CONSULTATION ON THE DEVELOPMENT OF THE GLOBAL DEMENTIA OBSERVATORY

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CONTENTS

Acknowledgements

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

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

Introduction

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

Dementia currently affects more than 47 million people worldwide, and this figure is expected to rise to 75 million by 2030. Dementia costs billions – in 2015 the global cost of caring for people with dementia was estimated to be US$818 billion – 1.1% of global gross domestic product (GDP). By 2030, this cost could be a staggering US$2 trillion or more, which would undermine social and economic development globally.[1] Sixty percent of people with dementia live in low- and middle- income countries, and this proportion is projected to only increase over the next decade, which will widen inequalities between countries and populations.[2]

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

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

Background and Rationale for Meeting

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

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

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

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

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

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[1] WHO. The epidemiology and impact of dementia: Current state and future trends. Geneva: World Health Organization; 2015, Document WHO/MSD/MER/15.3, available at:
http://www.who.int/mental_health/neurology/dementia/dementia_thematicbrief_epidemiology.pdf (accessed 22 November 2016)
[2] Prince M, Wimo A, Guerchet M, Ali GC, Wu Yutzu, Prina M. World Alzheimer Report 2015. The global impact of dementia: an analysis of prevalence, incidence, cost and trends. London: Alzheimer's Disease International, October 2015.
[3] Who First Ministerial Conference on the Global Action Against Dementia
http://www.who.int/mental_health/neurology/dementia/conference_2015/en/

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

Objectives and Expected Outcomes

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

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

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

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

Declaration of Interests

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

SUMMARY REPORT

The consultation began with discussions on the global landscaping conducted to assess the situation on dementia, working with countries to pilot a draft of the GDO and its conceptual framework. The results and feedback from pilot countries was presented and discussed followed by further discussion to arrive at next steps for the GDO and its framework.

Global Landscaping

Extensive, comprehensive reviews were undertaken as part of a global and national landscaping of the existing dementia situation to inform the development of the GDO (refer to Appendix 3 for reference list). The documents reviewed included:

- major international dementia source documents
- national dementia plans, strategies, frameworks, policies and guidelines accessed via national government websites and other collations such as MindBank[4]
- global and regional observatories (e.g. WHO-AIMS, WHO Mental Health Atlas, the European Observatory on Health Systems and Policies and the WHO Global Health Observatory)
- projects supported under the 7th Framework Programme and Horizon 2020 of the European Commission
- other work led by the Organization for Economic Cooperation and Development (OECD), Alzheimer's Disease International (ADI, including 10/66 dementia research group), European Commission (EC, including the Joint Programme – Neurodegenerative Disease Research - JPND), Alzheimer's Europe (AE) and the World Dementia Council (WDC) in the area of dementia

Publicly available dementia plans, strategies and guidelines as well as available data observatories were systematically searched for all Member States. The landscaping also identified, at a national level, the ministries and departments likely to be involved in the data collection process (e.g. Departments of Health, Social Services, Ageing or Research). Data was extracted independently by two reviewers and analyzed as a whole.

The landscaping served multiple purposes: 1) systematically map priorities and objectives 2) identify currently available indicators and data collected 3) identify a broad group of stakeholders and advisers to consult with during the development of the GDO and 4) determine readiness of potential pilot countries.

Stakeholder Analysis

A broad range of stakeholders were identified to provide inputs to the development of the framework and indicators of the GDO. These consisted of:

- Policy makers and service delivery representatives - Focal points for mental health, ageing, noncommunicable disease and dementia unit within Ministries

- Researchers – These included directors of dementia institutes, primary investigators of large cohort studies and early/mid career researchers specialized in dementia

- Community & Consumer Representatives – People living with dementia and their carers, nongovernmental organizations, civil societies, Alzheimer's associations

The stakeholders were identified based on their expertise, country of origin to ensure representation from all six WHO regions and from all country income levels. In addition, representatives from key global organizations were invited to participate.

Pilot Testing Process

A description of the pilot testing process served as a segue to the main objective of the meeting. Countries were invited based on their expected readiness to participate in the pilot or their expressed interest in testing the draft

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[4] Available at: http://www.mindbank.info/

Observatory instrument. Countries from all six WHO regions were represented as well as across low-, middle- and high-income countries, selected in close collaboration with WHO regional and country offices (Refer to Appendix 4 for further detail).

Country focal points who are often also Mental Health, Ageing or Noncommunicable Disease focal points, were appointed by each pilot country's Ministry of Health. The focal point liaised with the WHO Global Dementia team and received ongoing technical support as well as developed a data collection strategy.

A dementia landscaping was conducted for each potential pilot country to identify their dementia 'readiness', or level of dementia support currently available. The search strategy included reviewing peer-reviewed published literature as well as grey literature across 5 broad topics in combination with country names (Figure 1).
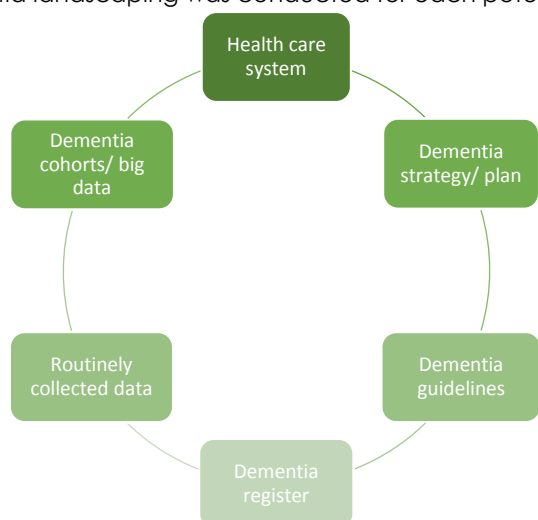
Figure 1: Topics and data collected for pilot country landscaping to identify dementia readiness

The retrieved information was also checked against published reports and existing online databases/platforms for validation purposes. This cross-validation included but was not limited to the ADI website, Alzheimer Europe website, the World Dementia Council, WHO's Mindbank as well as published review articles on national dementia plans/guidelines and population level studies.

Conceptualization of the Global Dementia Observatory Framework

Based on the global landscaping and in close collaboration with relevant stakeholders including leading international dementia experts, organizations and persons with dementia and their carers, a draft conceptual framework for the GDO was developed. The draft framework used as its foundation, the following documents:

- o The ten objectives of the OECD/WHO dementia care framework (2015)[5]
- o The recommended objectives for a national dementia plan made in the ADI report titled 'Ideas and Advice on Developing and Implementing a National Dementia Plan' (2013) [6]
- o The European Commission Council Conclusions on Supporting People Living with Dementia (2015)[7]
- o The WHO Call for Action resulting from the First WHO Ministerial Conference on Global Action against Dementia (2015)[8]

The framework included major domains and cross-cutting themes within which all indicators aligned.

The major domains are described as the building blocks or levers that countries could employ to develop their health systems to support people with dementia. They are as follows:

1. **Policy** - Availability and state of implementation of action plans, frameworks, policies or guidelines related to dementia, mental health or ageing

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[5] Available at: http://www.oecd.org/health/addressing-dementia-9789264231726-en.htm

[6] Available at: https://www.alz.co.uk/sites/default/files/pdfs/global-dementia-plan-report-ENGLISH.pdf

[7] Available at:
https://ec.europa.eu/health/sites/health/files/major_chronic_diseases/docs/councilconclusions_1505515_en.pdf

[8] Available at: http://www.who.int/mental_health/neurology/dementia/call_for_action/en/

2. **Resources** - Encompasses data on health care system, formal/informal human resources, psychosocial interventions for patients and carers, service utilization and financing of resources
3. **Research** - Financial national commitment to dementia research, ongoing (population-level) research studies
4. **Burden & Impact** - Comparative epidemiological data to assess disease prevalence and burden

The cross-cutting themes can be considered objectives or goals that countries would aspire to achieve within their health systems. These are outlined in Table 1 and mapped against major objectives identified by three other international frameworks.

Table 1: Cross-mapping of Global Dementia Observatory key objectives against the four key documents used as the foundation of the Observatory Framework

	Global Dementia Observatory	OECD/WHO Framework	ADI Framework	EC council conclusions	WHO Call for Action
1	**Putting dementia on national agenda**	-	Monitor progress	Dementia plan, strategy or action plan	Raising the priority accorded to global efforts for dementia; supporting plans and policies at all levels, esp for LMICs
2	**Respect for and inclusion of the person living with dementia**	-	-	-	engagement, respecting human rights
3	**Dementia awareness and literacy**	-	Improve awareness and education	Awareness-raising	Promoting a better understanding of dementia, raising public awareness, reducing stigma and discrimination
	Dementia-friendly communities	Early Dementia - Safe Communities	-	Dementia-friendly communities	Gender-sensitive approach
4	**Risk reduction**	Risk reduction	-	Health promotion and prevention in dementia	Advancing prevention, risk reduction
5	**Capacity building of health and social workforce**	-	Improve training for healthcare professionals	Workforce development	capacity building of the workforce
6	**Timely diagnosis and treatment**	Diagnosis	Improve (early) diagnosis and treatment	Timely diagnosis & post-diagnostic services	Advancing diagnosis and treatment consistent with evidence
7	**Care coordination**	Care coordination	Better integrate care pathways and the coordination of care		Advancing coordinated delivery of health and social care
	Dementia management in the community	Advanced dementia – access to social care	Improve support available at home	Health care (including social services)	identifying and addressing barriers to dementia care
	Dementia in residential care	Advanced dementia – safe & appropriate environments	Improve residential/ institutional care	-	-
	Dementia in hospital	Advanced dementia – health service effectively manage dementia	-	-	-
	End of life care	End of life care	-	-	-
8	**Caregiver support**	Early dementia – caregivers are supported	Strengthen support available to family care-givers	Support to Patients/Families/in formal carers	support mutual care-taking across generations and strengthening support and services for caregivers
9	**Research and innovation (domain)**	Role of technology	-Commitment to research	Epidemiology & data collection	-Increasing collective efforts in dementia

		-Recognise the role of innovative technologies		research and fostering collaboration -Facilitating technological and social innovations

Representatives from the OECD, ADI and the EC were present at the Consultation meeting and described the work that had taken place in the development of their frameworks, which the GDO framework was mapped against. In addition, three other global organizations/initiatives, EU Joint Action Against Dementia (JPND), World Dementia Council and Dementia Alliance International, presented brief commentaries on the GDO, its framework and complementary work they are conducting to support evidence-based decision making in dementia.

All six organizations emphasized the collaborative approach required and taken to developing the GDO framework and the importance of leveraging mutual expertise and harmonization with existing indicators to standardize definitions and reduce the burden of data collection on Member States. The broad scope of the GDO and the coverage across countries were seen as significant addition. All organizations reiterated the need for data on dementia to support policy and service planning. They identified the need to ensure sustainability of the GDO for it to meet its objectives and encouraged the future focus on quality of life indicators that can better measure outcomes for people with dementia.

Below are summaries of the presentations, discussion and outcomes by domain (outlined below).

Domain	Sub-domain
Policy	Policy, strategy, or plan
	Legislation
	Guidelines & frameworks
	Monitoring
	Government spending
Service delivery	Infrastructure
	Workforce
	Services and interventions
	Social supports & benefits
Research	Ongoing research
	Innovations
Epidemiology (Burden & Impact)	Prevalence
	Incidence
	Mortality
	Disability
	Economic cost
	Risk factors

Domain 1: Policy

The Policy domain contains 5 sub-domains: Policy, strategy or plan; Legislation; Guidelines & frameworks; Monitoring; and Government spending.

Currently data is unavailable for the majority of this domain except for a count of the number of countries that have developed national dementia plans, strategies, frameworks or policies. This data is available through Alzheimer's Disease International as well as collated by WHO's MiND Bank, a database of resources covering mental health, substance abuse, disability, general health, human rights and development.

Domain 1: Results of Pilot Phase

Of the 22 countries that participated in the pilot, 21 countries provided at least some data as well as feedback on all the indicators in the Policy domain (Figure 2). There was an average of 65% data completion, feedback for the domain with the highest completion being for the Guidelines and Framework sub-domain, and the lowest completion being for the Government spending sub-domain.

During discussions, focal points for pilot countries indicated that aggregating data on government spending for dementia is particularly difficult because most budgets are not stratified by disease. As well, this can be further compounded for countries with federated or decentralized health systems. However, focal points did agree that being able to consolidate this data would be valuable if available. A similar limitation was raised for the Legislation sub-domain as this data is generally not disease specific.

The Guidelines and frameworks sub-domain was the easiest for focal points to aggregate data on as this information is readily available (if guidelines exist), is disease specific and is often at a national level.

Figure 2: Completion of data and feedback for the Policy domain stratified by sub-domain

These comments was correlated by the results of pilot countries' feedback on the relevance and feasibility of providing data for each subdomain (Figure 3) with Government spending having the highest percentage of non-feasible and/or non-relevant data.

Figure 3: Feedback from pilot countries on relevance and feasibility of data within the Policy domain, stratified by sub-domain
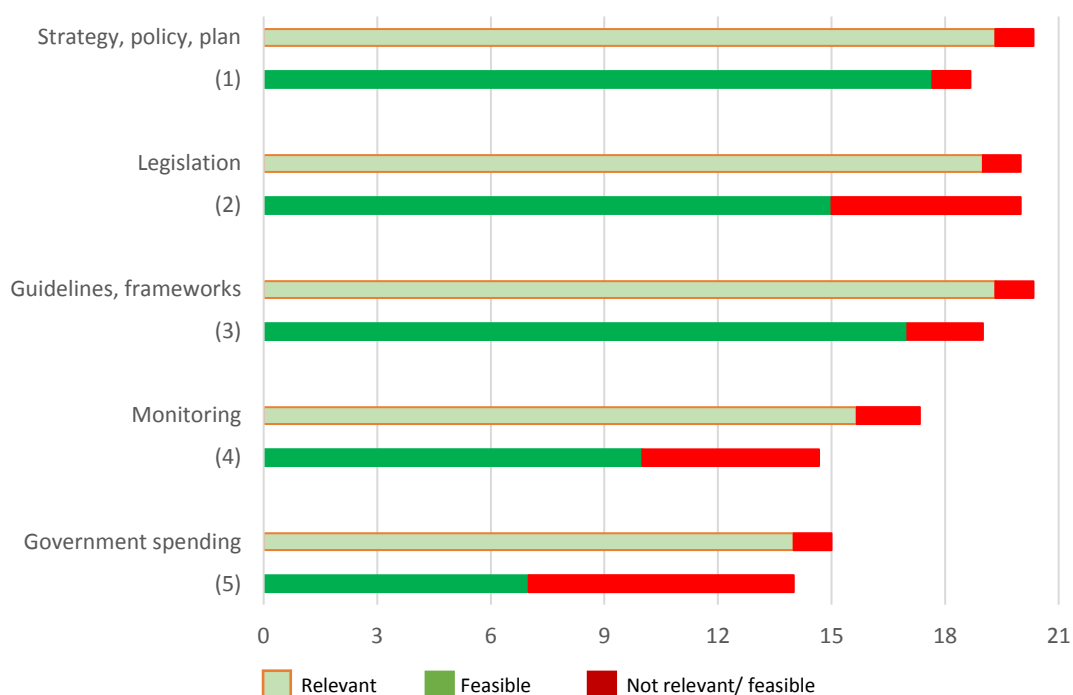
In their feedback, pilot countries described enablers and barriers to the collection of data as well as data sources and infrastructure encountered for the Policy domain (Table 2). Some of the key enablers overall identified by pilot countries were: providing more technical guidance in terms of assessing the available policies or plans as well as having access to electronic versions of the policies and plans to facilitate ease of data extraction.

Table 2: Enablers and Barriers to the Policy Domain, stratified by sub-domain

Sub-domain	Enablers	Barriers
Policy, strategy, plan	▪ Having a national dementia plan was considered a key enabler to supporting ongoing data collection ▪ Having an implementation plan along with the national dementia plan ▪ More guidance around assessing integrated plans or assessing plans that exist at national and regional levels	▪ Lack of awareness at the policy maker level and difficulties accessing plans in electronic formats were considerable barriers ▪ It was noted that assessing implementation status is difficult despite having an implementation plan and may not be conducive for cross-country comparisons given the qualitative nature of the responses
Legislation	▪ The legislation sub-domain indicators were considered to be largely relevant but not entirely feasible by pilot countries	▪ Appreciating that legislation is rarely disease specific and adapting the indicators as such ▪ Determining how legislation is operationalized is often not feasible
Guidelines	▪ The ongoing revision and updating of guidelines at a national level is an enabler to providing relevant information ▪ WHO's mhGAP also provides a very useful framework for developing guidelines if needed	▪ The indicator definition includes 'government approved' guidelines and this is not always the case, which should be captured ▪ Guidelines may only be available at a regional/local level and for different contexts (e.g. public/private, hospital/primary care)
Monitoring	▪ Having access to: health information systems, electronic medical records, national insurance claims data or patient registries on dementia would be beneficial. This was not possible during the pilot phase	▪ Policy makers may not be aware of concerns with data, or the use of data for this purpose ▪ The under-reporting of dementia is a serious limitation even when electronic information is available

Government spending	▪ National research estimates on cost and national reports are key data sources	▪ Disease specific budget line items are rare at the national level in government ▪ Regional budgets combined with local budgets can be difficult to separate ▪ Determining cost of all care (including comorbidities) for people with dementia vs. only the cost of caring for dementia

The primary feedback provided by pilot countries for the Policy domain is that the indicators are mostly relevant and of value to monitor over time, though there are some issues with feasibility given the level of detail requested in the data. It was suggested this may be circumvented if measures can be defined differently, allowing for broader definitions or developing sub-measures for specific indicators.

Domain 2: Resource

The Resource domain consists of 4 sub-domains: Infrastructure; Workforce; Services & interventions; and Social supports & benefits. Despite the value of this data in health system planning, global, regularly collected data is only available on the numbers of health professionals who could provide care for dementia through the Global Health Observatory, the OECD and the EU (through the EuroStat database). The WHO Mental Health Atlas collects mental health specific data which often has some overlap with dementia with regard to facility capacity as does the OECD on long-term care data, but regularly updated dementia specific information is limited.
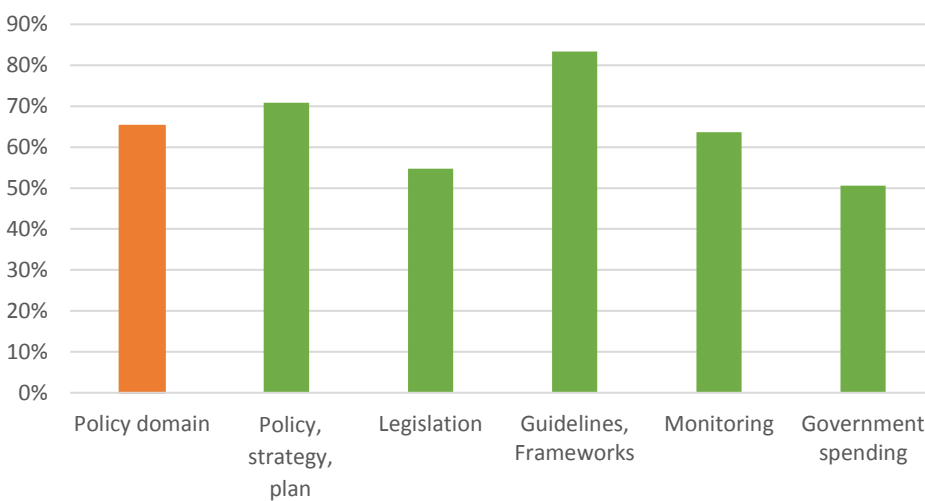
Domain 2: Results of Pilot Phase

Of the 22 countries that participated in the pilot, 20 countries provided at least some data as well as feedback on indicators in the Resource domain. The sub-domain with the lowest completion was the Workforce sub-domain (Figure 4).

Figure 4: Completion of data and feedback for the Resource domain stratified by sub-domain
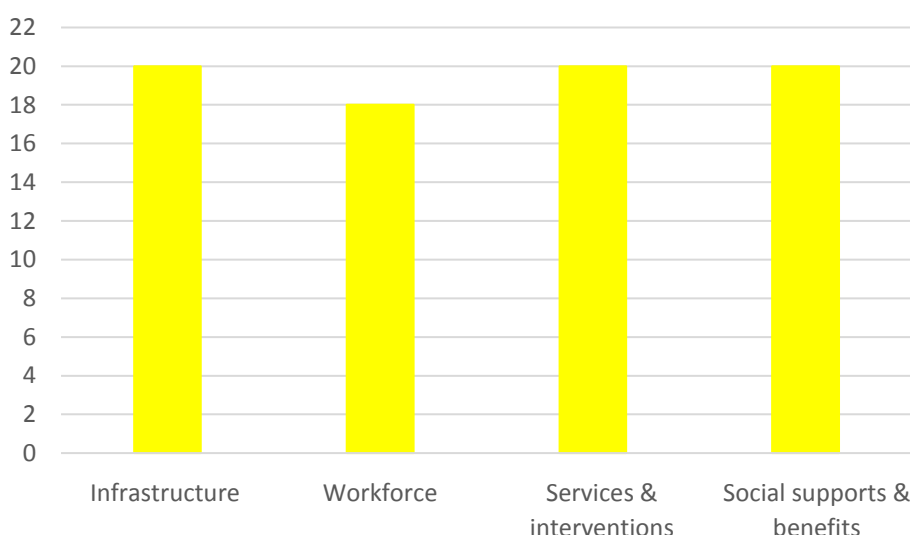
Many pilot countries were unable to provide data on Workforce as it would require dementia-specific information that is not aggregated or not frequently updated, primarily related to dementia training of the workforce. Focal points did agree however, that while this information may not be readily available, it is data that countries should aspire to collect and develop systems for aggregation over time. Data on dementia training for non-health professionals was also considered highly relevant but not necessarily feasible data in the short-term. For the other 3 sub-domains, the majority of data was considered to relevant as well as feasible in terms of aggregating at a national level (Figure 5).

As was correlated in the completion data, feedback from pilot countries on the feasibility of indicators in the Workforce sub-domain was the lowest, though considered highly relevant. Pilot countries with federated systems had difficulty with aggregating data at a national level, though feedback was given that this may be possible given more time.

Figure 5: Feedback from pilot countries on relevance and feasibility of data within the Resource domain, stratified by sub-domain
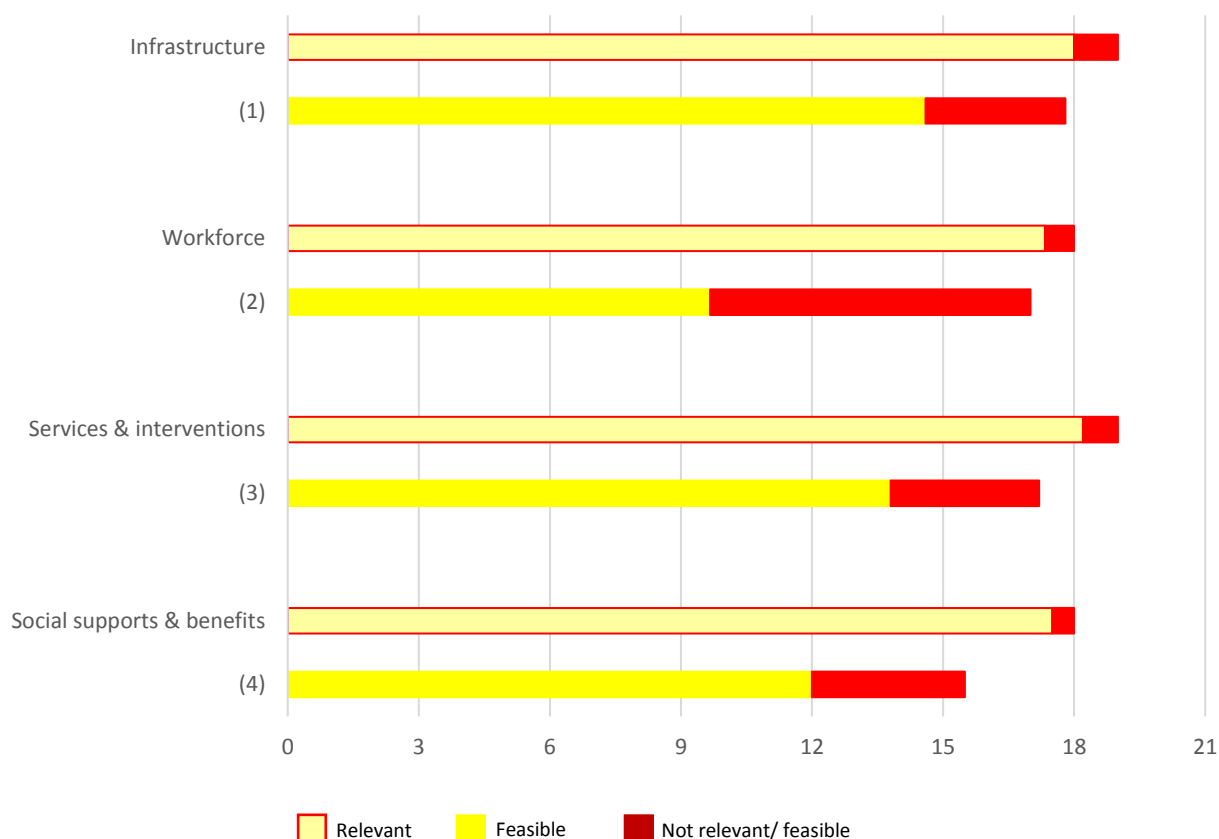
In overall comments for the Resource domain, pilot countries identified clearer and concise definitions with specific data categories would be enablers to support cross-country comparisons of data (Table 3). Due to the variability in facility definitions and functions for example, or service definition and coverage. Participants identified that with multi-jurisdiction or decentralized systems, information on Resources can often be difficult to aggregate or link data and that the ability to reflect this regional variability would be an enabler to providing the data. Other limitations were possible issues with the quality of available data.

Table 3: Enablers and Barriers to the Resource Domain, stratified by sub-domain

Sub-domain	Enablers	Barriers
Infrastructure	▪ Establishing a common global classification system would support comparison between countries of facilities ▪ There is often regional/provincial variability that may need to be reflected in measures	▪ Limitations in the ability to collect dementia-specific numbers and admissions data as well as validity of available data is a barrier ▪ Some health systems do not have a gate-keeper approach making it difficult to link data and respond ▪ Health systems with a mix of private and public facilities have difficulty monitoring across facilities
Workforce	▪ Density of the workforce is more informative but total numbers is a useful preliminary determinate	▪ Often, data do not specifically identify staff who specialise in providing care for people with dementia
Services & interventions	▪ Measures are useful to understand programming for providing accurate information, particularly non-cognitive symptoms such as BPSD ▪ The data would be useful for the development of local and global guidelines and policy and to make comparisons between countries ▪ Some categories are too broad and may overlap, consider re-defining	▪ Legal and privacy agreements may prevent disclosure of sales and cost data on drugs, though it is monitored ▪ There are a variety of services provided by a mix of NPOs as well as government making it difficult to capture this information

Social supports & benefits	▪ May be some limitations with definitions regarding cash benefits versus pensions, clearer definitions would be useful	▪ Subjectivity of data is a limitation as well as the possible overlap of funding

The key take-away from this session was that the Resource domain is essential for collecting comparable information for cross-country comparisons and that the indicators are relevant to most countries regardless of income level, however there are feasibility issues that can only be addressed over time, particularly with dementia-specific data.

Domain 3: Research

The research domain is the smallest domain of the GDO consisting of only two sub-domains: Ongoing research, and Innovation. While data on research does exist and is frequently aggregated, it has been difficult to map its scope for comparability due the broad variability of dementia research as well as the often disparate funding. This domain will therefore attempt to build on the lessons learned from previous initiatives in collating the scope of global dementia research in order to identify good practice as well as gaps in the literature.

Domain 3: Results of Pilot Phase

Of the 22 countries that participated in the pilot, a maximum of 20 countries provided at least some data as well as feedback on indicators in the Ongoing Research sub-domain while 17 countries provided at least some data and feedback on the Innovations sub-domain (Figure 6).

Figure 6: Completion of data and feedback for the Research domain stratified by sub-domain
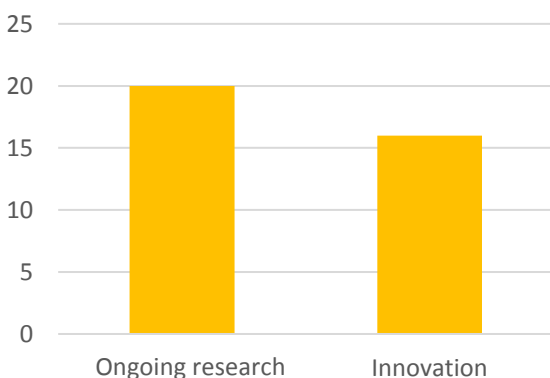
In overall comments, countries found this domain the most difficult to provide data and feedback on due to the often decentralized systems in place to fund research and due to limitations in categorization.

While the data for these sub-domains were considered highly relevant, they were not always feasible (Figure 7). Participants discussed the interest in dementia diagnostic, treatment and care innovation as well as the limitations with scalability and spread of best practice.

There is a significant body of work that occurred and is currently underway through other organizations to better capture the scope of dementia research occurring globally. The Joint Programme Neurodegenerative Disease Research (JPND)[9] has conducted detailed mapping exercises on a sub-set of countries within the EU to categorize the type and amount of funded research in neurodegeneration, which includes dementia. Similarly, the International Alzheimer's Disease Research Portfolio (IADRP)[10] developed a database on funded dementia research supported by private and public organizations in the US and abroad, though this was not always at a national level.

Lastly, the WHO & OECD conducted a one-time Funding Portfolio Analysis to create understanding and awareness of the research landscape for dementia across the G7 countries. The WHO also conducted a Research Prioritization study recently published, to identify key dementia research priorities[11]. It all cases, it was agreed that by understanding the spectrum of research covered in dementia, it is possible to identify gaps and

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[9] Available at: http://www.neurodegenerationresearch.eu/

[10] Available at: https://iadrp.nia.nih.gov/cadro-web/

[11] Shah H, Albanese E et al. (2016). Research priorities to reduce the global burden of dementia by 2025. Lancet Neuro 15(12), 1285-1294

shifts in trends, however moving forward with consistent classification that is comparable and has good coverage of the scope of research can be difficult.

Figure 7: Feedback from pilot countries on relevance and feasibility of indicators within the Research domain, stratified by sub-domain
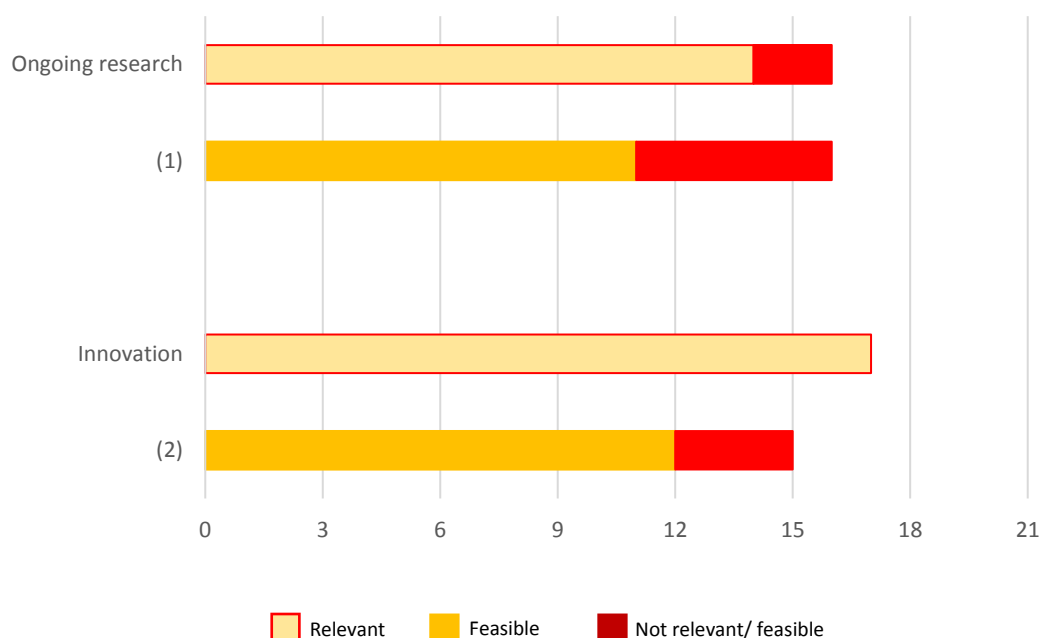
The previous experiences of collecting data on this domain was reflected in the enablers and barriers discussed by focal points at the meeting (Table 4).

Table 4: Enablers and Barriers to the Research Domain, stratified by sub-domain

Sub-domain	Enablers	Barriers
Ongoing research	▪ Data can be collected from different organizations and institutes but the category of dementia must be clearly defined ▪ Important to understand gaps in research topics so that new research studies can focus on important topics not covered by current or recent studies ▪ Ensure that overlap between categories is minimal	▪ May be difficult to estimate national funds for dementia research in decentralized systems ▪ Too many sources of information can make full coverage difficult to achieve ▪ Can be difficult to identify dementia specific projects or scope of dementia despite clear definitions ▪ Possible underreporting of data
Innovation	▪ Many experiences are at the regional and local level, need to find ways to capture this ▪ Clearer definition of 'innovative technology' would support more appropriate data capture	▪ May be difficult to collect data or to report systematically experiences in this field

The limitations of the Research domain, as well as its strengths, are best summarized on two ends of the spectrum. The first is that in low resourced countries, not much research is occurring resulting in little reporting and more emphasis needed on building research infrastructure. For high resourced countries, a substantial amount of research is occurring however this is often fragmented and not centrally collated making it very difficult to provide national level information. Both these perspectives need to be captured in the GDO.

Domain 4: Epidemiology (Burden & Impact)

The Epidemiology domain includes six sub-domains consisting of: Prevalence, Incidence, Mortality, Disability, Economic costs and Risk factors associated with dementia. This domain did not require significant piloting as

most of the data would be centrally generated by WHO or linked to data from other sources such as the WHO Global Health Observatory, WHO Mortality database, the Global Burden of Disease study data and the OECD (See Appendix 3). However, pilot countries provided feedback on the feasibility of collecting data for this domain. This domain is the largest of the four domains with the largest number of indicators that would require quantitative data.

Estimates for data in this domain have been previously produced by other organizations such as Alzheimer's Disease International[12,13], though these are not on an annual basis (previously produced in 2006, 2009, 2012 and 2015). Representatives from these organizations and from the collaborating research centres that helped produce these results were in attendance at the Consultation meeting and presented on the methodology developed, as well as the successes and limitations experienced.

The systematic and standardised methodologies for producing global, regional and country-level estimates of dementia burden and impact were presented to participants. These estimates required conducting a full systematic review of all relevant country-level studies available. A challenge however has been the rapid demographic transitions that make it difficult to generalize individual study results and require the regular collection of data at a national level from countries, which would be facilitated by the GDO.

Similar presentations were made on the global societal economic cost of dementia. These figures were based on a global database of service or resource utilisation studies, and unit or total costs for individual countries estimated from assumed relationship with GDP. While producing useful estimates previously unavailable, these estimates had limitations due to their dependence on dementia prevalence data which is not always available and cost of illness data from local studies that are extrapolated to the larger country-level population. Again, the regular collection of national level data from countries through the GDO would be extremely beneficial in mitigating some of these limitations.

This domain also includes dementia risk factors. The current evidence for dementia risk factors were reviewed, including possible inter-relationships between dementia and noncommunicable disease and lifestyle-related risk factors. These risk factors include for example physical inactivity, obesity, unbalanced diets, tobacco use, harmful use of alcohol, diabetes mellitus and mid-life hypertension. Reducing the level of exposure of individuals and populations to these potentially modifiable risk factors, beginning in childhood and extending throughout life, can strengthen the capacity of individuals and populations to make healthier choices and follow lifestyle patterns that foster good health and healthy ageing. Population prevalence rates of these risk factors are already routinely monitored by WHO as part of the voluntary targets in the Global Action Plan for Prevention and Control of Noncommunicable Diseases 2013–2020[14]. Other potentially modifiable risk factors presented specific to dementia include social isolation, low educational attainment, cognitive inactivity and mid-life depression.

Overall feedback was that pilot countries would find this domain extremely valuable in being able to measure population trends and the impact of dementia in their country. The standardized approach can enable useful comparisons across countries of similar income, population size and health system structure.

Domain 4: Results of Pilot Phase

At least 17 of the 22 pilot countries provided feedback on the relevance, feasibility and limitations of these sub-domains (Figure 8). The lowest amount of feedback was provided for the Risk factors sub-domain. This was likely due to these indicators already being collected for the purposes of the Global Action Plan for the Prevention and Control of Noncommunicable Diseases 2013-2020[14].

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[12] Alzheimer's Disease International (2010). World Alzheimer Report 2010 – Global Economic Impact on Dementia; available at: https://www.alz.co.uk/research/world-report-2010
[13] Alzheimer's Disease International (2015). World Alzheimer Report 2015 - The Global Impact of Dementia, available at http://www.worldalzreport2015.org/downloads/world-alzheimer-report-2015.pdf
[14] Available at http://www.who.int/nmh/publications/ncd-action-plan/en/

Figure 8: Completion of feedback by pilot countries for the Epidemiology domain stratified by sub-domain
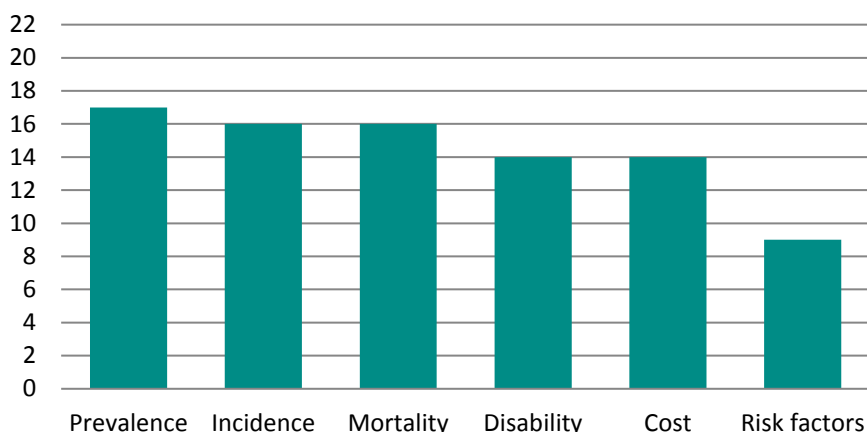
In their feedback pilot countries described enablers and barriers to the collection of data in this domain, as well as possible alternate data sources and infrastructure needs encountered (Table 5). In general, strengthening the capacity and capabilities of health information systems in their routine monitoring of key dementia indicators across multiple sectors and settings was perceived as highly valuable. On the other hand, the persistent lack of large-scale population-based epidemiological dementia research and under-reporting of dementia diagnoses in administrative data hinder accurate planning at this stage.

Table 5: Enablers and Barriers to the Epidemiology Domain, stratified by sub-domain

Sub-domain	Enablers	Barriers
Prevalence/ incidence	▪ Mandatory reporting through the use of dementia registries or health information systems would be a key enabler ▪ Data can be generated centrally using a standardized methodology ▪ Noting that it is easier to collect data in some settings vs others, e.g. hospitals, public vs private	▪ No prevalence studies available for some countries and for some large regions making extrapolations difficult ▪ The under-reporting of dementia ▪ Different specialities treating dementia can be a barrier in reporting
Mortality	▪ The use of ICD-10 coding on death certificates, death records enables standardization ▪ Linking mortality to health information systems ▪ Training workforce in completing death certificates and coding dementia as primary or secondary cause of death would significantly improve quality	▪ Under-reporting of dementia on death certificates ▪ Quality of reporting of dementia on death certificates ▪ Inconsistent use of codes/varying definitions
Disability	▪ Training of information system staff on disability weighting methodology ▪ Educating through awareness to encourage engagement ▪	▪ Significant barrier is the lack of technical and financial capacity for many countries ▪ Dementia is often not considered a disability
Economic costs	▪ Data can be generated centrally using a standardized methodology ▪ Some countries produce their own cost estimates	▪ Costs vary for public and private system ▪ Indirect family costs are not routinely collected, but could be established through population surveys ▪ Some countries do not have the capacity to calculate cost estimates
Risk factors	▪ Data for most risk factors can be easily extracted and leveraged from NCD monitoring	▪ Literacy rate not available for many countries ▪ Relevant age-stratification of risk factors might not be available ▪ Lack of evidence/evolving evidence ▪ More research needed regarding causal mechanisms, thresholds for risk, optimal levels of protective factors, for different populations

The overall feedback was that the methodology and data from this domain are paramount for health system planning, but will require rigour and time to establish baselines within countries.

The Way Forward

The two-day Consultation meeting on the development of the GDO had 4 key objectives:

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

The conceptual framework formed the basis of the indicators pilot tested in the draft Observatory instrument. After reviewing the landscaping conducted for the development of the GDO and the feedback from pilot countries, participants reached consensus on the conceptual framework. It was agreed that the matrix format of the framework with the domains and cross-cutting themes together contribute to a comprehensive coverage of the key issues faced in dementia diagnosis, treatment and care across the continuum.

In June 2016, the WHO Executive Board in decision EB139(1)[15] requested the Secretariat to develop a draft *Global Action Plan on the Public Health Response to Dementia*, with clear goals and targets. Subsequently, in January 2017[16] the Executive Board considered the draft dementia global action plan and recommended to the Seventieth World Health Assembly to adopt the decision to endorse the plan during its review in May 2017.

WHO's vision, as described in the draft action plan, is a world in which dementia is prevented and people with dementia and their carers live well and receive the care and support they need to fulfil their potential with dignity, respect, autonomy and equality. The action plan has seven strategic areas, 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 and Dementia research and innovation. The GDO will serve as the monitoring mechanism of the global dementia action plan, collecting data for the global targets as well as data more broadly on the status of dementia at a national level.

The conceptual framework was revised subsequent to the Consultation meeting to align more closely with the global dementia action plan. These revisions include aligning the conceptual framework themes with the 7 action areas of the action plan as well as the cross-cutting principles and based on feedback from participants, reducing the number of domains (revised framework, Appendix 5).

The follow were identified as next steps to move the GDO and dementia agenda forward:

- Revising and finalizing the indicators pilot tested in the Observatory instrument
- Developing an e-tool and used for data collection
- Developing the web-based knowledge exchange platform

The GDO platform will support evidence-based service planning and strengthening of policies. The comparable analytics at country-level as well as the dissemination of resources will support dementia readiness and progress.

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[15] WHO Executive Board. 139th session decisions and list of resolutions; June 2016.
(http://apps.who.int/gb/ebwha/pdf_files/EB139/B139_DIV2-en.pdf)
[16] WHO Executive Board. 140th session decisions and list of resolutions; Jan 2017.
(http://apps.who.int/gb/ebwha/pdf_files/EB140/B140(7)-en.pdf)

APPENDICES

Appendix 1: Meeting Agenda

DAY 1 AGENDA – Tuesday 5TH JULY 2016

Registration	08:00– 9:00AM
Introductions	9:00 – 9:30AM

Welcome Address	Oleg Chestnov (Assistant Director General, Noncommunicable Diseases and Mental Health, WHO)
WHO Global Dementia Observatory	Shekhar Saxena (WHO)
Objectives and agenda of the meeting	Tarun Dua (WHO)

Session 1. The Global Dementia Observatory Conceptual Framework	9:30AM – 10:45AM

The development of the Global Dementia Observatory conceptual framework	Tarun Dua (WHO)
Perspectives from different stakeholders Dementia Alliance International (DAI) Organization for Economic Co-operation and Development (OECD) The European Commission (EC) EU Joint Action Against Dementia (JAAD) Alzheimer's Disease International (ADI) World Dementia Council (WDC)	

Coffee Break	10:45AM – 11:15AM
Session 2: Domain on Monitoring Dementia Burden & Impact	11:15AM – 12:30PM

Overview of the dementia burden and impact domain	Katrin Seeher (WHO)
Methodology to estimate dementia prevalence, incidence, mortality, disability and cost	Martin Prince (King's College London)/ Anders Wimo (Karolinska Institute)
Monitoring dementia risk factors	Kaarin Anstey (Australian National University)
Discussion	

Lunch Break	12:30PM – 2:00PM
Session 3: Domains on Monitoring Dementia Policy and Resources	2:00PM – 3:30PM

Plenary summarizing policy and resource domain data and feedback; format of breakout group sessions	Tarun Dua (WHO)
Breakout group sessions (Salle A, M105, M205)	

Coffee Break	3:30PM – 3:45PM

Session 3: Continued breakout group sessions	3:45PM – 5:30PM
Continued breakout group sessions	
Reception	6:00PM – 7:30PM

DAY 2 AGENDA – Wednesday 6TH JULY 2016

Session 4: Feedback from breakout group sessions on Dementia Policy and Resources	9:00AM – 10:30AM
Plenary – Feedback from breakout group sessions	
Discussion	
Coffee Break	10:30AM – 11:00AM
Session 5: Domain on Monitoring Research and Innovation	11:00AM – 12:15PM
Global efforts to monitor dementia research	Martin Rossor (University College London)
Overview of the dementia research & innovation domain	Saskia Sivananthan (WHO)
Discussion	
Lunch Break	12:15PM – 1:45PM
Session 6: Next steps	1:45PM – 2:45PM
Presentation of data collection strategy, output formats of the Observatory, function of knowledge exchange platform and next steps	Tarun Dua (WHO)
Discussion	
Session 7: Inputs on Developing the Draft Global Action Plan on Dementia	2:45PM – 4:00PM
Preliminary feedback from the participants	Shekhar Saxena (WHO)
Coffee break	4:00PM – 4:30PM

Appendix 2: Participant List

Consultation on the Global Dementia Observatory

WORLD HEALTH

ORGANIZATION

05 & 06 July 2016 Geneva, SWITZERLAND

Venue: Salle A, WHO Main Building

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Appendix 3: Documents reviewed in global landscaping

Alzheimer's Disease International (2015). World Alzheimer Report 2015 - The Global Impact of Dementia, available at http://www.worldalzreport2015.org/downloads/world-alzheimer-report-2015.pdf

Alzheimer's Disease International (2014). World Alzheimer Report 2014 – Risk reduction, available at: https://www.alz.co.uk/research/world-report-2014

Alzheimer's Disease International (2013). World Alzheimer Report 2013 – Long-term care, available at: https://www.alz.co.uk/research/world-report-2013

Alzheimer's Disease International (2012). World Alzheimer Report 2012 – Overcoming stigma, available at: https://www.alz.co.uk/research/world-report-2012

Alzheimer's Disease International (2011). World Alzheimer Report 2011 – Early diagnosis and intervention, available at: https://www.alz.co.uk/research/world-report-2011

Alzheimer's Disease International (2010). World Alzheimer Report 2010 – Global Economic Impact on Dementia; available at: https://www.alz.co.uk/research/world-report-2010

Alzheimer's Disease International (2013). Ideas and Advice on Developing and Implementing a National Dementia Plan; available at: https://www.alz.co.uk/sites/default/files/pdfs/global-dementia-plan-report-ENGLISH.pdf

Alzheimer's Disease International database of all publications resulting from 10/66 research projects; available at: http://www.alz.co.uk/1066/1066_publications.php

Alzheimer's & Dementia edition on Neuroimaging Initiatives; Alzheimer's & Dementia, Volume 6, Issue 3, May 2010

Alzheimer Europe (2015-2006). Dementia in Europe Yearbooks 2006 to 2015; available at: http://www.alzheimer-europe.org/Publications/Dementia-in-Europe-Yearbooks

Global Burden of Disease Study (2015). Global, regional, and national age–sex specifi c all-cause and cause-specifi c mortality for 240 causes of death, 1990–2013: a systematic analysis for the Global Burden of Disease Study 2013; available at: http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736%2814%2961682-2.pdf

Global Dementia Framework; available at: https://globaldementiaframework.wordpress.com/leadership/

Organization for Economic Co-operation and Development, OECD (2015). Addressing Dementia: The OECD response

Organization for Economic Co-operation and Development, OECD (2013). A Good Life in Old Age?: Monitoring and Improving Quality in Long-Term Care,

World Health Organization & Alzheimer's Disease International (2012). Dementia - A public Health priority, available at: http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf?ua=1

World Health Organization (2015). First WHO Ministerial Conference on Global Action against Dementia Report; available at: http://www.who.int/mental_health/neurology/dementia/ministerial_conference_2015_report/en/

World Health Organization (2015). Thematic briefs for the first WHO Ministerial Conference on Global Action against Dementia; available at: http://www.who.int/mental_health/neurology/dementia/thematic_briefs_dementia/en/

World Health Organization MiNDbank: More Inclusiveness Needed in Disability and Development; available at https://www.mindbank.info/tag/dementia?page=all

World Health Organization Global Health Observatory; available at: http://apps.who.int/gho/data/node.imr

World Health Organization Global Health Workforce Statistics: The 2014 update, Global Health Workforce Statistics, World Health Organization, Geneva (available at: http://www.who.int/hrh/statistics/hwfstats/)

World Health Organization Mental Health Atlas 2014, available at: http://apps.who.int/iris/bitstream/10665/178879/1/9789241565011_eng.pdf?ua=1&ua=1

World Health Organization WHO-AIMS, available at: http://www.who.int/mental_health/evidence/WHO-AIMS/en/

Appendix 4: Countries that Participated in the Observatory Pilot Phase

WHO REGION	PILOT COUNTRIES		
AFRICA	Mauritius	Swaziland	Togo
AMERICAS	Chile	Costa Rica	Dominican Republic
SOUTH-EAST ASIA	Bangladesh	Maldives	Myanmar
EUROPE	France	Hungary	Italy	Netherlands
	Sweden	Switzerland	UK
EASTERN MEDITERRANEAN	Jordan	Qatar	Tunisia
WESTERN PACIFIC	Australia	Fiji	Japan

Appendix 5: Draft Global Dementia Observatory Data Framework

Domains	Policy	Service delivery	Information&Research
	• Strategy / plan • Legislation • Guidelines	• Infrastructure • Workforce • Treatments & support	• Dementia epidemiology & cost • Risk factor prevalence • Research

Governance

1: Dementia as public health priority

Population

2: Dementia awareness and friendliness

3: Dementia risk reduction

Individuals

4: Dementia diagnosis, treatment, care and support

5: Support for dementia carers

6: Information systems for dementia

7: Dementia research and innovation

Cross-cutting principles	• Human rights • Empowerment • Evidence-based	• Multi-sector • Universal health • Equity	• Prevention, cure & care

CONSULTATION ON THE DEVELOPMENT OF THE GLOBAL DEMENTIA OBSERVATORY

This document presents the report on the consultation convened by WHO on the Development of the Global Dementia Observatory on 5-6 July 2016.

The WHO Global Dementia Observatory (GDO) is an interactive web-based data and knowledge exchange platform. The primary objective of the GDO is to collate and disseminate key dementia data from Member States to facilitate evidence-based service planning and policies as well as strengthening health and social care systems to support people with dementia and their carers.

WHO convened this consultation with Member States, policy makers, dementia experts, people with dementia and their carers, civil society representatives and other stakeholders who are involved in the development and implementation of national dementia policies and strategies. The meeting objectives were to present the landscaping, conceptual framework and feedback from pilot testing to arrive at a common vision for the GDO and a way forward for its further development