dementia care is proper care for everyone
Slovenia	<ul style="list-style-type: none"> • Equal access to services
Appropriate attention to dementia prevention, cure and care	
Switzerland	<ul style="list-style-type: none"> • Access to high quality dementia services during all stages of the disease for integrated psychosocial and medical care • Appropriate compensation and financial viability of needs-appropriate services for people with dementia are guaranteed

Sources: (22,27,34,38,17,40,41).

Similar to the chosen vision statement, guiding principles should act to unite all concerned partners and stakeholders by representing the national and cultural context (9). Reference may be made to the national constitution, relevant national health and non-health plans (e.g. poverty reduction, international development) and international treaties, instruments and/or commitments (e.g. CRPD, 2030 Agenda for Sustainable Development, UHC) (9). Principles that are operational in nature may include public health approaches to dementia (e.g. person-centred, rights-based, gender-sensitive, evidence-based) or stated commitments (e.g. to stakeholder engagement, empowering people with dementia, principles of UHC,¹ multisectoral collaboration, transparency, accountability) (9).

1. The principles of UHC include ensuring financial risk protection and equitable access to a broad range of promotive, preventive, diagnostic and care services.

Figure 5.5. Global dementia action plan seven cross-cutting principles

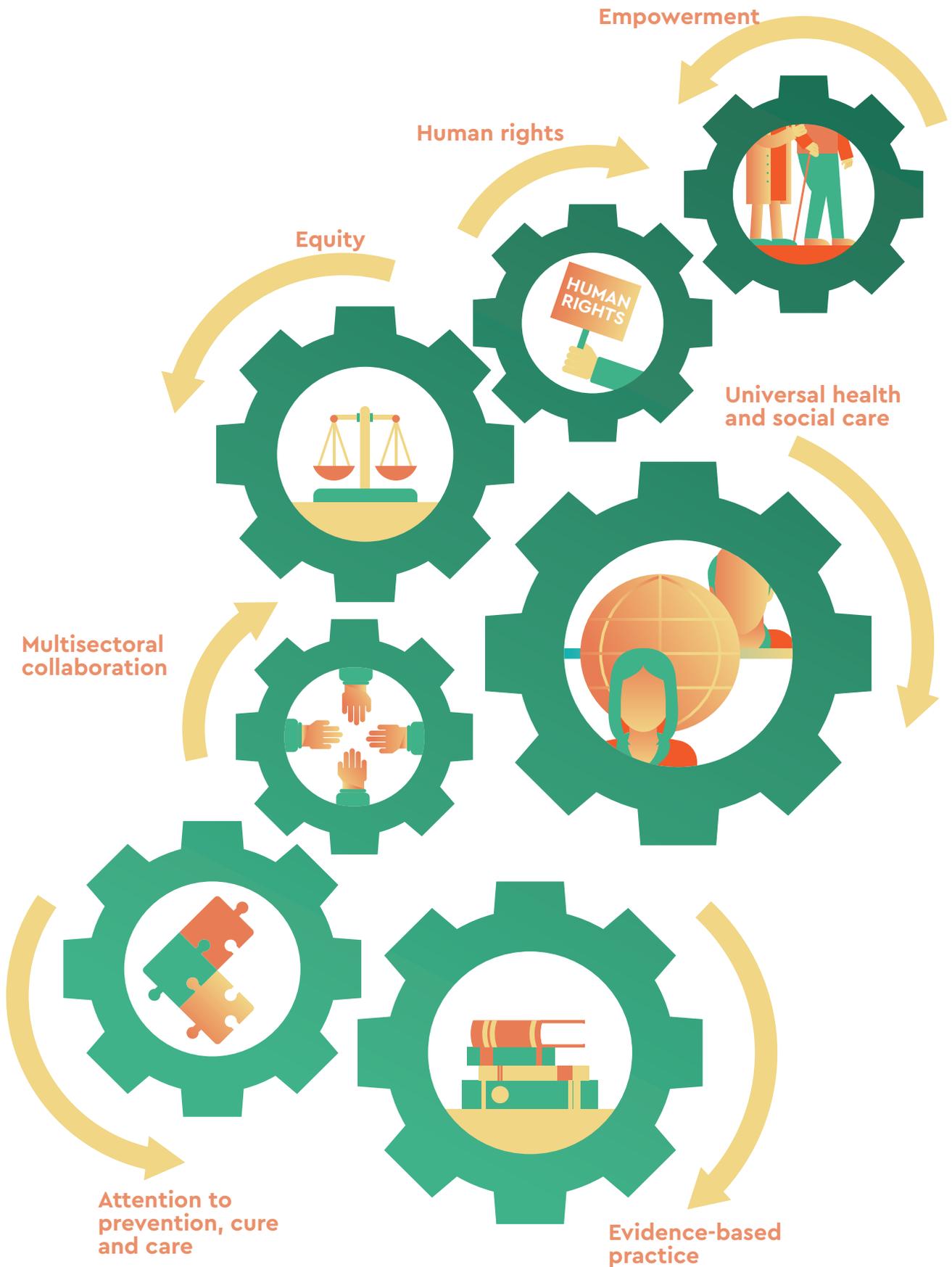


Table 5.5. Examples of goals and objectives from existing dementia plans

Country	Goal(s)	Objectives
Indonesia	To achieve the management of Alzheimer and other dementia disorders: towards healthy and productive older persons	<ul style="list-style-type: none"> ● To implement coordination on management of cognitive and dementia issues ● To implement healthy brain; promoting productive older persons ● To implement management of cognitive disorders to prevent dementia
Japan	Create a society where people with dementia can live with dignity in a pleasant and familiar environment as long as possible	<ul style="list-style-type: none"> ● Raise awareness and promote understanding of dementia ● Provide timely and appropriate health and long-term care services as the stages of dementia progress ● Strengthen measures for early onset dementia ● Support carers of people with dementia ● Create age and dementia-friendly communities ● Promote the dissemination of dementia prevention, diagnosis, cure, care and rehabilitation research findings ● Prioritize the inclusion of people with dementia and their families across all activities
Malta	Enhance the quality of life of individuals with dementia, their carers and family members	<ul style="list-style-type: none"> ● Increase awareness and understanding of dementia ● Improve timely diagnosis and early intervention ● Develop a workforce specialised in patient-centred dementia care ● Improve treatment and care ● Promote the best ethical approaches to dementia management and care ● Promote and foster research in the dementia field
Mexico	Promote the well-being of people with Alzheimer's disease and similar diseases and their families by improving the response from the Mexican health system in synergy with other responsible institutions	<ul style="list-style-type: none"> ● Promote awareness of Alzheimer's disease and other dementias to reduce or eliminate stigma as well as associated negative stereotypes to increase acceptance of people with dementia
Republic of Korea	Establish a support system that protects patients and their rights, and reduces family carer burden	<ul style="list-style-type: none"> ● Establish support for family members of people with dementia through counselling, education and self-help groups ● Implement support for psychological evaluation and counselling of family members of people with dementia ● Increase tax benefits and improve promotion of employment policies to support family carers

Sources: (27,36,37,40,42).

Goals and objectives

A dementia plan will include one, or more, goals that provide a broad statement of the overall, expected outcome(s) to be achieved (19). For example, the global dementia action plan states the following goal: “[...] improve the lives of people with dementia, their carers and families, while decreasing the impact of dementia on them as well as on communities and countries” (1). Goals identify, at a high level, the actions that need to be taken to achieve the stated vision. They reflect, and are closely linked to, priorities identified in Step A. 2.

An objective is more specific than a goal, can be achieved through the implementation of the dementia plan and is usually accompanied by a target and timeframe (see Table 5.5). Multiple objectives may be defined for a stated goal, which will need to be prioritized based on identified needs and resources. Given that government resources are limited, it may be that priority is given to objectives that will impact the largest proportion of the population, are most feasible in terms of operationalization, or for which there is the greatest political support (9).

Action areas

The dementia plan will detail the main areas where **action needs to be taken**. Action areas will be logically linked to both the stated objectives and priorities identified in Step A.2, particularly with respect to relevance and feasibility (19). Each action area will include a series of activities that, together, provide a general sense of how the objectives included in the dementia plan will be achieved (19). Box 6 identifies the key elements included in comprehensive action areas (19).

Box 6. Key elements of action areas

Comprehensive action areas will identify:

- activities, i.e. how sector areas will be expanded, tested, reformed or strengthened to achieve stated objectives;
- different sectors' and key partners' roles, responsibilities, strengths and limitations;
- ways in which resources, programmes and sectors will be harmonized to avoid duplication of labour;
- country-specific considerations (e.g. socioeconomic, cultural and political factors);
- the sectors, system levels (e.g. national, regional, municipal/district, community, etc.) and organizations to be targeted, their roles and responsibilities;
- the populations and/or geographic areas to be targeted;
- the aspects of dementia to be targeted (e.g. prevention, care coordination, caregiver support, risk reduction, surveillance, etc.);
- alignment with existing national policies, legislation, programme-specific strategies and plans;
- alignment with the seven action areas and cross-cutting principles identified in WHO's global dementia action plan.

The global dementia action plan lists action areas and proposed activities that can be used as a starting point for developing comprehensive action areas (see Table 5.6). Action areas and associated activities included in the dementia plan will be used to formulate a detailed operational work plan in Phase C.

Table 5.6. Examples of proposed activities and implementation considerations by global action area

Global action area	Proposed activities	Implementation considerations
<p>Dementia as a public health priority</p>	<ul style="list-style-type: none"> • Develop and implement a dementia plan • Implement legislation to protect the human rights of people with dementia, their carers and families • Create mechanisms to monitor the protection of people with dementia regarding their human rights, wishes and preferences • Identify a focal point, unit or functional division responsible for dementia • Allocate sustainable financial resources to the dementia plan • Establish mechanisms for tracking expenditures on dementia across sectors 	<ul style="list-style-type: none"> • Equity, dignity and human rights of people with dementia • Consult people with dementia and other stakeholders • Align legislation with the CRPD and other human rights instruments • Allocate funding based on identified service needs and resource requirements
<p>Dementia awareness and friendliness</p>	<ul style="list-style-type: none"> • Organize national and local public health and awareness campaigns • Modify social and built environments to make them more age- and dementia-friendly to promote respect and acceptance and enable safety, inclusion and care at home • Develop programmes to encourage dementia-friendly attitudes in the community, public and private sectors 	<ul style="list-style-type: none"> • Campaigns are community- and culturally specific • Focus on reducing stigma, promoting early diagnosis and emphasizing gender- and culturally appropriate responses • Organize campaigns and develop programmes in collaboration with people with dementia and other stakeholders • Target a variety of community and stakeholder groups
<p>Dementia risk reduction</p>	<ul style="list-style-type: none"> • Link dementia with other NCD risk reduction and health promotion programmes, policies and campaigns • Develop, deliver and promote interventions and training for health care providers 	<ul style="list-style-type: none"> • Focus on physical activity, healthy and balanced diets, cessation of tobacco use and harmful use of alcohol, formal education, mentally stimulating activities and social engagement • Training is evidence-based, age-, gender-, disability and culturally sensitive • Training aims to proactively manage modifiable risk factors

Global action area	Proposed activities	Implementation considerations
Dementia diagnosis, treatment, care and support	<ul style="list-style-type: none"> • Develop a coordinated care pathway for people with dementia • Build health and social care providers' knowledge and skills • Improve quality of care towards the end of life • Shift care from hospitals to multidisciplinary, community-based settings • Enhance access to person-centred, gender-sensitive, culturally appropriate care 	<ul style="list-style-type: none"> • Embed the care pathway within an integrated health and social care system • Use the care pathway to provide efficient, quality care and integrate multiple services • Build capacity to deliver evidence-based, culturally appropriate and human rights-oriented care • Earmark budgets and resources for training • Improve end of life care by: <ul style="list-style-type: none"> - Recognizing dementia as a condition requiring palliative care - Promoting awareness about advance care planning - Respecting the values and preferences of people with dementia - Training health care providers • Provide information to empower people with dementia to make informed choices about their care • Enhance collaboration between care providers and people with dementia, their carers and families
Support for dementia carers	<ul style="list-style-type: none"> • Provide accessible and evidence-based information, training programmes, respite services and other resources for carers • Train health and social care providers to identify and reduce carer stress and burn-out • Develop or strengthen carer protection • Involve carers in care planning 	<ul style="list-style-type: none"> • Focus on improving carer knowledge and skills, reducing isolation and providing peer support • Protect carers through social and disability benefits as well as anti-discrimination policies and legislation • Focus on the wishes of people with dementia and their families
Information systems for dementia	<ul style="list-style-type: none"> • Develop, implement and improve national surveillance and monitoring systems • Create supportive policies or legislation to routinely monitor and report on dementia data 	<ul style="list-style-type: none"> • Focus on improving access to high-quality, multisectoral data on dementia • Leverage data to improve service delivery and coverage as well as policies and plans

Global action area	Proposed activities	Implementation considerations
Dementia research and innovation	<ul style="list-style-type: none"> Develop, implement and monitor a national dementia research agenda on prevention, diagnosis, treatment and care Increase investment in dementia research and innovative health technologies Foster the development of technological innovations that respond to the physical, psychological and social needs of people with dementia, their carers or people at risk of developing dementia Promote equitable opportunities and access for people with dementia and their carers to participate in clinical and social research 	<ul style="list-style-type: none"> Develop the research agenda in collaboration with academic and research institutions Support projects that promote academic collaboration on national and international dementia research priorities, open access to research data and knowledge translation Support research aimed at understanding the causes of dementia, identifying a cure and developing new treatments Innovations may include diagnosis, disease monitoring, and assessment, assistive technologies, pharmaceuticals and new models of care

Putting it all together

A section on **implementation considerations** may accompany the dementia plan to provide a general indication of how key activities will be implemented, monitored and evaluated. This might involve specifying elements, such as barriers to implementation, expected outcomes, the types of evaluations that will be carried out and intervals at which M&E will take place. Risk and mitigation strategies associated with implementing the activities may also be specified. In higher resource contexts, a draft M&E framework may also be included, highlighting high-level outcomes and indicators as well as evaluation methodologies and data sources.

Once the dementia plan is drafted, consensus can be reached amongst stakeholders across and beyond government, with a particular **focus on involving people with dementia, their carers and families**. A multisectoral dialogue, or public consultation, will be particularly useful in determining whether the scope of the framework, number of objectives and range of action areas are feasible from a resource perspective, and relevant to the needs of those affected by dementia. It will also be helpful in assessing how the framework aligns with priorities identified in Step A.2.

Engaging people with dementia, their carers and families may take various forms, including obtaining feedback through established external advisory committees (see Section 4: leadership, governance and multisectoral collaboration) and working groups, or focus groups and interviews. A draft of the dementia plan can be circulated in advance to stakeholders in an easy read format, accessible to people with dementia.

Engaging people with dementia, their carers and families: lessons learned from Scotland

In developing the third Scottish National Dementia Strategy (2017–2020), the Scottish Government held a series of engagement events across Scotland to allow interested parties to comment on the progress of the second strategy and on the questions posed by the Scottish Government's National Dementia Dialogue 2015 consultation paper. This helped shape the policy direction and ambitions for the subsequent three years.

The Scottish Dementia Working Group (a national campaigning group for people with dementia and the independent voice of people with dementia within Alzheimer Scotland) and the National Dementia Carers' Action Network (a national campaigning network whose members have personal experiences of caring for people with dementia) were engaged throughout the process.

This close collaboration throughout the process ensured that the voices of people with dementia, their carers and families were heard when developing the new dementia plan. It also helped shape a common vision between the Scottish Government and Alzheimer Scotland.

Step B.2: determine resource implications

A general indication of key resource implications should accompany the dementia plan to demonstrate **feasibility** and **soundness** to political decision-makers. This can be achieved by formulating a resource estimate, which will be included in, or accompany, the dementia plan. It will identify broad budget categories, estimated resource requirements (i.e. financial and human resources, as well as capital costs) and strategies to mobilize these. Once approved, the resource estimate will form the basis of the implementation budget (see Step C.2). Developing an accurate and comprehensive resource estimate is therefore highly important.

The dementia focal point, or secretariat, in partnership with the financial management or central planning unit of the leading ministry will need to determine the implementation costs of activities delineated in the dementia plan, as well as those associated with M&E efforts. An assessment of what can feasibly be undertaken, relative to available resources, can then be carried out. Instruments such as the WHO-CHOICE OneHealth Tool can provide assistance in this process (43).

As part of the cost estimate, a resource rationale can also be included, justifying why the stated resources are required, how they will be used and how they can advance existing programmes and/or services (e.g. for mental health/ageing more generally). Data collected through the situational analysis (Step A.1) can be used as the basis for this rationale. The resource rationale will help strengthen a budgetary request for dedicated, earmarked funding for the dementia plan. Earmarked funding is pivotal to ensuring follow-through for implementation and avoiding the diversion of funds away from other areas of the national/subnational health care budget (10,44).

Step B.3: seek stakeholder and political approval

The final step in developing a dementia plan involves obtaining stakeholders' and political decision-makers' approval. Once the dementia plan is agreed upon amongst government stakeholders and the necessary approvals are obtained, it should be presented to a wide range of stakeholders for feedback, including **people with dementia, their carers and families**. This can be done by holding public consultations or dialogues or creating a brief document highlighting key points featured in the dementia plan, which is then circulated to stakeholders for input. The document should be easy to read and accessible to people with dementia. As much as possible, it is recommended that stakeholders be engaged at all stages prior to securing political approval.

Given the multisectoral nature of dementia, multiple ministers will likely need to approve the dementia plan, e.g. ministers of health, social welfare, finance, housing, etc. Depending on the country, the submission will then be approved by the cabinet, council of ministers or Head of State (9). The approvals process may involve a policy submission (i.e. the dementia plan and associated documents), financial request (i.e. implementation budget), or both (recommended).

The importance of public consultation: lessons learned from Australia

Australia's National Framework for Action on Dementia 2015–2019 (NaFAD) built on Australia's previous National Framework for Action on Dementia 2006–2010 and additional subnational government dementia frameworks. NaFAD identified seven priority action areas aligned with an overarching vision, rationale and guiding principles. The guiding principles and action areas closely align with those included in the global dementia action plan.

Public consultations were held with service providers as well as people living with dementia, their carers and families over one month. Public consultations involved 16 sessions covering Australia's eight states and territories and included both metropolitan areas and regional centres. The participation of people from culturally and linguistically diverse and indigenous communities was supported throughout the process.

Consultations focused on the strengths and weaknesses of pre-existing programmes and how these should inform the national dementia plan. Consultations identified the shared interest and commitment by government and nongovernmental participants to establish a national dementia plan that could inform actions at national, subnational and local levels by governmental and nongovernmental actors.

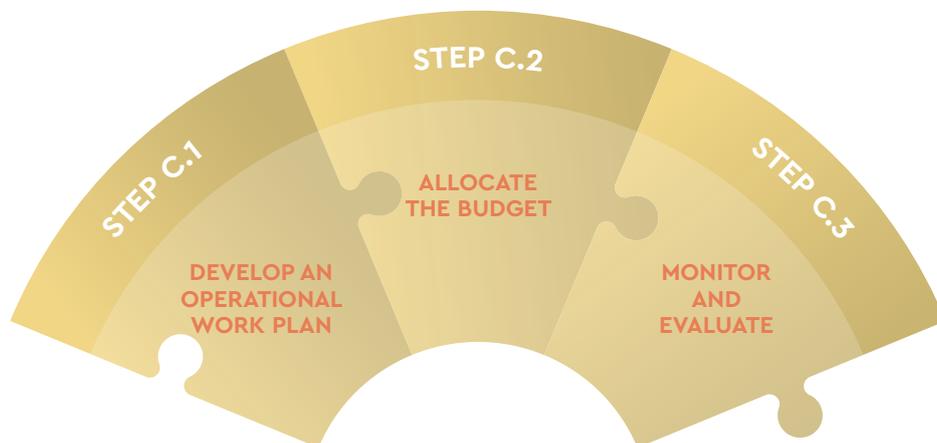
Reaching a consensus on the NaFAD, which ensured that the needs and concerns of all stakeholders were reflected did delay the development of the dementia plan. However, this resulted in a stronger dementia plan, well received by all stakeholders, including people living with dementia, their carers and families. In addition to continuing to inform government policy and programme development, service providers also use the NaFAD for service level planning.

Phase C: implementing the dementia plan



Implementation defines the activities, or how the government will address dementia. For the purpose of this guide, the implementation phase is broken down into three steps: developing an operational work plan, allocating the budget, and establishing an M&E framework (see Figure 5.6).

Figure 5.6. Steps involved in implementing the dementia plan



Step C.1: develop an operational work plan

Once stakeholder and political approval has been obtained, an operational work plan, also referred to as an implementation framework or activity plan, can be developed. An operational work plan highlights the concrete steps and activities that need to be taken by identified stakeholders and partners at each level of the health and social system to operationalize the dementia plan (19). Contrary to the dementia plan, an operational work plan is short term, dictates the government's day-to-day activities in the area of dementia and is frequently reviewed, updated and edited (19). The ministry(ies) that led the development of the dementia plan typically plays a lead role in creating the operational work plan but will need to work closely with all levels of the health and long-term care system by providing appropriate budget allocations and empowering local leadership (10).

The first step in developing an operational work plan is to identify an operational team, or focal point. The operational team/focal point will play an active role in developing the operational work plan and coordinating its activities, across ministry sectors and stakeholders, e.g. subnational governments, regional/local health authorities, municipalities. As much as possible, existing governance mechanisms can be utilized to ensure continuity between planning, development and implementation phases and leverage pre-established relationships (44).

A phased approach to implementation: lessons learned from Chile

Chile's National Dementia Plan was developed under the supervision of an expert working group, including health and social care providers and civil society representatives. Emphasis was placed on creating a participatory process involving people with dementia and their families, academics and the broader society. Surveys and field interviews were conducted to identify operational priorities for health and social care programmes. Based on these findings, programmatic gaps and strategic implementation partners were identified.

In 2017, the implementation of the dementia plan began, alongside periodic working group meetings. These allowed for the tracking, evaluation and improvement of system weaknesses related to stigma and data gaps. Primary health care (PHC) teams were strengthened to enable dementia promotion, prevention, diagnosis, treatment and follow-up for people with dementia and their carers. Memory units were established to address more complicated cases of dementia as well as to provide differential diagnosis and more intensive treatment programmes. Community support centres were created to provide people with mild to moderate cases of dementia with comprehensive treatment, carer respite and psycho-education. Finally, community mental health centres offer specialized treatment for people with dementia and their carers when they need it. Currently, these programmes and services have been implemented in 10 territories, representing an investment of approximately US\$ 7 million.

The service delivery assessment carried out as part of the situational analysis (see Step A.1) provides an overview of needs/gaps in existing dementia services, programmes and resources within and beyond the health care sector (e.g. hospital beds, care facilities, health and social care workforce), as well as service utilization patterns. The operational work plan builds on what has been done in the past in the area of dementia, mental health, ageing, disability and/or NCDs, by making improvements based on these findings. The operational work plan is usually created in a matrix format (see Annex 5), is succinct and includes the following elements (13,19):

- a description of the activities linked to the stated action areas and objectives delineated in the dementia plan;
- a timeline for the overall operational work plan and each activity;
- clear targets, milestones and associated indicators for each activity;
- the institution(s) or person(s) responsible (ideally both) for each activity;
- estimated resources required to implement each activity and strategies to mobilize these;
- a method to measure the status and progress of each activity (i.e. monitoring).

Operational work plans must be flexible and iterative, adjusting activities and timelines based on feedback from all levels of the health and social system. To facilitate this process, some countries have appointed dementia leads/coordinators or case managers to ensure timely and effective implementation, liaison across multiple system levels and coordination of health and social care activities (44–46). Other countries have embedded dementia within national health operational plans to emphasize its importance and highlight inter-linkages with other areas of the health system (10).

To be effective, the operational work plan should **address the needs of people with dementia**, their carers and families, highlighting the importance of ongoing stakeholder consultation. Most importantly, operational work plans must be **feasible** and adapted to the **local context**. They should maximize available resources, avoid duplication of labour and prevent gaps in dementia care and services. The scope of the operational work plan will be based on the resource estimate created in Step B.3 and grounded in the approved budget (see Step C.2).

Making effective use of limited resources: lessons learned from Cuba

The national dementia plan was conceived on the basis of existing and planned resources, which allowed Cuba to make significant progress in the area of dementia. Cuba offers universal health coverage and free access to medical and dental services. Additionally, people with dementia receive comprehensive specialized care at the PHC level from their general practitioner in coordination with a multidisciplinary team from the Department of Mental Health. Community-based geriatric and gerontology services have been expanded, reaching the country's 168 municipalities. A variety of geriatric courses are currently available, including a diploma and a master's degree in dementia syndromes, as well as carer schools at the PHC level. Finally, Cuba has enhanced clinical and basic research to improve diagnosis and treatment options.

Despite significant progress, ongoing challenges remain. These include overcoming the stigma associated with dementia, achieving gender equity in care settings and improving information systems for dementia. Other challenges involve the need to build capacity across the health and social sectors to enhance health and social care providers' capability to offer a more comprehensive level of attention to patients and their carers. Finally, creating dementia-friendly communities and cities remains an important hurdle.

Lessons learned from Cuba's experience include the importance of prevention, which is one of the fundamental principles of the country's health care system, risk reduction and the significance of multisectoral collaboration.

Step C.2: allocate the budget

The budget is based on the resource estimate submitted for political approval alongside the dementia plan in Step B.3, including any requests for earmarked funding. The resource estimate may be approved in full, or in part, and will impact the financial envelope available to fund the implementation of the dementia plan by the lead ministry(ies). This financial envelope will need to support activities identified within the operational work plan, across specified sectors and government levels. While the budgeting process presented here focuses on the governmental level (i.e. national or subnational), each level of the health and social system as well as each organization involved in implementing the dementia plan will need to undertake similar steps.

Financial planning can be done in accordance with each country's budget cycle and financial structures and will involve (13,47):

- calculating the total annual cost of the operational work plan and each associated activity, for every year of operation;
- determining allocations to other levels of the health and social system;
- developing contingency plans and risk management strategies to accompany the budget;
- adjusting implementation activities and timeframes based on the amount of funding available;
- reviewing the implementation timeline, costs and resources mobilized annually.

It will be important to identify responsibility for budgetary oversight and management at each level of the system, both within government institutions (e.g. regional health authorities) and beyond (e.g. nongovernmental, community-based clinics). Once approved, ministries will have authority to commit funding according to the agreed budget. Annual implementation timelines, costs and resources mobilized will need to be reviewed based on M&E activities (see Step C.3).

Step C.3: monitor and evaluate

Monitoring and evaluation is important as it provides information to improve service delivery, plan and allocate resources, and demonstrates results for accountability purposes (48). Most importantly, it accounts for how the implementation budget is being spent and whether under- or over-expenditures exist. Data collected through M&E can inform whether any adjustments to the operational work plan or resource allocation are necessary.

Monitoring identifies how well the plan is being implemented. Using a core set of indicators and targets linked to the objectives of the dementia plan, monitoring provides information regarding implementation progress and performance (e.g. dementia service functioning and care quality), determines whether targets have been reached, and detects over- and under-spending (19,48,49).

Evaluation identifies whether objectives stated in the dementia plan have been effectively and efficiently achieved, determines the impact of planned activities after a pre-determined period of time (e.g. 6–12 months), and informs future planning and budgeting (19,49). The type of evaluation used should correspond to the aspect of the intervention that is being assessed as well as the goal of the evaluation. Examples include formative, outcome, economic and impact evaluations (49,50).

The importance of M&E: lessons learned from France

The French experience with dementia plans began in 2000. France is currently implementing the fourth plan, extended to other neurodegenerative diseases.

The monitoring of the third Alzheimer plan was very structured. A steering committee oversaw the dementia plan and directly reported to the President of the Republic. This direct link to the highest political level facilitated the mobilization of different ministries. A monitoring plan described the context, objectives, roles and responsibilities, timelines, required resources and indicators for each measure. This allowed for adjustments to be made to the timeline and resources, as necessary. External experts carried out an evaluation to provide a global and qualitative assessment.

The fourth plan is led by the Ministry of Health and the Ministry of Research. Regional health agencies are strongly involved in implementing this plan according to local contexts. A number of important lessons learned were recorded.

- M&E should be conceptualized before the dementia plan is implemented in order to mobilize required resources and plan the evaluation of new services.
- M&E requires the use of epidemiological data collected through a situational analysis.
- The evaluation should be organized independently from the monitoring.
- A steering committee or similar governance mechanism can assist in monitoring progress.
- Achieving desired outcomes takes typically longer than anticipated; timelines for designing and implementing new dementia services should be realistic. A plan should include a limited number of measures.

Building M&E capacity for dementia

The GDO framework and indicators used to collect information as part of the situational analysis (Step A.1) provide an important starting point for strengthening information systems, including M&E capacity. The first step in building M&E capacity for dementia is to determine the country's capacity to collect, analyse and report on data based on information collected through the situational analysis (Step A.1). This information will provide insight into the types of data being collected, the indicators reported on, including baseline and targets, and associated data sources. It will also reveal data gaps (in baseline data for dementia, core indicators, technical capacities and data management processes) and opportunities – areas where data management can be better coordinated both within the health sector and between health and social sectors (19).

It is a good idea to identify an **M&E focal point** in the dementia operational team who will oversee M&E procedures, train M&E officers and advise on changes to the operational work plan as a result of ongoing M&E (48,49). An **M&E framework** can then be developed, highlighting how M&E activities are aligned with the objectives of the dementia plan and priorities included in the operational work plan. More detailed M&E frameworks might also identify how M&E activities are aligned with national M&E mechanisms and HIS. At a minimum, the M&E framework will outline processes for coordinating M&E across dementia programmes, associated costs, a set of core dementia outcomes and indicators as well as corresponding data sources (19). An M&E framework may also delineate strategies to address identified data gaps, and procedures for data collection, management, analysis, use and dissemination (19). As much as possible, outcomes and indicators should align with those delineated in the GDO.

As part of the M&E framework, a **logic model** will identify how inputs into the system lead to dementia-related outputs, outcomes and impacts (see Annex 6) as well as delineate the indicators that will be used to measure these (19). Before starting data collection, it is a good idea to train M&E officers/teams in health and social care facilities, community-based clinics and district-level administrators. The M&E framework should be shared with relevant stakeholders for feedback, including **people with dementia, their carers and families**.

Collected data should be shared with all operational stakeholders and partners to ensure financial and operational accountability. This can be done through M&E meetings and the dissemination of annual M&E reports, which are particularly useful in ensuring knowledge sharing. M&E data will allow for modifications and improvements to the operational work plan, with resources being reallocated as necessary.

Setting measurable indicators: lessons learned from Japan

Given the growing number of people with dementia amongst the ageing population, the Japanese Government launched the Comprehensive Strategy to Accelerate Dementia Measures (New Orange Plan) in 2015. The New Orange Plan is the first national plan to realize age- and dementia-friendly communities in Japan and represents a multisectoral collaborative effort amongst 12 ministries and agencies. The New Orange Plan was strongly supported by the Prime Minister and aims to accelerate progress towards achieving the dementia measures outlined in the previous five-year Orange Plan (2012) by 2025. The New Orange Plan includes the following activities and corresponding indicators to monitor its implementation.

I. Coordination of medical and long-term care

1. Early support: intensive support teams for the initial phase composed of medical care and long-term care specialists established in all municipalities.
2. Improving care providers' capacity: 75 000 doctors participate in training and capacity building for primary care doctors.
3. Coordination of medical and long-term care: dementia coordinators are established in all municipalities.

II. Research for prevention and cure

4. Prevention: 10 000 people participate in a nationwide prospective dementia cohort study aimed at identifying risk and protective factors, and establishing prevention in the community.
5. Cure: cross-ministerial Project for Psychiatric and Neurological Disorders is completed, aiming to start clinical trials of drug candidates originating in Japan for dementia treatment.

III. Age- and dementia-friendly community

6. Dementia supporters: 12 million dementia supporters with good knowledge and understanding of dementia are trained.
7. Safety: cross-ministerial support such as community watch system, protection against consumer fraud, etc. are established.

Concluding remarks

Planning, developing and implementing a dementia plan is a complex process, whereby the capacity of various sectors and needs of multiple stakeholders need to be taken into account. It requires moving from gathering evidence, to strategic planning to resource mobilization for implementation. Particularly important to the success of a dementia plan is the participation of people with dementia, their carers and families.

While this document provides a comprehensive multi-phased, step-wise approach to preparing for, developing and implementing a dementia plan, countries are encouraged to identify, apply and adapt the sections that are most relevant to their resource settings and health needs. Every dementia plan will ultimately reflect the health, social, economic and political context of the country/region. Most importantly, a dementia plan will address the needs of those most impacted by the disease and be feasible from a resource standpoint, ensuring follow-through in implementation.

The process of planning, developing and implementing a dementia plan can be slow, requiring the mobilization of political will, resources and partners across sectors. Impacts and outcomes may only be achieved after multiple years of planning, consultation and sustained resource mobilization. However, the experiences of countries that have gone through this process demonstrate the positive health impacts and benefits for people with dementia, their carers and families. Despite the barriers and complexities associated with planning, developing and implementing a dementia plan, improvements in the human rights, mental health, well-being and quality of life of people with dementia, their carers and families provide an undeniable motivation to achieve success.

Glossary

Accountability	The obligation of an organization and its members to be answerable for delivering specific results that have been determined through a clear and transparent assignment of responsibility, subject to the availability of resources and constraints posed by external factors.
Action areas	The general areas where action needs to be taken; they provide a general sense of how the objectives will be achieved.
Activity plan	See Operational work plan.
Carer/caregiver	<p>A person who provides care and support to a person with dementia. Such support may include:</p> <ul style="list-style-type: none">● 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. <p>Carers/caregivers may include relatives or extended family members as well as close friends, neighbours and paid lay persons or volunteers</p>
Civil society	Refers to the wide array of nongovernmental and not-for-profit organizations that have a presence in public life, expressing the interests and values of their members or others, based on ethical, cultural, political, scientific, religious or philanthropic considerations. Civil society is the "third" sector of society, along with government and business (51).
Data quality	All data are subject to limitations, such as missing values, bias, measurement error, and human errors in data entry and manipulation. Data quality assessments provide an understanding of how much confidence can be put in health (or other) data presented. It is particularly important to know the reliability of national coverage estimates and other estimates derived from HIS data and data generated for health sector reviews and annual monitoring.

<p>Dementia</p>	<p>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, such as motor neurone diseases, Prion disease, Parkinson's disease and related disorders, Huntington's disease, spinocerebellar ataxia, and spinal muscular atrophy. The following International Classification of Diseases (ICD) codes relate to dementia – ICD-9: 290, 330–331; ICD-9 BTO: B222, B210; ICD-10: F01, F02, F03, G30–G31.</p>
<p>Dementia plan</p>	<p>A written organized set of principles, objectives and/or actions for reducing the burden attributable to dementia in a population (30). A dementia plan may be stand-alone, i.e. specific to dementia, or integrated into other mental health, ageing, NCDs or disability plans.</p>
<p>Disability</p>	<p>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.</p>
<p>Evaluation</p>	<p>The process of tracking key outcomes and impacts related to the different elements of the dementia plan, and assessing whether the goals and objectives are being achieved.</p>
<p>Financial resources</p>	<p>See Resources.</p>
<p>Framework</p>	<p>Provides a set of guiding principles for the provision of evidence-based health services.</p>
<p>Global Dementia Observatory (GDO)</p>	<p>WHO's GDO is a monitoring and knowledge exchange platform that aims to strengthen health systems and policies related to dementia treatment and care. The GDO can be accessed at: http://www.who.int/mental_health/neurology/dementia/Global_Observatory/en/ and its data portal at: http://apps.who.int/gho/data/node.dementia.</p>
<p>Goal</p>	<p>A broad statement of the overall, expected outcome(s) to be achieved.</p>

Governance	In this context, the multisectoral, coordination structures and processes that organize and oversee the development and/or implementation of a dementia plan, and ensure accountability, transparency, responsibility, equity, inclusiveness and empowerment (52).
Guiding principles	An agreed upon set of precepts or values that guide the dementia plan. These may be ethical or operational in nature, will differ between countries, regions and organizations, as well as amongst cultural, ethnic, religious and/or social groups.
Health information system (HIS)	The process by which data are collected from the health and other relevant sectors, compiled, analysed, synthesized, used and disseminated. It includes processes related to data quality management and the conversion of data into information that can be used by decision-makers within and beyond the health care sector.
Health (care) system	Refers to: a) all the activities whose primary purpose is to promote, restore and/or maintain health; and b) 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.
Human resources	See Resources.
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.
Implementation	The process of putting a decision or plan into effect.
Implementation framework	See Operational work plan.
Indicator(s)	Measures of impacts, outcomes, outputs and inputs that are monitored and/or evaluated during the implementation of the dementia plan to assess progress towards achieving objectives (53). Indicators organize information in a way that clarifies relationships within the M&E framework and identifies problems that can impede achievement of objectives (53).

Integrated	See Dementia plan.
Leadership	In this context, refers to the action of leading a group of people or organizations through the process of planning, developing and implementing a dementia plan and associated elements. The leadership may be political, administrative or clinical in nature.
Legislation	A law or set of laws, which have been enacted by the governing bodies in a country. For the purpose of this document, legislation refers to legal provisions that are either specific to dementia or are applied to people with dementia. They typically focus on issues such as civil and human rights protection of people with dementia, treatment facilities, personnel, professional training and service structure.
Long-term care	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. These activities include the integration of social care, health care and the contribution of other sectors.
Long-term care system	A national system that ensures long-term care that is appropriate, affordable, accessible and upholds the rights of older people and carers alike.
Monitoring	The ongoing action of collecting information about all project/programme activities. In this context, it determines whether the dementia plan is being implemented as intended and helps individuals identify and solve problems quickly.
Monitoring and evaluation (M&E)	A process that provides information on what an intervention is doing, how well it is performing and whether it is achieving its goals and objectives. It is an important part of accountability to funding agencies and stakeholders.
Monitoring and evaluation (M&E) framework	Identifies core indicators and includes inputs into the system, processes, outputs, outcomes and impacts. Sometimes referred to as a logic model.
Monitoring and evaluation (M&E) plan	Highlights how M&E activities are aligned with the objectives of the dementia plan as well as national M&E mechanisms and HIS. It also outlines processes for coordinating M&E across dementia programmes, a set of core dementia outcomes, indicators and corresponding data sources, strategies to address data gaps, and procedures for data management, analysis, use and dissemination.

Multisectoral	Involving agencies and organizations from the different sectors of society, including governments, NGOs, private for-profit sector, and civil society working within and beyond the health sector.
Multisectoral collaboration	Refers to cooperative actions affecting health outcomes undertaken by sectors beyond the health sector, leading to a shared, mutually beneficial outcome.
Noncommunicable diseases (NCDs)	These 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 (e.g. heart attack and stroke), cancers, chronic respiratory diseases (e.g. chronic obstructed pulmonary disease or asthma) and diabetes.
Nongovernmental organizations (NGOs)	NGOs are created and operated to contribute to the public's benefit. The ways that NGOs pursue that goal vary widely and they usually work on a not-for-profit basis. They can be organized 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 organizations, consumer organizations, etc.
Objective	Achieved through implementation (e.g. of the dementia plan), usually accompanied by a target and timeframe.
Operational work plan	Highlights the concrete steps and activities that need to be taken by identified stakeholders and partners at each level of the health and social system to operationalize the dementia plan. Also referred to as an implementation framework, activity plan or work plan.
Outcome	In this context, the result or consequence of an action or sequence of actions taken as part of the dementia plan.
Output	In this context, what is produced as a result or consequence of an action or sequence of actions taken as part of the dementia plan.
Partner	An individual, group of individuals or an organization that work together to achieve a common goal or interest.
Priority setting	The consensus-based process of determining which issues take precedence based on agreed upon assessment criteria.

Private sector	The part of a country's economy that consists of industries and commercial, for-profit companies that are not owned or controlled by the government.
Private, not-for-profit entity	Non-profit organizations that receive financial support from only a few sources, such as a dedicated donor or investment income (51). These organizations typically do not solicit funds from the general public. Examples include private foundations (51).
Rationale	In this context, a stated reason justifying the need for a dementia plan and why action to prevent and address dementia is required.
Resources	Unless otherwise specified, the human and financial resources required to prepare for, develop and/or implement a dementia plan. Human resources refer to the number of staff needed and the skill mix required. It refers to both social and health care providers such generalist and specialized physicians, nurses, pharmacists, social workers, personal support workers, community health workers, as well as policy, programme, management and support staff that do not deliver care but are essential to the performance of the health system. Financial resources refer to the funds (money) that are budgeted and allocated to support the preparation of, development and implementation of the dementia plan.
Resource allocation	The process of deciding what is needed to carry out an activity and providing for those needs. This can include making provision for financial resources (money), capital resources (such as buildings and computer hardware) and human resources (including the number of staff needed and the skill mix required).
Risk factor	Social, economic or biological status, behaviours or environments which are associated with or cause increased susceptibility to a specific disease; in this case dementia.
Scope	Defines the breadth of the dementia plan, i.e. what it does and does not cover.
Service provider	Covers both health care and social care providers. See respective definitions.
Situational analysis	An assessment of the current situation within, and beyond, the health care sector and fundamental to designing and updating national policies, strategies and plans.

Social care	Assistance with activities of daily living (such as personal care, maintaining the home); synonym – home and community care.
Social care provider	A professional providing basic nursing and personal care to people due to the effects of ageing, illness, injury, or other physical or mental impairment. They provide health advice to patients and families; monitor patients' conditions; and implement care, treatment and referral plans usually established by medical, nursing and other health professionals. They have completed formal training in nursing at a recognized, university-level school for a diploma or degree, or have acquired extensive on-the-job training.
Stand-alone	See Dementia plan.
Stakeholder	Refers to an individual, group of individuals or an organization that has an interest in the institutions and delivery of health care for people with dementia.
Strategic alignment	The process of aligning the dementia plan, and/or its components, to existing political priorities and investments.
Strategic framework	Highlights key elements, including a vision, guiding principles, goals, objectives and action areas for developing a dementia plan, which are aligned with existing political priorities and maximize the use of existing resources.
Structure	In this context, refers to the format of the dementia plan, e.g. stand-alone versus integrated into existing plans for general health, mental health, NCDs, disability, or ageing, or strategic versus operational plan.
Subnational	Refers to individual states, territories, provinces or regions within a country.
Sustainable development goals (SDGs)	The 17 goals adopted by world leaders on 15 September 2015 as part of the 2030 Agenda for Sustainable Development. The SDGs came into force on 1 January 2016 and include specific targets to be achieved over the next 15 years (53). For more information see: http://www.un.org/sustainabledevelopment/development-agenda/ .
Target	The intended level or situation to be achieved.

Timeframe	The period of time by when an action, project, programme or plan should be completed; in this case, the dementia plan.
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 UHC at: http://www.who.int/mediacentre/factsheets/fs395/en/ .
Vision	A broad, evidence-based statement of a desired future state that will be reached after multiple years of successful implementation.

Annexes

Annex 1: checklist for preparing, developing and implementing a dementia plan

The following checklist can be used to ensure that the key elements related to preparing, developing and implementing a dementia plan are accounted for. The checklist is organized using a step-wise approach, to reflect the structure of the overall document.

Cross-cutting elements

Leadership, governance and multisectoral collaboration

- A lead entity (e.g. dementia focal point, coordinating team or secretariat) is identified with clear roles and responsibilities.
- Partner institutions/ministries and collaborators across multiple sectors are identified, their roles and responsibilities outlined and a joint plan for collaboration is established.
- Stakeholder engagement includes people with dementia, their carers and families as well as other multidisciplinary types of stakeholders and may involve formal stakeholder mechanisms such as external advisory committees/boards.
- Human rights, gender and equity experts are involved.

Phase A: preparing for the dementia plan

Step A.1: situational analysis

- Situational analysis data to perform policy, service delivery and epidemiological assessments are collected through the GDO.
- Stakeholder mapping is completed.
- Stakeholders are engaged in performing the situational analysis and identifying needs and gaps; their feedback is incorporated.

Step A.2: setting priorities

- Priority-setting criteria are established with inputs from stakeholders, taking into consideration the evidence-base, feasibility, acceptability and relevance.
- Priorities are assessed according to selected criteria with inputs from stakeholders.
- Priorities are grounded in the findings of the situational analysis.

Priorities align with the following strategic action areas of the global action plan on the public health response to dementia 2017–2025:

- dementia as a public health priority
- dementia awareness and friendliness
- dementia risk reduction
- dementia diagnosis, treatment, care and support
- support for carers
- information systems for dementia
- dementia research and innovation.

Priorities align with the following cross-cutting principles of the global action plan on the public health response to dementia 2017–2025:

- human rights of people with dementia
- empowerment and engagement of people with dementia and their carers
- evidence-based practice for dementia risk reduction and care
- multisectoral collaboration on the public health response to dementia
- universal health and social coverage for dementia
- equity
- appropriate attention to dementia prevention, cure and care.

Phase B: developing the dementia plan

Step B.1: strategic dementia framework

- The scope of the dementia plan is established.

The strategic dementia framework includes the following components:

- vision
- guiding principles
- goal(s)
- objectives
- action areas.

- Stakeholders (especially people with dementia, their carers and families) are engaged in developing the strategic framework.

- The dementia plan includes an overview of how it will be implemented, monitored and evaluated.

Step B.2: determine resource implications

- The dementia plan includes a resource estimate that outlines broad budget categories, resource requirements for specific activities, strategies to mobilize resources and a resource rationale.

- The dementia plan includes a budgetary request for dedicated, earmarked funding.

Step B.3: seek stakeholder and political approval

The dementia plan is approved by the following groups (select all that apply):

- stakeholders within the ministry of health
- stakeholders in other ministries
- people with dementia, their carers and families
- other external stakeholders
- the minister of health
- other ministers
- the Head of State/country leader.

Phase C: implementing the dementia plan

Step C.1: develop an operational work plan

- A lead ministry/entity is identified to develop an operational work plan.
- An operational team or focal point is identified.
- A feasible and cost effective operational work plan is developed in consultation with partners and stakeholders (especially people with dementia and their carers).

The operational work plan includes the following:

- descriptions of all activities within each action area
- a timeline for the overall work plan and each activity
- clear targets, milestones and associated indicators for each activity
- the institution(s) or person(s) responsible for each activity
- resource requirements for each activity
- a method to measure/monitor progress for each activity.

Step C.2: allocate the budget

- The budget is directly linked to the resource estimate (see Step B.2).
- The budget is based on the financial envelop approved by government (see Step B.3).
- The budget aligns with the country's budget cycle and financial structures.
- Responsibility for budgetary oversight and management is identified for all relevant partners (i.e. ministry of health, other ministries and operational partners) and at each level of the system (e.g. national, regional, municipal).

The budgeting process involves the steps below.

- Total annual cost of the operational work plan and each associated activity calculated for every year of operation.
- Allocations to other levels of the health and social system are determined.
- Operational activities and timeframes are adjusted based on the amount of funding available.
- Implementation timeline, costs and mobilized resources are reviewed annually.
- Budget allocations are shared with operational partners.

Step C.3: monitor and evaluate

- The country's capacity to collect, analyse and report on data is determined by identifying types and existing sources of dementia-related data that are collected; indicators that are reported on; and existing data gaps and opportunities.
- An M&E focal point is identified who oversees M&E procedures, trains M&E officers and advises on changes to the operational work plan.

-
- An M&E framework is developed using a logic model; highlighting M&E activities aligned with the GDO and the dementia plan's objectives and operational priorities; processes for coordinating M&E across dementia programmes; and associated costs and budget allocations.
-
- The logic model specifies indicators and corresponding data sources to demonstrate how inputs into the system lead to dementia-related outputs, outcomes and impacts.
-
- The framework is shared with stakeholders and their feedback incorporated.
-
- Collected data are shared through M&E meetings and/or annual M&E reports.

Annex 2: stakeholder mapping tool

The stakeholder mapping tool can be used to identify the stakeholders that need to be engaged when developing and implementing the dementia plan. It can also be used to map each stakeholder's interest in, and influence on, the process.

Using the tool

1. Under the stakeholder type column, indicate all the categories of stakeholders that are currently affected by dementia-related issues and that will be impacted by the dementia plan. Insert additional stakeholder categories as necessary.
2. For each stakeholder category, list all relevant stakeholders. Examples might include specific national or regional ministries, elected officials, health and social care providers, community leaders, people with dementia, their carers and families, research institutes, health insurers, international aid agencies, etc.
3. Indicate each stakeholder's level of interest in engaging in the dementia plan process.
 - You can use the following rating scale: 1 = very interested, 2 = somewhat interested, 3 = not interested.
 - If "very interested" or "somewhat interested" please explain. If "not interested", please state reason(s).
4. Indicate each stakeholder's level of influence on the dementia plan process.
 - You can use the following rating scale: 1 = very influential, 2 = somewhat influential, 3 = not influential.
 - If "very influential" or "somewhat influential" please explain. If "not influential", please state reason(s).
5. Begin to consider the patterns of stakeholder groupings that emerge.
 - Stakeholders rated as very interested and very influential are those with whom you will want to consider working in partnership. This might involve working on developing and/or implementing the dementia plan by forming a working group or committee, or an implementation team. These stakeholders may also act as champions for the dementia plan either within government or the broader policy arena.
 - Stakeholders rated as very influential yet not interested are actors that you will need to convince of the importance and value of developing and/or implementing a dementia plan. It may be helpful to leverage evidence to demonstrate how the dementia plan will align with their respective priorities and benefit their agenda. It might also be useful to develop an engagement plan to keep these stakeholders abreast of progress and successes. Champions' influence may also be helpful in communicating to this group of stakeholders.
 - Stakeholders rated as very interested yet not influential are likely highly impacted by dementia, or dementia-related issues, but do not have the capacity to mobilize and influence the policy-making process. These stakeholders should not be disregarded, as their input will be highly valuable to developing and implementing the dementia plan. Mechanisms to continuously engage these stakeholders should be established.
 - Stakeholders rated as not interested and not influential are those that do not know much about dementia, or who are not impacted by it. If they will not be influential in the dementia plan process, you may prefer to focus efforts on the other three stakeholder groups.

		Interest		Influence	
Stakeholder type	Stakeholder	Level (1=very interested to 3= not interested)	Explanation	Level (1=very influential to 3= not influential)	Explanation
Government					
Service providers					
Civil society					
Academic institutions and research agencies					
Private, for-profit entities					
International, regional and subregional organizations					
Media					
Other (specify)					

Sources: (49,54).

Annex 3: scope and priority-setting tool

The following checklist can be used to identify the scope of activities within each priority identified in Step A.2. Using the table below, select the activities that you will undertake for each action area. To help you prioritize these activities, select criteria from the following list, or others that you wish to use: *evidence-based*; *feasibility* (with respect to financial and human resources); *acceptability* (to stakeholders); *relevance* (to political priorities).

Other examples of prioritization criteria may include: *burden of disease*, *cost-effectiveness*, *fairness* and *contextual factors* (see p. 62 for additional information).

Action Area	Activities	Prioritization criteria
Dementia as a public health priority	<input type="checkbox"/> Identify key needs, gaps, opportunities and stakeholders across the health and social care sectors (situational analysis)	
	<input type="checkbox"/> Identify lead ministry and dementia representative	
	<input type="checkbox"/> Develop/implement stakeholder engagement process	
	<input type="checkbox"/> Secure/allocate dedicated government funding to implement the dementia plan	
	<input type="checkbox"/> Develop/pass legislation pertaining to the rights of people with dementia	
	<input type="checkbox"/> Develop/implement government approved guidelines or standards for dementia care/support	
	<input type="checkbox"/> Other:	
Dementia awareness and friendliness	<input type="checkbox"/> Develop/implement a public awareness-raising campaign for dementia	
	<input type="checkbox"/> Develop/implement modifications to the social and physical environments for dementia-friendliness	
	<input type="checkbox"/> Develop/implement dementia education/training for non-health care populations groups	
	<input type="checkbox"/> Other:	
Dementia risk reduction	<input type="checkbox"/> Include dementia risk reduction in policies (either dementia-specific or other)	
	<input type="checkbox"/> Develop/implement risk reduction guidelines	
	<input type="checkbox"/> Develop/implement dementia risk reduction management guidance for health and social care providers	
	<input type="checkbox"/> Other:	

Action Area	Activities	Prioritization criteria
Dementia diagnosis, treatment, care and support	<input type="checkbox"/> Monitor and report dementia diagnostic rate	
	<input type="checkbox"/> Implement community-based dementia services	
	<input type="checkbox"/> Increase access to community-based dementia services	
	<input type="checkbox"/> Develop/implement dementia care coordination mechanisms across sectors	
	<input type="checkbox"/> Develop/implement basic dementia competencies in curricula for health/social workforce	
	<input type="checkbox"/> Other:	
Support for dementia carers	<input type="checkbox"/> Develop/implement dementia carer services	
	<input type="checkbox"/> Develop/implement guidance for health/social care providers to identify and reduce carer stress	
	<input type="checkbox"/> Develop/implement financial benefits/social protection policies and programmes for dementia carers	
	<input type="checkbox"/> Other:	
Health information systems for dementia	<input type="checkbox"/> Develop/implement mechanisms to monitor number of people with dementia	
	<input type="checkbox"/> Develop/implement monitoring and evaluation system for dementia	
	<input type="checkbox"/> Other:	
Dementia research and innovation	<input type="checkbox"/> Develop/implement dementia research agenda	
	<input type="checkbox"/> Secure/allocate government funding for dementia research	
	<input type="checkbox"/> Develop/implement processes to involve people with dementia in research	
	<input type="checkbox"/> Other:	

Additional sample prioritization criteria (19)

Burden of disease

Quantitative, time-based measure, combining years of life lost (YLL) due to premature mortality and YLL due to time lived in states of less than full health.

- Do the identified activities address the most widespread, severe and urgent population needs?
- Do the identified activities respond to the needs of the stakeholders most directly affected by dementia?
- How do the identified activities impact each stakeholder group?
- How are different sub-populations affected by dementia? Do any need to be given priority based on the burden of dementia and/or pre-existing socioeconomic or political conditions?

Cost effectiveness

Measure assessing whether the identified dementia activities can be implemented in a manner that provides the most value for money.

- Can the activities for dementia be operationalized in a feasible, cost-effective and sustainable manner?
- Can sufficient funds be allocated, mobilized or redirected to operationalize the priorities?
- What are the risks and opportunity costs of selecting these activities over others?
- What is the likelihood that the selected activities will lead to expected results?
- How applicable and generalizable are the identified activities across population groups, regions and settings?
- How quickly does change need to occur and how fast can the identified activities be operationalized?

Fairness

The quality of treating people equally or in a way that is right or reasonable, and free from bias or injustice.

- How do the identified activities address the needs, expectations and human rights of people with dementia, their carers and families?
- How do the identified activities impact vulnerable populations, e.g. people with disabilities, older people and migrants?
- How do the identified activities support gender equity?
- How do the identified activities impact different geographical areas (e.g. urban versus rural and remote areas)?
- How do the identified activities impact different types of programmes, services and/or intervention (e.g. dementia prevention versus care)?

Contextual factors

The influence of national and international politics and political climate on defining dementia activities.

- How do the identified activities align with broader national and/or subnational health priorities, including mental health, ageing, NCD and disability priorities?
- How do the identified activities align with broader government priorities, e.g. age-friendly cities, urban planning, poverty reduction, etc?
- How do the identified activities align with existing international commitments, e.g. CRPD, SDGs, global action plans on dementia, mental health, NCDs, disability, health and human rights, UHC?
- How politically salient is each identified activities?
- Are there any political factors that may affect the likelihood of buy-in to the identified activities, e.g. elections, change in government?
- What influence do stakeholder groups have on the national dementia development process?

Annex 4: situational analysis and corresponding GDO indicators

The table below highlights the GDO indicators that are relevant to carrying out each of the assessments included in the situational analysis (Step A.1). These assessments cover policy, service delivery, epidemiology and stakeholder mapping.

Assessment	Relevant GDO indicators
Policy	1. Dementia governance
	2. Dementia policy
	3. Dementia legislation
	4. Dementia standards/guidelines/protocols
	5. Dementia care coordination
	17. Dementia research agenda
Service delivery	18. Dementia research investments
	6. Dementia health and social workforce
	7. Dementia diagnostic rate
	8. Community support services for dementia
	9. Dementia care facilities
	10. Anti-dementia medication and care availability
	11. Dementia-specific NGOs
	12. Dementia carer support services
	13. Dementia awareness and risk reduction campaigns
	14. Dementia-friendly environments
Epidemiological	15. Dementia education and training
	21, 22. Prevalence and incidence rates
	23, 24. Total deaths due to dementia and YLL
	25, 26. Disability-adjusted life years (DALYs) and years lived with disability (YLD)
	27. Total economic costs of dementia
Stakeholder	28–35. Prevalence of dementia risk factors
	N/A

Sources: (30).

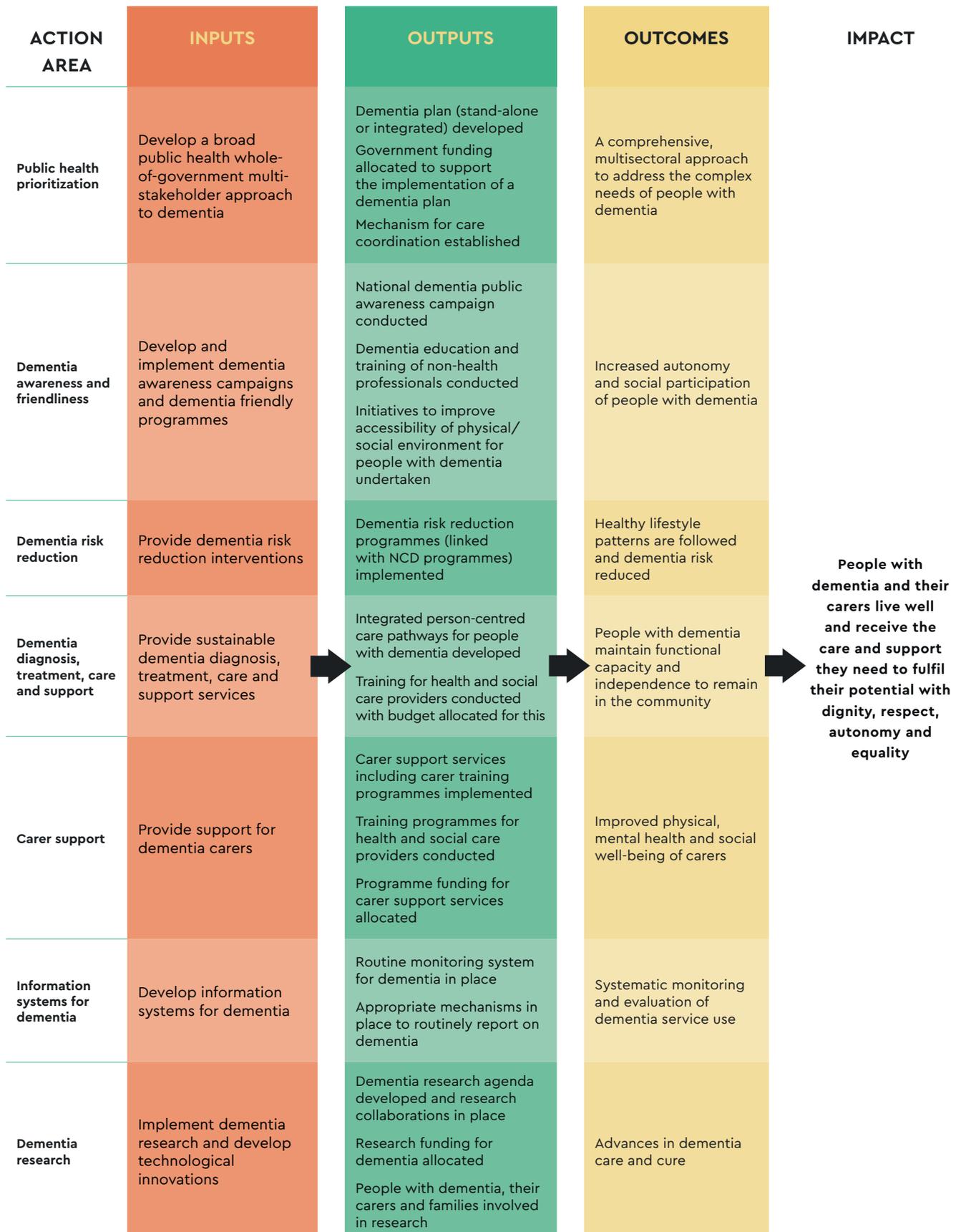
Annex 5: sample dementia operational work plan

The table below provides an example of an operational work plan for dementia.

Action area	Activities	Cost (US\$ million)	Source of funding	Mobilization (US\$ million)	Responsible	Completion date/status
Objective 1: develop and implement dementia awareness campaigns and dementia friendly programmes						
Dementia awareness and friendliness	Organize national and local public health and awareness campaigns	5	Ministries of Health and Social Welfare	2.75	National/ regional Alzheimer's associations/ NGOs	Completed
	Modify social and built environments to make them more age- and dementia-friendly to promote respect and acceptance and enable safety, inclusion and care at home	20	Ministry of Finance	10	Ministries of Health, Environment and Transportation	In progress
	Develop programmes to encourage dementia-friendly attitudes in the community, public and private sectors	2.5	Ministry of Health	0.25	Regional health authorities	In progress December 2017 December 2017
Objective 2: implement dementia risk reduction interventions						
Dementia risk reduction	Link dementia with other NCD risk reduction and health promotion programmes, policies and campaigns	2	Ministry of Health	0.5	Regional health authorities	December 2020
	Develop, deliver and promote interventions and training for health care providers	3.5	Foreign donor	3.5	Regional hospitals	January 2020

Annex 6: sample M&E logic model for dementia

The diagram below provides an example of a sample M&E logic model for dementia, including inputs, outputs, outcomes and impacts. The sample M&E logic model is aligned with the global dementia action plan.



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Developing and implementing a dementia plan is a complex process, involving ongoing multisectoral collaboration and stakeholder engagement. *Towards a dementia plan: a WHO guide* provides technical guidance to Member States in planning for, developing and implementing a dementia plan through a multi-phased, step-wise approach. Particularly important to the success of a dementia plan is the participation of people with dementia, their carers and families.



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