Alzheimer's Disease International

The global voice on dementia

From plan to impact

Progress towards targets of the Global action plan on dementia

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Contents

Note to reader

Throughout this report, distinction has been made between 'countries and territories' that have Alzheimer associations and WHO Member States. It is important to note that not all 'countries and territories' are WHO Member States and therefore do not align with the targets of the Global plan on dementia. For more information, please refer to page 34.

Notes

Every three seconds someone in the world develops dementia. Dementia affects 50 million people, costing the global economy over US$1 trillion in 2018. By 2030, there will be an estimated 82 million people with dementia, placing an unprecedented strain on health systems around the world.

In May 2017, the World Health Organization (WHO) adopted the *Global action plan on the public health response to dementia 2017-2025*[1]. This report provides an overview of the current responses to dementia around the world on the first anniversary of the adoption of the plan, in order that policy makers and civil society alike may come together for the realisation of a new era for people living with dementia and their care partners by 2025.

The following pages are ordered according to the 7 action areas and associated targets of the plan; *Dementia as a public health priority; awareness and friendliness; risk reduction; diagnosis, treatment, care and support; support for dementia carers; information systems for dementia; research and innovation.* For convenience, the latter sections have been included under *'Information systems, research and innovation';* and *'Support for dementia carers'* has been included under *'diagnosis, treatment, care and support'.* As the momentum behind targets of the Global plan grows, it is expected that each area will require appropriate additional analysis.

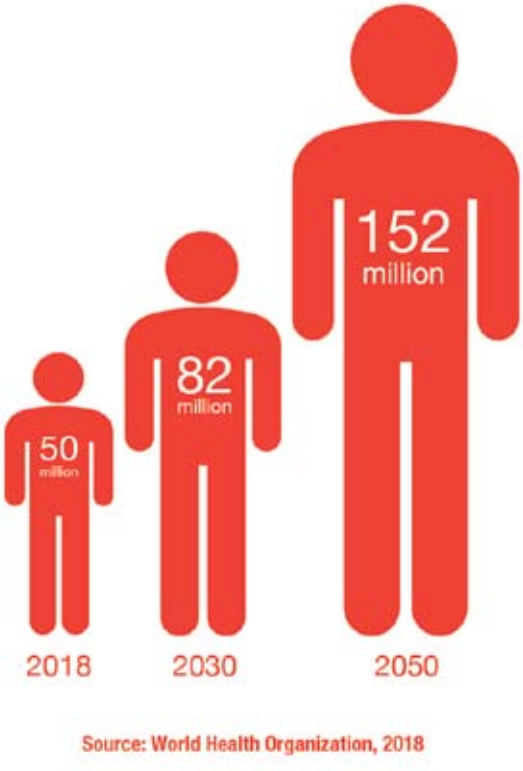


Figure 1: Estimated growth in number of people with dementia 2018-2050

As a first publication following the adoption of the Global plan, this report provides a limited view of the current policy landscape, based on the included definition of a dementia plan. Where possible, efforts have been made to broadly consider those governments that have made a significant inclusion of dementia in plans under the other areas of ageing, neurology or mental health. Plans on Non-Communicable Diseases (NCDs) are also briefly discussed on page 23. This approach does not recognise all plans and strategies on dementia that may exist as part of broader frameworks or policies on age or health. We welcome feedback on these areas for future editions.

Throughout the report, reference is made to the need for more research and data on dementia. In 2017, the WHO developed the Global Dementia Observatory, which will play a critical role in this area (see page 30).

The report reflects current information provided by Alzheimer associations in each country, key stakeholders and policy makers. Data used in the report includes that collated and sourced from the WHO Global Dementia Observatory between December 2017 and May 2018, from desk research on non-dementia policies and other frameworks and additional communication with Alzheimer associations and civil society groups in April and May 2018. The figures used in this report and on the ADI website are subject to ongoing revision, in order to include new information from Alzheimer associations and partners globally.

We welcome all feedback on this report, so that we may continue to strengthen the knowledge and debate for the development of a comprehensive response to the Global plan on dementia and its local impact.

1 World Health Organization (WHO), Global action plan on the public health response to dementia 2017-2025 (2017): http://www.who.int/mental_health/neurology/dementia/action_plan_2017_2025/en/

Foreword

Too little has changed since May 2017. Governments need to do more. This report comes one year after the unanimous approval of the Global plan on dementia by the World Health Organization (WHO). It is the first of a series that will gather the voices of civil society with the aim to ensure that the targets of the plan become reality and that it will make a tangible difference for people with dementia and their families all over the world. It is far from extensive, but will set out the current landscape in each of the strategic areas of the plan, including policy, awareness, research and data.

In 2017, WHO initiated the Global Dementia Observatory (GDO), a hugely important project that aims to gather governments' data on the progress of Member States against each target. In future, this report will play a key role in looking objectively at the GDO data, and comparing it with the real-life experiences of Alzheimer associations and other civil society organisations on the ground. Already, it is a wake-up call to over 120 governments that do not have a plan or are not yet contributing to the GDO, to add their efforts and expertise to the global fight against dementia.

Some governments are getting it right and we want to showcase their efforts. Much of this momentum has come from the Americas, where the impact of dementia is huge and effort to address it is great. Almost a third of the countries listed as having a dementia plan have listened to a key argument of ADI, which is to review progress, refine and adopt subsequent plans - examples include plans in Japan and Scotland.

Those who doubt plans can work can be inspired by these positive examples. Many governments are already doing a lot but often under the direction of different departments, authorities or ministries. At times, all that is needed is better information and coordination of existing activities. The result can be a pooling of resources and more provision of services for families that need them so badly.

What the report concludes is, in a nutshell, that at the current rate we will not achieve the targets by 2025. We need more action. I have witnessed first-hand the disinterest of some governments, or the decline of prioritisation of dementia, because of a change of leadership, or the emptiness of an unfunded plan.

Some governments are daunted by the 7 strategic areas of the Global plan, but civil society is here to help. We know that providing care, for example, is very expensive but we do need to see improvements in care now as well as investment in risk reduction, diagnosis and research for the future. The World Alzheimer Report 2016 showed that better coordination of health care systems can both improve outcomes for those affected and reduce the economic cost of addressing dementia over the long term.

All areas of the plan mean more if they work together. In fact, we can all achieve more if we work together.

Let's make 2018/9 the year when we really step up national efforts to get plans off the ground and make a considerable step towards a better world for people with dementia and their carers everywhere.

Paola Barbarino
Chief Executive Officer

Journey to the Global plan

ADI has advocated for a global response to dementia for over a decade. In May 2017, the Global plan became a reality, following comprehensive engagement with ADI and others on the concepts, vision and measurements of the plan. ADI is proud to have been a part of this process, representing the valuable, expert and personal input of Alzheimer associations, researchers, civil society, people with dementia and carers around the world. The key themes of inclusion and respect, timely diagnosis and continuous, quality care at all stages of the condition, including palliative care, are examples of some of the areas of the plan strengthened by this involvement, and from the achievements of the Alzheimer movement over a longer period.

Box 1.1

Vision

'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.'

Source: WHO, Global action plan on the public health response to dementia 2017-2025 (2017)

The first plan on dementia, adopted in 2001, set an example for attention to the impact of dementia at the national level. In 2009, ADI emphasised the significance of dementia globally with the launch of the first ever World Alzheimer Report[2] on dementia prevalence and the influence of new dementia plans developed in Australia, South Korea, England, Norway and the Netherlands.

In 2012, the significance of dementia was recognised by the WHO in a landmark publication with ADI, *'Dementia: a public health priority'*[3]. The title of this report is now the title of the first target of the Global plan; to develop additional national responses to dementia by 2025. In 2015, this was followed by the first ever WHO Ministerial Conference on Global Action Against Dementia[4], attended by representatives of over 80 countries and marked by a statement by ADI and 40 Civil Society Organisations containing key recommendations for the future.

Following the existing commitment of the G7 group of governments to address dementia, the conference positioned dementia as a global problem. By 2015, dementia plans had been adopted in over 20 countries, followed by the critical adoption of the first regional plan on dementia, in the Americas, by the Pan American Health Organization (PAHO, which serves as the WHO regional office for the Americas).

The PAHO plan was followed by development of the Global plan by WHO. In 2016, a 'zero draft' of the Global plan was made available for consultation by civil society groups worldwide. In January 2017, a new draft of the plan was presented at the 140th session of the WHO Executive Board, where representatives of 21 countries urged that the plan be considered for adoption in May that year.

ADI would like to reiterate its thanks to the entire WHO team, country representatives and all other individuals and groups that supported the unanimous adoption of the Global plan in 2017. The journey to make the plan truly matter begins now. On the first anniversary of this historic decision, it is vital to remember that we have a long way to go to realise the vision in box 1.1.

2 Alzheimer's Disease International (ADI), World Alzheimer Report (2009): https://www.alz.co.uk/research/world-report-2009

3 WHO and ADI, Dementia: a public health priority (2012): http://www.who.int/mental_health/publications/dementia_report_2012/en/

4 WHO, Ministerial Conference on Global Action Against Dementia,16-17 March, Geneva, Switzerland (2015): http://apps.who.int/iris/bitstream/handle/10665/179537/9789241509114_eng.pdf?sequence=1

Action areas

Dementia as a public health priority

75% of countries will have developed or updated national policies, strategies, plans or frameworks for dementia, either stand-alone or integrated into other policies/plans, by 2025.

Dementia awareness and friendliness

100% of countries will have at least one functioning public awareness campaign on dementia to foster a dementia-inclusive society by 2025.

50% of countries will have at least one dementia-friendly initiative to foster a dementia-inclusive society by 2025.

Dementia risk reduction

The relevant global targets defined in, and in keeping with, the Global action plan for prevention and control of noncommunicable diseases 2013–2020 and any future revisions are achieved.

Dementia diagnosis, treatment, care and support

In at least 50% of countries, as a minimum, 50% of the estimated number of people with dementia are diagnosed by 2025.

Support for dementia carers

75% of countries provide support and training programmes for carers and families of people with dementia by 2025.

Information systems for dementia

50% of countries routinely collect a core set of dementia indicators through their national health and social information systems on which they report every two years by 2025.

Dementia research and innovation

The output of global research on dementia doubles between 2017 and 2025.

CHAPTER 1

Dementia as a public health priority

Defining national plans on dementia

75% of countries will have developed or updated national policies, strategies, plans or frameworks for dementia, either stand-alone or integrated into other policies/plans, by 2025.

The target of the first strategic area of the Global plan[5] sets the stage for governments of 146 countries to act on dementia. One year into the action plan, 32 plans have been adopted, including 27 WHO Member States - 18% of that target.

The government of Chile is the only one that has developed a plan in the period since the adoption of the Global plan in May 2017, while the approval of Bill C-233 for the development of a plan in Canada has been widely praised.

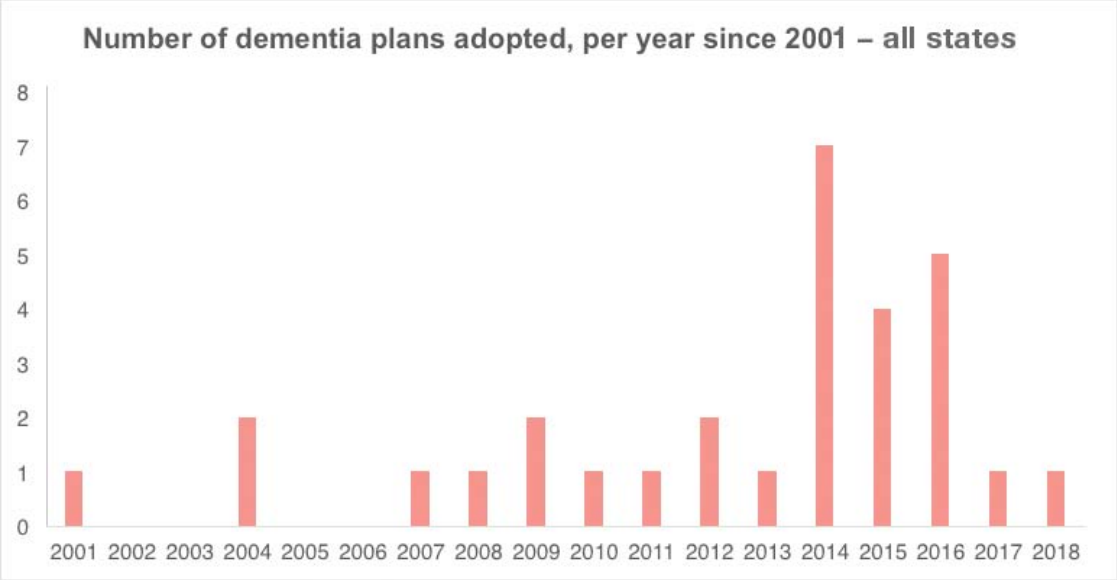
28 plans are in varying stages of development, from discussion to draft plans being considered for adoption in WHO Member States. Plans in final stages in approximately 10 countries, including the Canadian plan, are not expected before early to mid-2019. Policies including dementia, featured under mental health, ageing and Non-Communicable Diseases (NCDs) have also been developed in an additional 5 countries.

Box 1.2

National plan development in 2018

- Plans adopted in 32 countries (27 WHO Member States)
- 28 new plans being developed
- Target of 146 plans by 2025

If all current policies and plans went on to be adopted or were replaced by new plans, under a third of the WHO target would be achieved in the near future (60 plans, 41%).



15 plans on dementia have been implemented in WHO Member States in the last 5 years. Area one of the Global plan would require at least 15 new plans to be developed every year between 2018 and 2025.

5 World Health Organization (WHO), Global action plan on the public health response to dementia 2017-2025 (2017): http://www.who.int/mental_health/neurology/dementia/action_plan_2017_2025/en/

A qualitative estimate based on past plan development and current progression, accounting for the views of the relevant Alzheimer or dementia organisation in each country, would suggest a more realistic achievement of slightly less than this figure. Progress is evident, but slow: Upon mid-term review of the Global plan in 2021, it is likely that still less than half of the 146 countries target will have been met.

It is important to consider the quality of plans and their effect. This will depend greatly on whether plans are allocated appropriate funds in national budgets (see 'Funding'). Every new plan creates opportunities for improved lives, new knowledge, awareness and commitments for future generations to build on. Plans developed in countries either with large populations (China, India), with significant rural populations or that are expected to experience the greatest increase in cases of dementia (South East Asia and Latin America) could profoundly influence the future of understanding, care and research.

Box 1.3

Components of a national plan

The following areas are included as an example of common themes and objective areas for national plans or other policies on dementia. While most plans focus on awareness and support, few plans contain substantive focus on research, or on the use and monitoring of data for dementia.

- Awareness and education
- Risk reduction
- Timely diagnosis and access to treatment
- Support at home, and for family carers
- Coordination of care, including community care
- Training for health professionals and service providers
- Human rights, disability support and enablers
- Dementia friendliness
- Commitment to research

Funding

Less than half of adopted plans have received funding for effective implementation. Others have allocated specific budgets for the first year of the implementation of a plan only. In most cases, cost of dementia is addressed but falls short of identifying a clear budget for specific actions in the public domain, or how a budget, where allocated, will be distributed.

The planning, implementation and evaluation stages of national plans all require thoughtful consideration of the resources needed, which department or functions of the government may best meet the specific cost demands of each area, and which roles other stakeholders may play in the distribution of, or support for funding. For example, it is reasonable to expect that budgets should be reserved for the important collaboration with Alzheimer associations in each country, including an obvious opportunity for governments to directly align national awareness activities with World Alzheimer's Month globally. Training of healthcare professionals, investment in research, information dissemination and monitoring are all significant costs that should be considered not just by the Ministry or other department for health or ageing, but in partnership with policy makers in finance departments who can support realistic but funded goals of a plan.

Countries that have dedicated substantial funding to the implementation of dementia plans and related activities and infrastructure include Australia, Chile, Greece, Indonesia, Netherlands, Norway, the UK and USA.

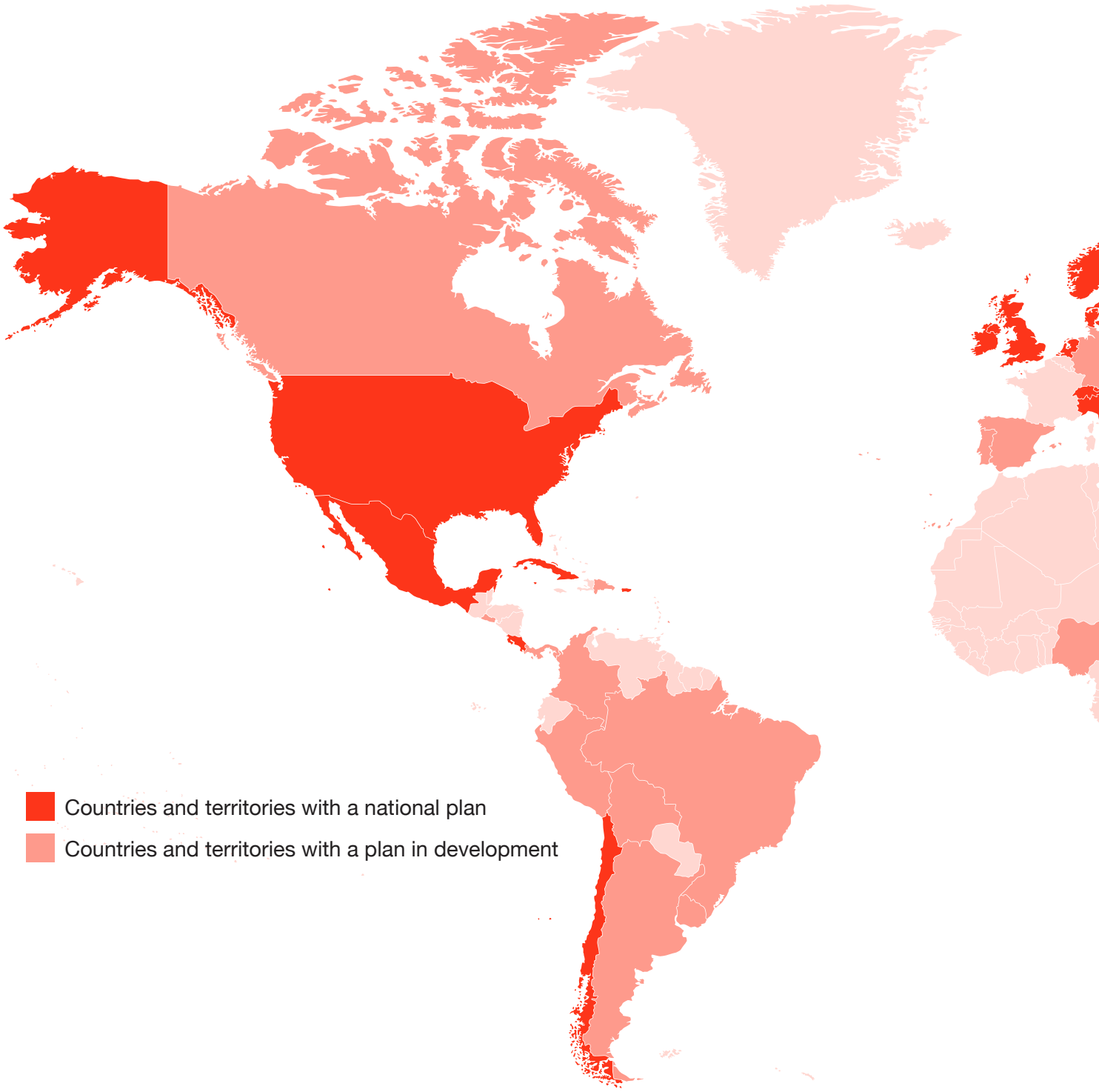
Focus on strategic areas

ADI reviewed the effectiveness of national plans on dementia against the new strategic areas of the WHO Global plan in 23 WHO Member States during 2017. *National Dementia Plans: Examples for Inspiration*[6] showed that, of the data available, the difference in attention paid to each area was significant. While most plans included chapters and actions on awareness, training, and support for carers, research and data attracted much less focus.

Figure 3: Focus areas by inclusion in sample of 23 plans (November 2017)

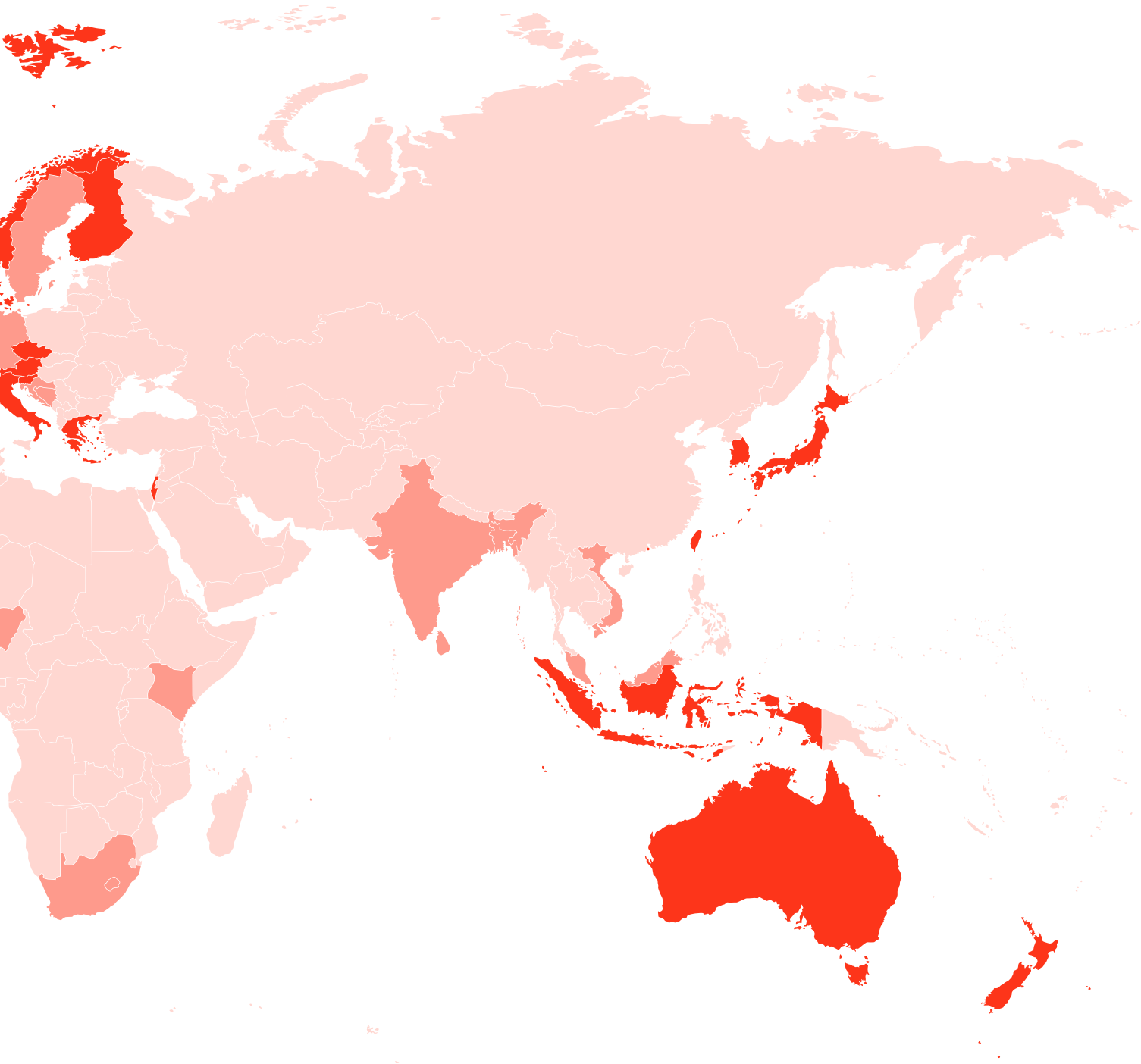
6 ADI and Swiss government Federal Office of Public Health, National Dementia Action Plans; Examples For Inspiration (2017): https://www.alz.co.uk/sites/default/files/pdfs/national-plans-examples-2017.pdf

Countries and terrritories with plans on dementia or in development in 2018



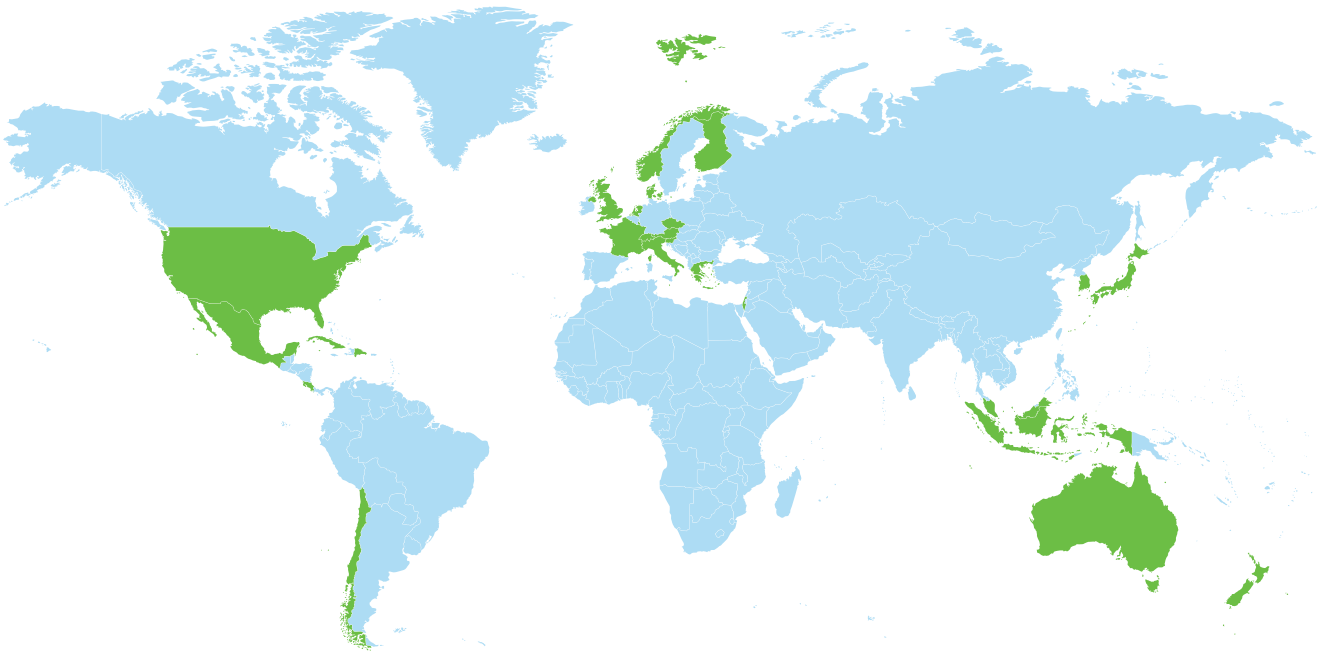
Countries and territories with national dementia plans

Australia	Czech Republic	Israel	Malta	Puerto Rico	UK
Austria	Denmark	Italy	Mexico	Republic of Korea	USA
Chile	Finland	Japan	Netherlands	Slovenia	
Costa Rica	Greece	Luxembourg	New Zealand	Switzerland	
Cuba	Indonesia	Macau SAR	Norway	TADA Chinese Taipei	



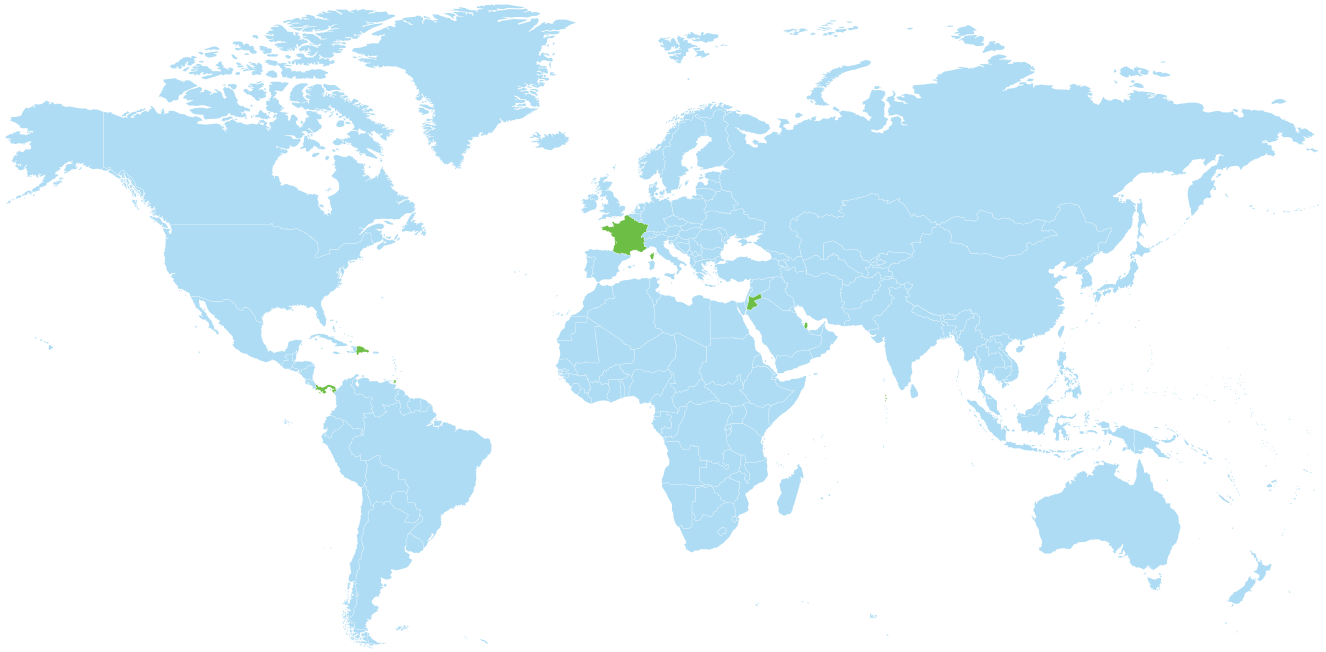
Countries and territories with national dementia plans in development

Argentina	Bonaire	Croatia	India	Panama	Sri Lanka
Bangladesh	Bosnia-Herz.	Dominican Rep.	Lesotho	Peru	Sweden
Barbados	Brunei	El Salvador	Malaysia	Portugal	Vietnam
Brazil	Canada	Germany	Mauritius	South Africa	Uruguay
Bolivia	Colombia	Kenya	Nigeria	Spain	



WHO Member States with existing plans or other policies on dementia

- Australia
- Austria
- Chile
- Costa Rica
- Cuba
- Czech Republic
- Denmark
- Dominican Republic
- Finland
- France
- Greece
- Indonesia
- Israel
- Italy
- Japan
- Luxembourg
- Malta
- Mexico
- Netherlands
- New Zealand
- Norway
- Republic of Korea
- Singapore
- Slovenia
- Switzerland
- UK
- USA



WHO Member States with other plans or other policies, that include dementia (ageing, mental health, NCDs and neurological disease)

Other policies that include dementia

- Dominican Republic
- France

Other policies in development

- Jordan
- Maldives
- Panama
- Trinidad and Tobago
- Qatar

Risk reduction features in over half of national plans adopted since 2004, but is less likely to be accompanied by clear targets or indicators than other targets. Risk reduction must also follow a 'learning curve', following an increase in public awareness to a point of sufficient interest in prevention. Chapter 3 includes more information on risk reduction.

A lack of data is a key issue for developing a plan on dementia. In the majority of low and middle income countries (LMICs) and high income countries (HICs), statistics on prevalence, incidence or specific demographic trends in dementia are not readily available. In all states, these systems are needed to encourage and share new knowledge, and to provide a benchmark from which to measure indicators such as diagnostic rates.

The World Alzheimer Report 2015 is still widely used as a key source of reliable global data on dementia, and features regional estimates for prevalence of dementia only recently updated by WHO[7].

Box 1.4

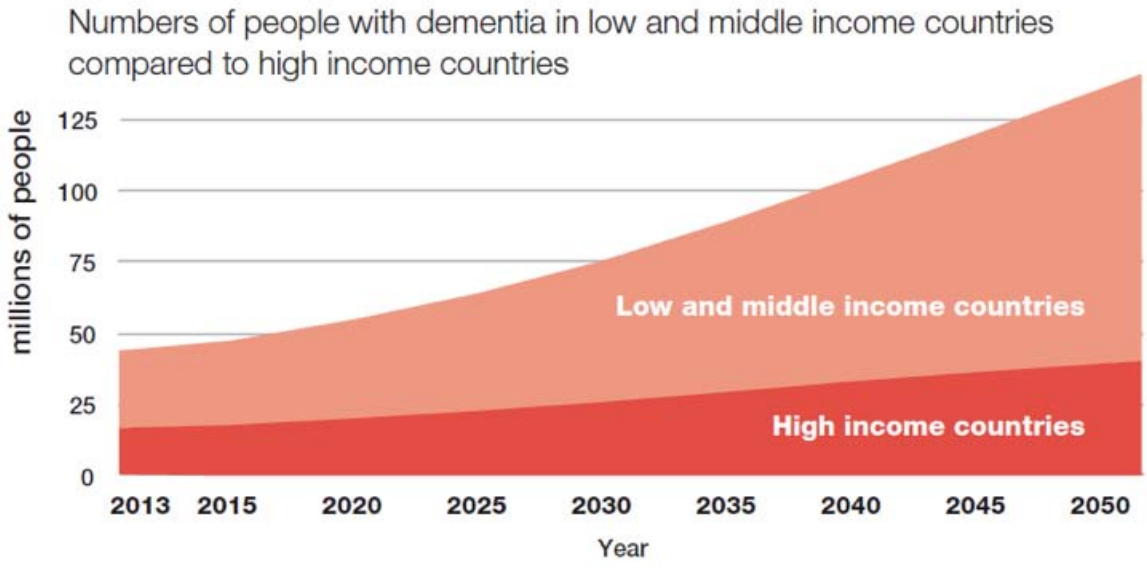
Example: French Alzheimer's Plan 2001-2005

The French government was the first in Europe to launch a national plan on dementia. The plan lasted 5 years from 2001 and included a budget of €1.6bn to achieve the following objectives; identification of the early symptoms of dementia; creation of a network of "memory centres" to enable earlier diagnosis; agreement on new ethical guidelines for families and care homes for the management of dementia; financial support for people with dementia; the establishment of day care and local information centres; new care homes and improvements to existing homes; and increased support for research and clinical trials on dementia.

Two subsequent plans have continued the impact of the original plan (2004-2007, 2008-2013). In 2008, the third plan established the French National Alzheimer Database to record information on dementia demographics, clinical trials, diagnosis and other information from Memory Centres and dementia specific services. The plan also included key budget allocations and goals for each year of its implementation, including the recommendation for clear pathways of care for dementia (see page 27).

Since 2014, specific plans on dementia have been replaced by the Plan maladies neuro-dégénératives 2014-2019. Development of a new dedicated plan on dementia would continue to strengthen the response to dementia in France, but does not appear to be in process at the time of writing.

Focus on low and middle income countries



7 WHO Department of Mental Health and Substance Abuse; Global Observatory for Ageing and Dementia Care, King's College London, January 2018

Most people with dementia live in LMICs. There are almost twice as many LMICs in the world as countries with high income. In LMICs in particular, awareness and support for dementia is growing, but faces significant challenges to awareness, diagnosis and support.

Of 32 plans on dementia worldwide, only 4 exist in LMICs (Cuba, Dominican Republic [policy, plan in development], Indonesia and Mexico). However, a concerted effort by ADI, WHO and others to support messaging on the importance of dementia plans in LMICs particularly, is supported by the number of plans in current development, of which over 70% are expected in LMICs (20 countries).

Efforts for health development in LMICs have tended to focus on reproductive and women's health, as well as infectious diseases that spread quickly and require large scale interventions. Rapid population growth, especially in LMICs, means that aged care, and age related diseases including dementia, are becoming more important, and will have a greater cost and visible impact. The pace of change in low income economies in particular, including changes to the traditional family network and emigration, means that many countries remain unprepared to provide concerted, quality care for dementia on a greater level.

Box 1.5

National plans check list

- ✔ **Multidisciplinary, meaningful engagement** with stakeholders including people with dementia and their carers
- ✔ **Adequate funding** to meet national challenges, including investment in resources, awareness and training – not just for the first year
- ✔ **Clear goals** that set the agenda for action on dementia – assigned roles for who will achieve them
- ✔ **Monitoring systems** for dementia that publicly assist the review and evaluation of the effectiveness of plans, including submitting data to the Global Dementia Observatory

Figure 7: Percentage of dementia plans in LMICs and HICs 2018

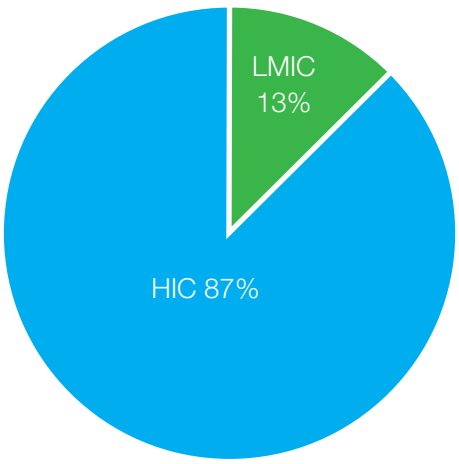
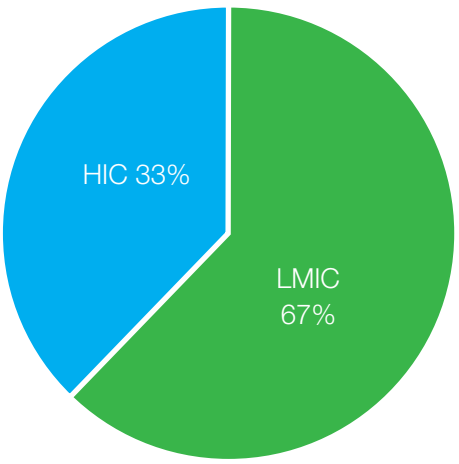


Figure 8: Percentage of dementia plans in development in LMICs and HICs in 2018

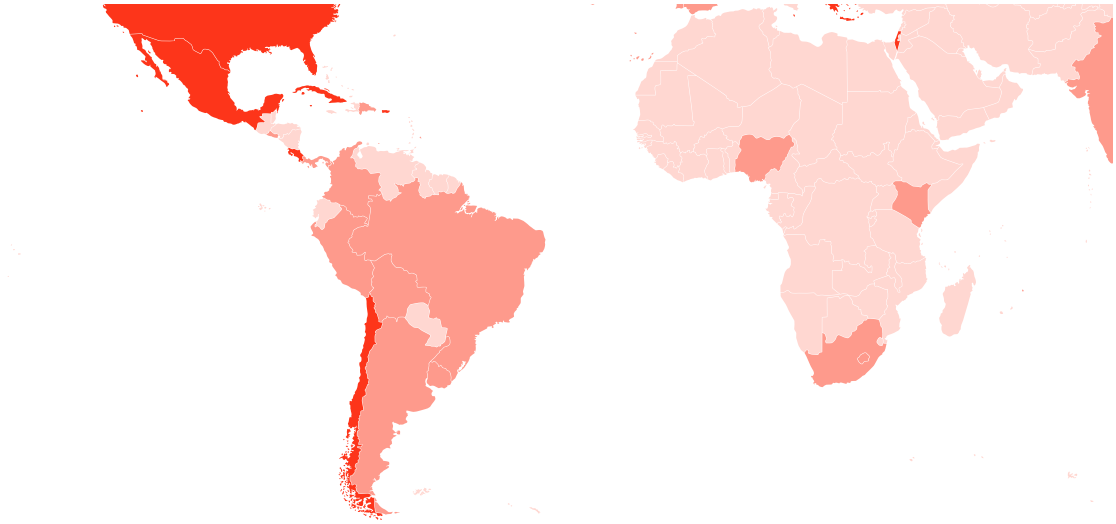


8 Ministerio de Salud Pública, Departamento Nacional de Adulta Mayor, Asistencia Social y Salud Mental, Centro de Estudios de Alzhéimer, República de Cuba, Estrategia Cubana para le enfermedad de Alzhéimer y los sindromes demenciales: La demencia, un problema de todos (2013).

Secretaría de Salud y Instituto Nacional de Geriatría de México, Plan de Acción Alzheimer Y otras Demencias (2014).

Plan nacional para le enfermedad le Alzheimer y demencias relacionadas esfuerzos compartidos (2014-2024)

Latin America and sub-Saharan Africa



Latin America and sub-Saharan Africa warrant special attention. The first regional plan on dementia, adopted by PAHO for the Americas in 2015, set an important precedent for the Global plan. The PAHO plan encourages Member States in 35 countries to develop national plans on dementia that include the promotion of risk reduction strategies through public health programmes, ensuring a rights-based approach to the provision of care and support for people living with dementia and better training for health professionals. The initial term of the PAHO plan will be evaluated in 2019.

The World Alzheimer Report 2015 showed that, of all regions, those in Latin America were expected to see the greatest proportionate increase in people living with dementia between 2015 and 2050 - more than 300%. Mexico, Cuba and Costa Rica were among the first countries in the world to develop national responses on dementia[8].

Governments in the region, supported by Alzheimer associations, continue to lead in the development of responses to dementia, that include a strong clinical and care focus; 11 plans on dementia, out of 28, are currently in development in Latin America and the Caribbean, making these the most active of all regions.

By contrast, there are no plans on dementia in sub-Saharan Africa, the region expected to see the second greatest proportionate increase in numbers of people living with dementia by 2050. The WHO is represented in 46 countries in sub-Saharan Africa, the largest grouping after Europe (53 countries), making it a focus region for awareness and policy development in response to the Global plan.

Without immediate attention to the development of the dementia landscape in sub-Saharan Africa, the target of 146 plans by 2025 is near impossible. If every other WHO Member State in the world developed a plan in the next 8 years, it would only result in 2 more plans than the target amount.

Box 1.6

Example: Chilean National plan on dementia 2017

In 2017, the government of Chile approved a national plan on dementia that includes targets for improving awareness, access to care, support and treatment, research and risk reduction of dementia by 2025. A draft of the plan was uniquely available for public consultation for several months, ensuring a wide engagement in its development. It is estimated that 180,000 people are living with dementia in Chile, resulting in a cost of care per person of almost USD $11,000 every year. The plan follows the examples of existing plans in Costa Rica, Cuba, Mexico, Puerto Rico and the USA, and includes a budget of USD $5.5m a year for implementation. The rights of people with dementia, and promotion of the dignity, inclusion and quality of life of those affected are central themes of the plan in Chile.

Alzheimer associations in Ghana, Kenya, Lesotho, Madagascar, Mauritius, Namibia, Nigeria, South Africa, Zambia and Zimbabwe are working hard to change the perception and experience of dementia in Africa and there are exciting developments in the design of national plans in Kenya and Nigeria. Partnership with these associations and other civil society groups offers extraordinary potential to reach almost a third of the global target in a region with a significant need.

In September 2017, ADI held the 4th Sub Saharan Regional Conference in Nairobi, co-hosted by Alzheimer's Kenya. The conference was attended by delegates from across the region, including representatives of several African governments. The conference featured the first public speech by a person with dementia in the country, and led to the important commitment from the Kenyan Ministry of Health to develop the region's first plan on dementia in 2018.

In October of the same year, ADI joined representatives at the 10th International Congress of Alzheimer Iberoamerica, hosted by Asociacion Dominicana de Alzheimer in the Dominican Republic. For the first time, an official PAHO meeting was held during the congress to discuss progress on the PAHO plan, including representatives from Alzheimer associations in over 8 countries.

Joost Martens, ADI's Regional Director for the Americas said, *"The design and implementation of national plans - in line with the implementation of the global action plan - requires governments and civil society agencies to work together. The invitation by PAHO for both these groups of actors to participate and work together in this meeting was an important confirmation of this vision."*

Throughout the congress, presentations by ADI and others focused on the development of national plans, including a workshop led by Asociación Alzheimer Bolivia with the support of the Costa Rican government and Asociación Costarricense de Alzheimer y otras Demencias Asociadas.

Inclusion of dementia in other policies

ADI urges every government to develop a dedicated national or state response to dementia. Dementia is a complex health, social and economic issue which deserves dedicated attention. Plans need to address, among other things, stigma, access to diagnosis and quality of care of dementia from a specific, tailored perspective.

In addition to these plans on dementia, ADI welcomes the development of supportive policies, on neurological diseases, ageing and Non-Communicable Diseases (NCDs), that may precede or complement the development of a committed, funded approach to dementia. Within the Global plan, it is argued that developing actions on dementia through alternative policies, such as on NCDs, could alleviate the impact of stigma and provide a greater benefit where resources are not specifically earmarked for dementia.

Where other policies include dementia in place of a dedicated plan, it should be stressed that attention must be paid to:

- Include specific reference to dementia
- Ensure that inclusion is aligned with the 7 Strategic Areas of the Global plan, and relevant targets; for example, by developing at least one awareness campaign or supporting access to diagnosis for 50% of the population.

NCDs, ageing and disability

The impact of NCD targets that include key risk reduction messaging and activities for cardiovascular health, can be directly measured against the Global plan on dementia (page 23). Common risk factors are shared between dementia and other NCDs that often receive more attention, such as diabetes. As such, NCD campaigns may offer an additional and valuable vehicle by which the impact of dementia as an NCD, and in its own right, can be reduced.

Despite this, less than 5 of almost 80 NCD plans worldwide contain any reference to dementia, Alzheimer's disease or related disorders. While stroke is widely addressed and is a significant risk factor for vascular dementia in particular, mental health and neurology in general are greatly underrepresented in NCD plans.

Ageing policies that encourage age-friendliness can relate to fostering dementia friendly environments and to raise awareness of dementia as a significant economic and health consideration that mostly affects older people. A danger of including dementia under ageing alone opens the risk of neglecting the 2-8% of cases of dementia which develop before the age of 60[9]. These individuals are likely to experience different social, work or home environments and factors when compared to older persons, and to experience the symptoms of dementia differently.

9 Prince et al., World Alzheimer Report 2015: The Global Impact of Dementia. Alzheimer's Disease International, August 2015.

10 ADI and Dementia Alliance International, Access to CRPD and SDGs by Persons With Dementia (2017) and Dementia Alliance International, The Human Rights of People Living with Dementia: From Rhetoric to Reality (2016)

Disability and rights access is an example of an area that holds special importance for all people affected by dementia, as well as their families and carers. The focus on human rights and respect for all people with dementia is referenced within the 'cross cutting principles' of the Global plan, as well as throughout the implementation advice for several of the targets. The importance of the United Nations (UN) Convention on the Rights of Persons with Disabilities is covered in separate publications by ADI and Dementia Alliance International (DAI)[10].

Plans on Neurological diseases or specific conditions also hold potential to have a beneficial impact on dementia, for example: Stroke, depression, Down syndrome.

Expired plans and proposed strategies

There are several areas of detail not covered in this report; for example, it is important to ask what is the next step for several countries that have adopted previous policies or plans on dementia, that have either reached the end of their term or are due to do so soon, in 2019 (Czech Republic, France, Ireland, Switzerland).

France was the first country in Europe to develop a dedicated national plan on dementia in 2001. The plan, now in 4th version, has been widely cited as an example of strong policy; development of a new plan would continue to strengthen the response to dementia in France, but does not appear to be in process at the time of writing.

A number of governments have also developed a draft plan or strategy on dementia, or received a strategy developed by the Alzheimer association or other non-state actor in their country. These have not been actively included in the counting for this report. As such, there are at least 10 countries where a previous opportunity to develop a response to dementia was missed but could be used as a catalyst to renew enthusiasm and action in response to the Global plan.

Box 1.7

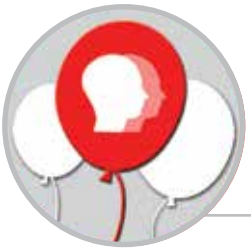
National plans by year – all states

- **2001**
  France
- **2004**
  Australia
  Netherlands
- **2007**
  Norway
- **2008**
  Republic of Korea
- **2009**
  Denmark
  UK
- **2010**
  Scotland (UK)
- **2011**
  USA
- **2012**
  Finland
  Japan
- **2013**
  Luxembourg
- **2014**
  Costa Rica
  Cuba
  Ireland
  Israel
  Italy
  Mexico
  Switzerland
- **2015**
  Austria
  Gibraltar (UK)
  Malta
  Puerto Rico
- **2016**
  Czech Republic
  Greece
  Indonesia
  Slovenia
  Macau SAR (China)
- **2017**
  Chile
- **2018**
  TADA Chinese Taipei

The development of other national plans or policies has been negatively affected by changes in government or political instability, at times in final stages of the drafting process. This has been the case in at least three countries home to Alzheimer associations who are members of ADI.

CHAPTER 2

Dementia awareness and friendliness



100% of countries will have at least one functioning public awareness campaign on dementia to foster a dementia-inclusive society by 2025. 50% of countries will have at least one dementia-friendly initiative to foster a dementia-inclusive society by 2025.

Awareness of the impact, symptoms and relevance of dementia is needed before other targets of the Global plan on dementia can be met. Awareness is required at an individual and family level to access diagnosis and support, and is also important to promote inclusion, respect and supportive attitudes in the community, including work spaces, in services and in all healthcare settings. All 194 Member States of the WHO are encouraged to take action to improve awareness in their countries**.**

Awareness is important at all levels, in all countries. Even in well informed settings, there remain many cases of persistent reluctance to talk about dementia. There is limited understanding globally that dementia also affects those at younger ages, and of which preventative actions can lower the risk of dementia or that may be helpful post diagnosis to improve quality of life. Awareness among the general population and non-specialised healthcare professionals in particular is needed to bolster support for and engagement with the goals of national dementia plans.

Countries with plans on dementia all feature awareness campaigns. In addition, other governments have also expressed support for the activities of the Alzheimer association in their country, World Alzheimer's Month and for other events and campaigns for dementia awareness.

Measuring awareness is complex. Identifying the relevant areas of awareness that require the greatest support among each segment of the population is an important first step for countries that do not have existing public awareness campaigns.

Population surveys in collaboration with groups of people with dementia and other civil society groups including Alzheimer associations can support this process, and also provide a baseline for all countries to note the effect of subsequent actions to increase awareness.

An effective awareness campaign could also 'unlock' many other areas of the global plan at national level. For example, a plan on dementia (target 1) may include a comprehensive awareness and training program (target 2) aimed at medical professionals, on enhancing diagnosis or at those caring for a person with dementia, on providing support (targets 4 and 5).

Outcomes for measuring the impact of awareness could include referrals from a specific campaign to seek a diagnosis or support for dementia, the popularity or attendance of events, resources and services in aid of awareness, or these areas measured over a specific time period.

Investing in research as well as its dissemination (target 6) can both greatly aid awareness of dementia and benefit from it as more individuals join clinical trials, engage with dementia registries and understand more about risk factors and prevention.

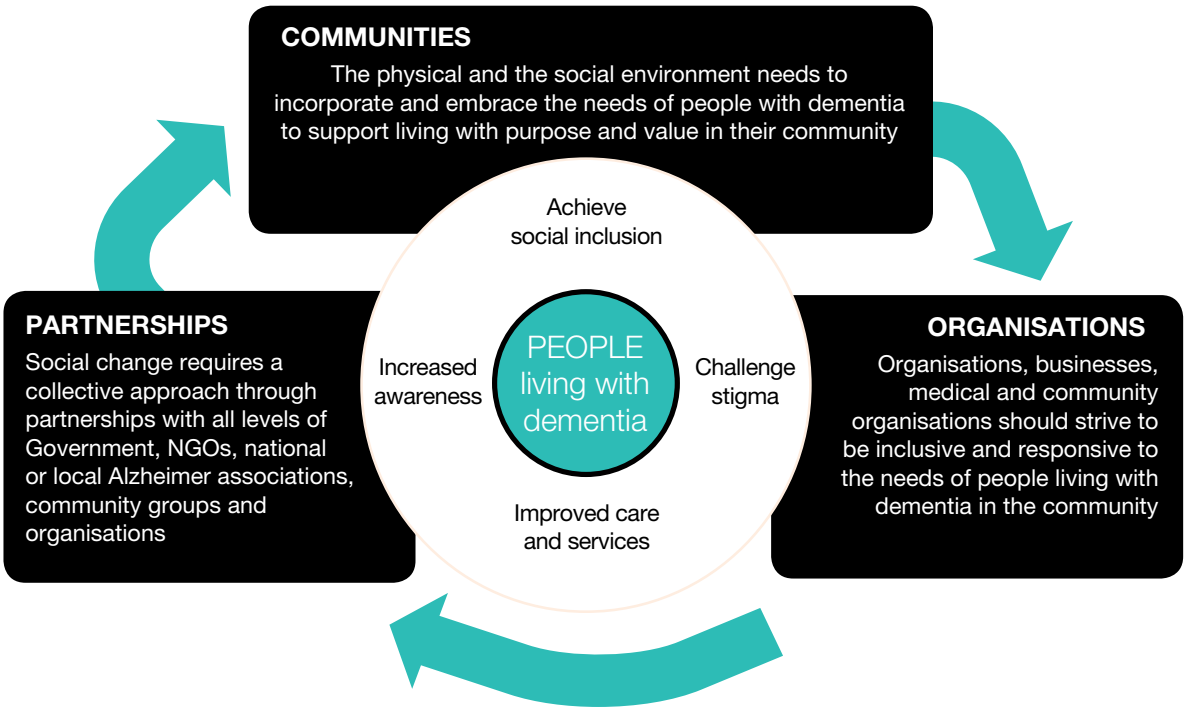
Reducing stigma is a fundamental objective of ADI. Activities of ADI include the global coordination of World Alzheimer's Month, as well as the longest running international conference on dementia, that both directly challenge stigma and raise awareness of the impact and individual experiences of the condition. The conference regularly attracts over 1000 delegates and is special for the broad audience it commands among policy makers, leading academics and scientists, carers and care organisations, healthcare professionals, people living with dementia and their families globally.

Throughout the year, ADI publishes new information on dementia, hosts regional ADI events and actively supports the events, advocacy and achievements of many associations, partners and other institutions that increase the understanding of dementia around the world. In 2018, ADI will launch the World Alzheimer Report 2018 on the current state of research.

ADI's strategic plan includes strengthening support for associations and communications, by creating more resources, translating assets and working harder to relate the impact of dementia to the media and public, including on social media. High profile ambassadors, Queen Sofía of Spain and Luis Guillermo Solís Rivera, former President of Costa Rica have joined ADI's global voice in 2017 and 2018.

More information on the achievement of the global target on awareness will be provided in later editions of this report.

Dementia friendliness



Source: Dementia Australia, principles of a dementia friendly community.

Dementia friendly communities or initiatives have the power to transform the social and physical environment for those affected. The above diagram shows three elements of creating a dementia friendly environment.

Themes of dementia friendliness include supporting individuals with dementia to live as long as possible in their home and daily social surroundings. Serious symptoms of dementia include depression and isolation; a familiar environment, understanding and empowerment to remain active in the community can improve quality of life, and is a basic right that should be accorded to all those affected.

The Global plan calls for 97 Member States to develop at least one dementia friendly initiative by 2025.

ADI has published twin reports on the key principles and examples of dementia friendly initiatives around the world, including campaigns and projects in over 40 countries. A dementia friendly initiatives toolkit is also currently being developed by WHO.

Dementia Friends

Inspired by the models in Japan and the UK, there are now over 14 million 'Dementia Friends' in 22 countries worldwide, and five other states are developing the programme in 2018.

Dementia Friends aims to transform the way the people think, act and talk about the condition. It is about learning more about dementia and the small ways that we can help. They learn basic information about dementia, common misconceptions and are reminded that there is so much more to a person than the dementia. To finish, everyone commits to an action which can help make their community more dementia-friendly.

Country	Number of Dementia Friends
Canada	1,058,240
China	85,523
Costa Rica	239
Croatia	201
Denmark	55,856
Dubai	300
England and Wales	2,462,500
Germany	26,956
Gibraltar	119
Hong Kong	1,012
Indonesia	50,000
Israel	6,000
Netherlands	104,703
New Zealand	NA
Nigeria	80,000
Northern Ireland	15,000
Pakistan	NA
Scotland	59,565
Singapore	19,000
South Korea	58,990
USA	16,951
Japan	10,151,589
Total	**14,252,744**

Source: Alzheimer's Society, UK (May 2018)

***Dementia Friendly Communities; Key principles and Global developments,* updated in 2017.**

Dementia friendliness in Ghana

Ghana is one of the countries most affected by dementia in Sub-Saharan Africa. Since 2015, Alzheimer's and Related Disorders Society of Ghana (Alzheimer's Ghana) has collaborated with over fifty traditional leaders, including Kings, Chiefs, Regents, sub-chiefs and Linguists (the traditional spokesperson for the chief), in the Greater Accra Region on the ***Dementia PET Project***.

Leaders are invited to pledge to make dementia their 'pet' project through:

- Supporting Alzheimer's Ghana to organise education and public talks on dementia in the various communities;
- Serving as ambassadors for dementia awareness in the local community;
- Offering direct engagement with the government through the National House of Chiefs, the Ministry of Culture and Chieftaincy and the Council of State;
- Potentially providing land for developing care centres.

One example of an awareness-raising activity was a durbar, an event called by a Chief, for the people of Bodada in the Volta Region. The durbar aimed to educate about dementia, raise awareness, and challenge the stigma and abuse of people with dementia. The event was attended by more than 250 people.

Alzheimer's Ghana also collaborated with the Theatre Department of the University of Winneba to create a drama on dementia which was performed in 20 local communities across the country to educate community leaders, chiefs and opinion leaders on the difficulties of living with dementia and the importance of creating a friendly environment and support for those affected and their families.

The project also engaged community radio stations to discuss management of dementia. Phone-in programmes were used to discuss common problems associated with dementia and how these were addressed in a better way.

The society continues to actively participate in World Alzheimer's Month, including holding events with people with dementia and their families in churches, with the media and local schools and colleges.

Source: Alzheimer's and Related Disorders Society of Ghana and ADI, Dementia Friendly Communities: Global developments, 2nd edition (2017)

World Alzheimer's Month

World Alzheimer's Month is the international campaign led by ADI and Alzheimer associations every September to raise awareness and challenge the stigma that surrounds dementia. World Alzheimer's Month was launched in 2012; World Alzheimer's Day is on 21 September each year and acts as a focal point for global, regional and national action on dementia. Examples include the launch of national dementia plans and new publications by ADI and others on World Alzheimer's Day, as well as public seminars, Memory walks and creative campaigns.

World Alzheimer's Month activites were held at Ng Teng Fong General Hospital in Singapore during September 2017.

World Alzheimer's Month is marked by associations and others in over 70 countries each year and provides a ready vehicle for governments in partnership with these associations and people with dementia to achieve the targets for awareness outlined in the Global plan. Materials and key messages are developed by ADI and can be translated and amended for the best impact.

Training and information for professionals is an important area in which awareness can play a role in the response to dementia. WHO mhGAP focuses on LMICs and general health practitioners who have contact with people with dementia.

The 2500 km Run Tomo event in Japan

Japan: Global influence of Ninchisho Supporters

In 2004, Japan's government announced the change of the word for dementia from 'Chiho', which carried negative connotations, to 'Ninchi-sho', meaning cognitive disorder. With this change, the country's government launched a nationwide dementia friendly campaign, *10-Year Plan to Understand Dementia and Build Community Networks.*

Among the projects inspired by this change was the Nationwide Caravan to train Ninchisho Supporters programme, which was launched in 2005, and continues to hold influence worldwide as the first example of a national dementia friendly movement. 'Dementia Friends', developed by the Alzheimer's Society in the UK was inspired by this movement, and is now being adapted in more countries around the world.

The Ninchisho Supporters training includes a 90-minute seminar held at schools, offices and for community groups across the country. Attendees learn about dementia, how it affects the lives of those living with it and what they should know in order to effectively provide support.

In 2018, there are over 10 million Ninchisho supporters across every prefecture of Japan.

The Ninchisho Supporters programme has resulted in other initiatives, such as the ***'Run Tomo'*** campaign. Hosted by Dementia Friendship Club, people with dementia, their care partners and members of the public can join the relay to raise awareness and show their support for those affected. Proceeds from ***'Run Tomo'*** are donated to the 'Be Orange' Dementia Friendly Community Fund in Japan.

Source: Alzheimer's association Japan and ADI, Dementia Friendly Communities: Global developments, 2nd edition (2017)

CHAPTER 3
Dementia risk reduction

The relevant global targets defined in, and in keeping with, the Global action plan for prevention and control of noncommunicable diseases 2013–2020 and any future revisions are achieved.

Dementia is not a normal part of ageing. Actions on dementia that address lifestyle related risk factors, including obesity and smoking, have the potential to greatly reduce the prevalence and incidence of the condition, and the impact of this on individuals and society. There is no cure for dementia.

The Global plan indicators for the target on risk reduction are not specific, instead considered within the framework of the existing targets of the *Global action plan for prevention and control of noncommunicable diseases 2013–2020*, adopted by WHO in 2013 (see box).

Objectives with relevance to dementia include reducing the impact of risk factors such as physical inactivity, salt, alcohol and tobacco use, and specific action on diabetes, obesity and cardiovascular disease. ADI continues to note the absence of dementia, and ageing generally, within this plan.

Targets of the Global plan on NCDs

- 10% relative reduction in prevalence of insufficient physical activity
- 30% relative reduction in prevalence of current tobacco use in persons aged 15 years and older
- At least a 10% relative reduction in the harmful use of alcohol, as appropriate, within the national context
- A halt in the rise in diabetes and obesity
- 25% relative reduction in the prevalence of raised blood pressure or contain the prevalence of raised blood pressure according to national circumstances
- A 25% relative reduction in overall mortality from cardiovascular diseases, cancer, diabetes or chronic respiratory diseases

A mid-term review of the achievement of the targets will take place during World Alzheimer's Month, September 2018. In December 2017, the NCD Alliance, of which ADI is a member, described progress outlined in the WHO NCD Progress Monitor 2017 as 'worryingly slow'.

Risk reduction should be accorded a high priority in government responses on dementia and could also be one of the most cost effective to implement - both in the resources required and in the potential reduction in health care complications, hospitalisation, and need for acute care. WHO is currently developing guidelines on risk reduction of cognitive decline and dementia.f

Unlike many diseases, most admissions to acute care and mortality of people with dementia are not directly caused by dementia but can be serious; the result of co-morbidities that share risk factors or directly impact brain health. Examples include stroke and pneumonia, while dementia itself eventually leads to disability, falls and dependence that places a high demand on health systems. This unique complexity both adds to the role of the healthcare provider and also offers a multitude of possible benefits of dementia risk reduction on concurrent goals of the health system - healthy ageing or improvements in cardiovascular health are two examples.

Dementia care is complex, and, as the dementia progresses, requires a coordinated long term system of supports, considerations and services that work best when personalised to the experience and unique symptoms of the individual. The healthcare costs associated with dementia are among the greatest relative to other conditions.

In July 2017, *The Lancet Commission on dementia prevention, intervention, and care*[11] estimated that as many as one in every three cases of dementia could be prevented if nine physical and social risk factors were eliminated. The research went beyond 'current' risk factors, by assessing the impact of possible risk factors in early, middle and late life as potentially modifiable (smoking, inactivity) and potentially unmodifiable (level of education, inheritance of the ApoE4 gene).

What the research says

Studies have illustrated that changes leading to dementia may occur in the brain as many as 20 years before symptoms develop. While age remains a significant factor in increasing dementia risk, up to 8% of dementia cases affect individuals under the age of 65.

Physical risk factors for dementia include obesity, hypertension and stroke. Diabetes and heart disease both increase the risk of developing dementia.

Individuals can address a number of social risk factors for dementia; tackling inactivity, poor diet, alcohol abuse and smoking in mid life has been shown to have a positive effect on healthy ageing and dementia in later years.

Depression and dementia are closely linked, although it is unclear if depression is a partial factor in, or a persistent symptom of, dementia. Isolation and related inactivity increase the risk of both depression and dementia.

Understanding of the risk factors for dementia is growing, in part due to advances in brain imaging technology but also through large scale lifestyle based studies such as the 2013-2015 FINGER study and its successor US-POINTER into the combined effects of changes in areas including diet, exercise and brain training[12].

Reduce your risk

Follow a healthy diet

Be physically active

Look after your heart

Challenge your brain

Enjoy social activity

NCDs and Dementia

"Six years out from the first UN High-level Meeting on NCDs in 2011, less than half of WHO Member States have put in place effective NCD governance that would go a long way to reduce the impact of, and provide crucial risk reduction of NCDs including dementia."

Katie Dain, CEO of the NCD Alliance

11 Livingstone, Gill et al, *Dementia prevention, intervention, and care,* July 2017: https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)31363-6/fulltext

12 Miia Kivipelto et al, A 2 year multidomain intervention of diet, exercise, cognitive training, and vascular risk monitoring versus control to prevent cognitive decline in at-risk elderly people (FINGER): a randomised controlled trial, Lancet (March 2015)

Alzheimer's Association, U.S. Study to Protect Brain Health Through Lifestyle Intervention to Reduce Risk (U.S. POINTER), (July 2017).

Non Communicable Diseases (NCDs) are the leading cause of death globally[13]. NCDs are diseases that are not caused by a contagion or infection, but that may be chronic and worsen over time - including dementia. Heart disease and stroke are two major NCDs that share risk factors and a causal link to dementia.

Including specific attention to dementia in NCD plans is an important step to meet the targets of risk reduction in the Global plan on dementia. Of over 80 NCD plans, only one plan mentions dementia (Norway). Mental health is included in plans in 4 countries, but does not directly relate to dementia (Ghana, Jamaica, Nigeria and Samoa).

3rd UN High-Level Meeting on NCDs - September 2018

"The HLM on NCDs represents an opportunity for a wider community to rally behind the global response to NCDs than ever before. Given the clear links between dementia and other NCDs - especially with regard to risk reduction, as outlined in the WHO Global action plan on the public health response to dementia 2017-2025 - we hope that both policy makers and the dementia community will engage together fully in the UN HLM process, both in terms of preparations and also implementation. In particular, the broader NCD response will make considerable advances by following in the footsteps of the dementia community, which has successfully and meaningfully engaged people living with dementia to ensure optimal and person-centred policy development and implementation to change lives." - Katie Dain, CEO of the NCD Alliance

Source: NCD Alliance, Enough. campaign (2018): https://enoughncds.com/

Extract: *WHO Noncommunicable Diseases Progress Monitor 2017 (page 5)*

"Most premature NCD deaths can be prevented or delayed by implementing a set of so called "best buys" and other interventions to prevent and control these conditions, primarily cardiovascular and chronic respiratory diseases, cancer and diabetes. These measures were endorsed by the 70th World Health Assembly and are available to all countries.

World leaders committed in the Agenda for Sustainable Development to reduce premature NCD deaths by one third by 2030 and promote mental health and wellbeing (Sustainable Development Goal target 3.4).

Since the 2011 High-level Meeting, governments have made many political commitments to prevent and control NCDs. Progress, however, has been insufficient and highly uneven. Unless political leaders accelerate commitments to take national action at the third UN High-level Meeting in 2018, the current rate of decline in premature death from NCDs will not meet the SDG target, leading to significant GDP losses and impoverishing millions of people through long-term healthcare costs."

Source: WHO, Noncommunicable Diseases Progress Monitor (2017): http://www.who.int/nmh/publications/ncd-progress-monitor-2017/en/

13 World Health Organization, *The top 10 causes of death,* 2015: http://www.who.int/mediacentre/factsheets/fs310/en/index2.html

CHAPTER 4

Diagnosis, treatment, care and support

In at least 50% of countries, as a minimum, 50% of the estimated number of people with dementia are diagnosed by 2025.

75% of countries provide support and training programmes for carers and families of people with dementia by 2025.

Access to diagnosis is both a fundamental right and essential start of the journey to receive care and support for those affected by dementia. In HICs, it is estimated that only half of people living with dementia will receive a diagnosis, while in LMICs as few as one in every ten people will receive a diagnosis[14].

Achieving a diagnostic rate of 50% of those affected in both LMIC and HIC is an ambitious target that will require significant further investment in the empowerment and training of general practioners, doctors, nurses and care workers, a great increase in awareness worldwide and political will to highlight dementia at every opportunity, especially among rural and special populations including minority groups, women, and adults with conditions related to dementia (such as diabetes). People with cognitive issues and family carers need to be better informed to seek assistance.

A formal diagnosis of dementia is additionally important to access treatment and has a two-way relationship with awareness and stigma. A first report on the impact of dementia in sub Saharan Africa noted a complete absence of any equivalent word for 'dementia' in several countries[14]. Without the necessary language, diagnosis cannot be sought. With a diagnosis, dementia becomes visible, adding to this language in which the disease is spoken about, understood and then accepted.

"The impact of dementia is not only significant in financial terms, but also represents substantial human costs to countries, societies, families and individuals." – World Health Organization, 2017

The Global Dementia Observatory has an important role to track the targets on diagnosis in particular (see page 31). Of the data currently available from the Observatory, only 3 countries out of 21 have provided any data on diagnostic rates or other indicators.

14 ADI, Dementia in sub-Saharan Africa: Challenges and opportunities (2017)

National plans must heighten the prioritization and tracking of diagnosis in dementia. Varied actions on diagnosis are however in a little over half of countries where plans have been adopted. Plans in Australia, Cuba, Czech Republic, Denmark, Greece, Indonesia, Israel, Italy, Japan, Korea, Malta, Netherlands, Norway, Slovenia, Switzerland and the UK include specific targets on diagnosis, emphasising earlier diagnosis in particular.

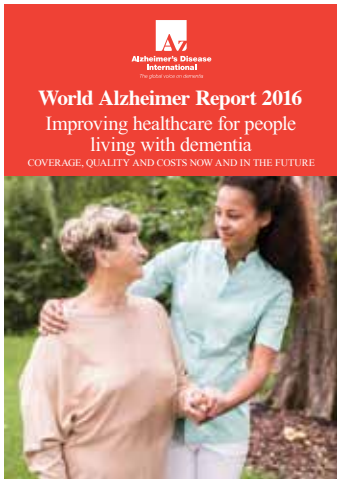
Earlier diagnosis and post diagnostic support

In most countries, diagnosis of dementia is made late in the course of the disease, leading to poor outcomes and reduced access to effective treatments. Evidence suggests that when people with dementia and their families are well prepared and supported, initial feelings of shock, anger and grief are balanced by a sense of reassurance and empowerment (see box).

A post diagnostic guarantee of support can reduce fear of seeking a diagnosis and is featured in the national response to dementia in Scotland. Including a guarantee that provides the right to support over a long-term period is important; to equip those affected to develop the tools, connections, resources and plans they need to live as well as possible with dementia and prepare for the future.

Establishing clear care pathways

The *World Alzheimer Report 2016: Improving healthcare for people living with dementia*, calls for concerted action to increase the coverage of healthcare for people with dementia worldwide.



'Care pathways' provide a structured and organised outline for the coordination, resourcing and delivery of care for a particular disease at each stage and are a common component of care for conditions such as diabetes, hypertension, and cancer.

Clear care pathways for dementia are important to help define roles and responsibilities within the healthcare system, and to establish shared standards and practice to be monitored. Case management is needed to support coordination and integration of different elements and providers of diagnosis and care, including healthcare in the home and redressing the balance between primary care for dementia, and specialist care.

Benefits of early diagnosis

Receiving a diagnosis of dementia can be a particularly distressing experience for the whole family. While there remains no cure, a diagnosis of dementia made early on in the course of the disease can make a significant difference to the quality of life of the individual then and in the future.

Timely diagnosis of dementia is important because it allows the individual and their loved ones to:

- Understand and address the stigma surrounding their condition
- Plan for the future, including explaining to family, friends and colleagues what has changed and how they can help
- Maximise quality of life, for example by making key decisions on support
- Benefit from treatments before symptoms worsen.

Alzheimer associations in over 100 countries and Dementia Alliance International can provide important support and advice for those seeking or in receipt of a diagnosis.

Improving the likelihood of earlier diagnosis can be enhanced at the national level through encouraging education and training among primary care doctors, introducing more services aimed at early stage dementia, such as Memory Clinics, and coordinating more effective care pathways for dementia.

Source: ADI, World Alzheimer Report: The benefits of early diagnosis and intervention (2011)

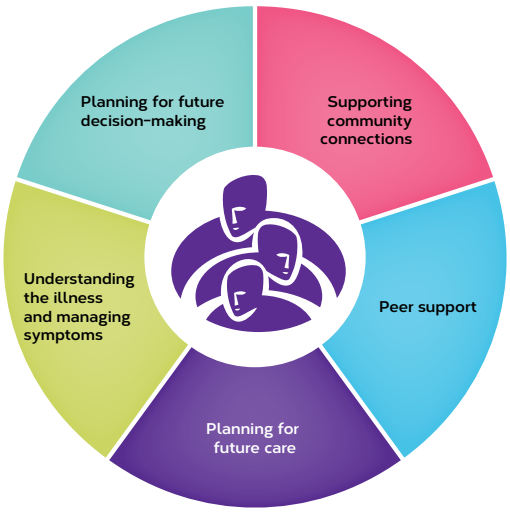
Alzheimer associations provide extensive services for the care and support of people with dementia and their care partners, including advocating for and monitoring standards of care. Training and support projects globally are too many to list. Instead, below are included some brief examples from Scotland, DAI and WHO.

Scotland – Five pillars model of post-diagnostic support

In April 2013, the Scottish Government announced its Post Diagnostic Support guarantee, meaning every person with a new diagnosis of dementia in Scotland is entitled to a minimum of one year of support from a named Link Workers. This PDS guarantee remains in place and forms a central component Scotland's third National Dementia Strategy (2017-2020).

High quality Post Diagnostic Support for every person who receives a diagnosis of dementia is vital to help a person come to terms with their condition and how to live well with the condition build resilience through peer support and community connections, whilst planning for future decision-making and care needs.

The 5 Pillars Model provides a framework for both professionals and people living with dementia, their families and carers as part of this process.

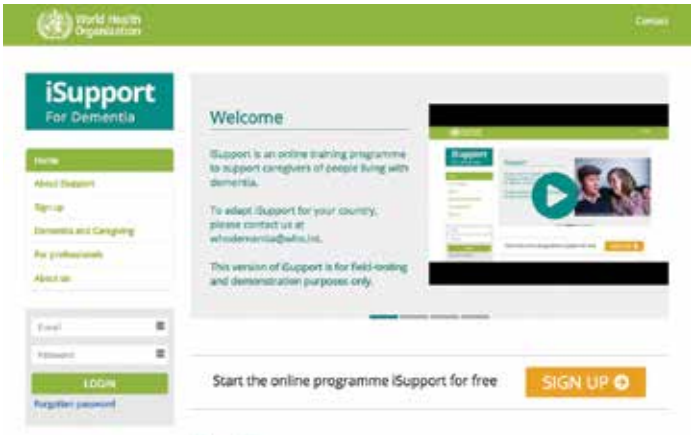


Source: Alzheimer Scotland, Five pillars model of post-diagnostic support, https://www.alzscot.org/campaigning/five_pillars

More information on Scotland's third National Dementia Strategy 2017-20 and post diagnostic support is available at: https://www.alzscot.org/campaigning/national_dementia_strategy

WHO iSupport program

iSupport is an online training program to support carers of people with dementia. Caring for a family member or friend with dementia can be difficult, stressful, and exhausting. iSupport helps carers to provide good care and take care of themselves. The program contains 23 lessons covering the following themes: (1) What is dementia; (2) Being a caregiver; (3) Caring for me; (4) Providing everyday care, and; (5) Dealing with challenging behaviour. Each lesson presents a topic and provides interactive exercises with instant feedback for carers.



iSupport has been developed by the World Health Organization developed with valuable help and advice from academic institutions and civil society including Alzheimer's Disease International and many other organizations, experts, people with dementia, and carers. Launched at the 32nd International Conference of ADI in Kyoto in April 2017, the program has been adapted in different countries and for different groups of carers. For more information, go to: www.iSupportForDementia.org.

WHO mhGAP

WHO's Mental Health Gap Action Programme (mhGAP) aims at scaling up services for mental, neurological and substance use disorders for countries especially with low- and middle-income. These priority conditions include depression, psychoses, self-harm/suicide, epilepsy, dementia, disorders due to substance use and mental and behavioural disorders in children and adolescents. The mhGAP package consists of evidence-based interventions for prevention and management of each of these priority conditions.

In order to provide support for the implementation of mhGAP, WHO developed several resources including the mhGAP-Intervention Guide that contains specific information on dementia including guidance on appropriate assessment and care pathways. Used in more than 100 countries and translated in over 20 languages, the Intervention Guide facilitates the delivery of evidence-based guidelines in non-specialised health care settings most suitable to low resource settings. In addition, WHO has developed mhGAP training manuals to help healthcare providers develop the competencies required to assess and manage priority disorders including dementia. The app version of the Intervention Guide, available in both iOS and Android, provides non-specialised healthcare providers with access to comprehensive information from their tablets or mobile phones.

The dementia module of the Intervention Guide focuses on the training of non-specialists health care providers in assessment of the disease, management of dementia including psychosocial and pharmacological interventions, as well as follow-up procedures to guarantee continued access to health and social care support. It also provides knowledge and support for dementia carers and families on how to deal with the disease and its effects. By covering these areas, the implementation of mhGAP offers an important support for the achievement of several areas of the Global plan on dementia, encouraging people to seek help, improving diagnostic rates of dementia, as well as provide a continued access to treatments, psychological support and decrease the exposure to risk factors that are shared with other noncommunicable diseases. For more information, go to http://www.who.int/mental_health/mhgap/en/

Dementia Alliance International — Online peer to peer support groups

Dementia Alliance International (DAI) is a global advocacy and support group for, and the global voice of people with dementia, and facilitates and provides free online peer-to-peer support groups and one to one mentoring for their members through an online video platform.

Online support groups are ideal for those who cannot drive to their local "in person" support group, or when there are none available locally. They are also ideal for those living in isolated or remote areas with limited access to conventional services. DAI also provided professional training for their support group hosts in 2017, who themselves are members of DAI, to ensure the quality of the service is truly professional. Find out about their support groups at www.dementiaallianceinternational.org/services/online-support-groups/

DAI also provides a number of other online services including educational Webinars and cafés. DAI's YouTube Channel was recently listed in the 2018 Top 20 Dementia YouTube Channels; you can watch many of the Webinars, and speeches or interviews given by people with dementia at www.youtube.com/channel/UC9OU-TO5MmvYPhmz6j7DYlg/

People with dementia can join DAI at www.joindai.org. Anyone can subscribe to DAI blogs and newsletters online.

CHAPTER 5
Information systems, research and innovation

50% of countries routinely collect a core set of dementia indicators through their national health and social information systems on which they report every two years by 2025. The output of global research on dementia doubles between 2017 and 2025.

Data and information systems on dementia are missing both in policy and in practice at national and regional levels. ADI reports and conferences have played a key role in communicating limited information on the exact impact of dementia – for example prevalence, incidence and diagnostic rates – since 2009, and to date, the World Alzheimer Report 2015 is the most popular and regularly cited source of much of the global information on dementia.

2017-2018 is a watershed year, following the establishment of the WHO Global Dementia Observatory (GDO) that will become the largest public and real time database of the achievement of the targets and data of the Global plan discussed in this report. It is currently populated with data from 21 countries and is expected to house information from 50 countries, roughly a third of WHO Member States, by the end of 2018.

While some countries include goals for measuring relevant data on dementia in their national plans, determining how and to what extent these commitments were carried out is not simple. In future editions, this report will assess the importance and role of this information in the GDO more closely.

It is positive to note that several developing plans will include reference to monitoring data, with the added opportunity to frame this both within the adoption of the Global plan in 2017, and to update the GDO as a result. ADI asks that other countries that have relevant data on dementia also submit this to the GDO to support its critical role.

For example, the government of Brunei is not yet represented among the pilot countries of the GDO but is considering the development of a dedicated dementia Unit within the Ministry of Health responsible for progress on a developing national plan. Bru-HIMS, an electronic patient record system used within the Ministry could include detail from patient records to map the locations and factors of highest occurrence of dementia, in order to support planning of targeted actions in education, training and risk reduction[15].

15 Communication with Alzheimer's Disease Foundation Malaysia (May 2018)

Research has the potential to drive changes in both the perception and understanding of dementia, but is lacking in many areas of both science and care. LMICs that experience the greatest impact of dementia require a special focus, and may present additional challenges to research as a result of factors of awareness, infrastructure and resources. WHO conducted a globally representative research prioritisation exercise that identified the research areas that need to be addressed to reduce the global burden of dementia.

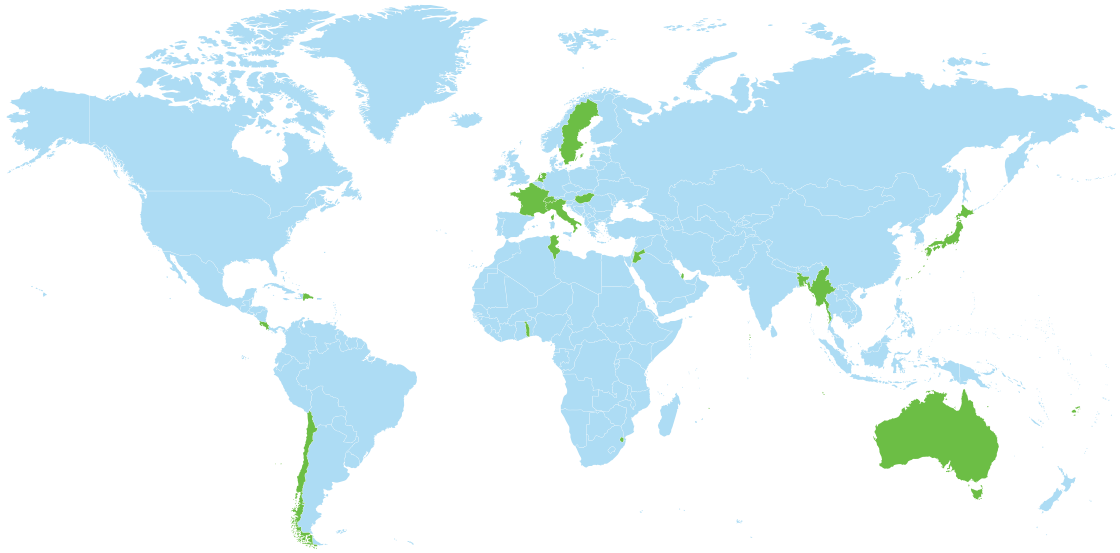
Efforts to enhance the focus on LMICs include the 10/66 Dementia Research Group supported by ADI and the STRiDE (Strengthening responses to dementia in developing countries) project that aims to build research capacity and provide much-needed evidence on dementia care in seven low and middle-income countries (Brazil, India, Indonesia, Jamaica, Kenya, Mexico, South Africa).

Research can be strengthened by direct investment or partnerships established as a result of dementia plans. It is important to note that research should not be confined to national boundaries. Positive attention to regulation and the rules that define how researchers in different parts of the world collaborate is one area that could greatly improve and provide balance to the understanding of dementia and work towards a cure.

In order to strengthen the areas of information, research and innovation, ADI calls on every government, as well as corporate and civil partners to collaborate for the:

- Increased investment in dementia research, particularly on care and in low resource settings
- Establishment of national monitoring systems for dementia data on understanding, care and science to support better outcomes. Where possible, data should be made available for research and public, including submission to the WHO GDO
- Important role of data collection and monitoring, of research and innovation to be included and prioritised in national plans and policies on dementia

WHO Global Dementia Observatory (GDO)



GDO Pilot countries

- Australia
- Bangladesh
- Chile
- Costa Rica
- Dominican Republic
- Fiji
- France
- Hungary
- Italy
- Japan
- Jordan
- Maldives
- Mauritius
- Myanmar
- Netherlands
- Qatar
- Swaziland
- Sweden
- Switzerland
- Togo
- Tunisia

The GDO is a data and knowledge exchange platform that was launched by WHO in December 2017. The GDO has been designed, in consultation with international stakeholders and country focal points, to support countries in strengthening policies, service planning and health and social care systems for dementia. It can assist countries in measuring progress towards reaching national and global targets that include regular reporting on a core set of dementia indicators.

The GDO framework includes 35 indicators organised across three domains (policy, service delivery, and information and research), aligned within the seven action areas of the Global dementia action plan:

- Dementia as public health priority;
- Dementia awareness and dementia friendliness;
- Dementia risk reduction;
- Dementia diagnosis, treatment, care and support;
- Support for dementia carers;
- Information systems for dementia;
- Dementia research and innovation.

Currently, data from 21 countries covering all WHO regions can be viewed through the GDO data portal. For each action area, data can be accessed by target indicators of the Global plan outlined in this report, or through a drop-down menu, allowing users to access data tables that classify information by country, aggregated reports and visualizations such as interactive graphs or maps.

In addition, the GDO platform contains key resources and tools to support the implementation of the global action plan and enhance countries' response to dementia. Good practice examples for each of the seven action areas will continuously be identified and shared via the platform.

You can view the GDO data at: http://apps.who.int/gho/data/node.dementia

WHO MiNDbank

WHO MiNDbank is an online database collating international and country-specific resources, such as policies, strategies and constitutions, relating to mental health, substance abuse, disability, general health or human rights. It can be navigated either by country or topic, and therefore can be used for researching where dementia is included in other health policies, aside from a specific national dementia plan.

On numbers

Data presented in this report reflects ADI's network of Alzheimer and dementia organisations in over 100 states. There are 194 Member States represented by the WHO that form the basis for targets of the Global plan.

WHO Member States	
Target 2.1: 100% of Member States	194
Targets 1, 5: 75% of Member States	146
Targets 2.2, 4, 6: 50% of Member States	97
Countries/territories in the world	> 200

While ADI urges every government to act, targets of the plan are aimed at different numbers of WHO member states; for example, it is urged that 75% of Member States implement a national policy, framework or strategy on dementia – 146 States. The only target that requires action by 100% compliance by Member States is 2.1: 'Awareness'.

In addition, the governments of a small number of states have developed responses on dementia that will not be included against the targets of the Global plan (See appendix C).

Scotland, Northern Ireland, Wales and Gibraltar are included in the scope of this report as countries with Alzheimer associations, but are represented at WHO as 'UK' (one plan toward target). There are similar examples for the Netherlands and USA.

Where possible, the authors have endeavoured to provide the total number of states where a specific response to dementia or other policy including dementia has been designed and implemented, and to specify the type of plan and figure in accordance with the relevant target – for example by number of WHO Member States.

Summary and conclusion

The adoption of the Global plan on dementia has the potential to change the way that dementia is both experienced and perceived by future generations. This report has outlined some of the ways in which momentum to achieve the plan has already demanded the attention of policy makers in several regions – most notably in Central and South America – but it also highlights a substantial gap between action on dementia at the time of writing, and the much larger goal for dementia to be prioritised in most countries of the world by 2025.

The numbers show that the target, area one of the Global plan, requires a minimum of 15 new plans to be developed every year between now and 2025. This is over 7 times the average number of plans adopted since 2001 and almost as many plans that have been adopted in all states, including WHO Member States, over the last 5 years.

Without considerable and immediate attention to the development of the dementia landscape in sub-Saharan Africa, the second largest WHO region, this target is near impossible. In this and other regions, there is a need for every government to commit resources to the awareness of dementia at a much broader level – in most, if not all, societies dementia is yet to be freed from varying degrees of stigma, misinformation and discrimination.

Including those countries where there is a plan currently in development, an optimistic estimate could see dedicated plans on dementia in approximately a third of WHO member states by the mid term of the plan in 2021. Allocating dementia space within additional policies such as on Non-Communicable Diseases or mental health could increase this number considerably, but would mean little if the relevant sections on dementia are not squarely framed within the scope and targets of the seven areas of the Global plan.

Where there has been significant progress is in the groundwork that has provided key tools for future action - the WHO GDO in particular can play a critical role in both encouraging governments to monitor the impact of dementia, and as a vehicle through which civil society organisations can appraise progress towards the targets of the Global plan. GDO data has yet to be populated in areas including diagnostic rates for dementia. ADI urges every government to support the valuable role of the GDO by seeking out and actively contributing to the knowledge on dementia in their countries.

There is a significant opportunity to address the balance of dementia focus between high and low and middle income countries (LMICs). While there are currently only 4 LMICs with a plan or policy on dementia, the majority of those now in development are in LMICs.

Cost remains a significant barrier to greater action on dementia - while not specifically addressed in this report, themes of investment, infrastructure and funding for plans are at best partially considered by the current dementia policy landscape. Comprehensive plans on dementia in many countries lack the potential to achieve change through an absence of committed, publicly outlined funding.

There remain areas for future publications to explore. Research and innovation both merit a closer look and offer exciting prospects over the next year. While this report provides an overview of the development of plans to date, we have not sought to analyse the quality and implementation of plans in detail.

Action on dementia has taken immense strides in recent years. While an increasing number of governments have started to prioritise dementia in national policy, the most important measures of change are access to diagnosis, quality care and treatment, as well as increased understanding, empowerment and inclusion, to enhance the lives of people with dementia and their carers.

Appendix A

Table of states represented in WHO and ADI by region, GDO and plan status

Country	Region	ADI Member/ development	GDO Pilot	Plan Status
Afghanistan	EMRO			
Albania	EURO	YES		
Algeria	AFRO			
Andorra	EURO			
Angola	AFRO			
Antigua and Barbuda	PAHO			
Argentina	PAHO	YES		**Proposed strategy 2016**
Armenia	EURO	YES		
Australia	WPRO	YES	YES	**National Framework on Dementia 2015-2019,** Aged Care Service Improvement and Healthy Ageing Grant Fund (2012-2017)
Austria	EURO	YES		**Plan 2015**
Azerbaijan	EURO			
Bahamas	PAHO			
Bahrain	EMRO			
Bangladesh	SEARO	YES	YES	**Development; Mental Health**
Barbados	PAHO	YES		**In development**
Belarus	EURO			
Belgium	EURO	YES		
Belize	PAHO			
Benin	AFRO			
Bhutan	SEARO			
Bolivia	PAHO	YES		**In development**
Bosnia and Herzegovina	EURO	YES		
Botswana	AFRO			
Brazil	PAHO	YES		**In development**
Brunei	WPRO			**In development**
Bulgaria	EURO			
Burkina Faso	AFRO			
Burundi	AFRO			
Cambodia	WPRO			
Cameroon	AFRO			
Canada	PAHO	YES		**In development 2017-2018**
Cape Verde	AFRO			
Central African Republic	AFRO			
Chad	AFRO			
Chile	PAHO	YES	YES	**Plan 2017**
China	WPRO	YES		

Country	Region	ADI Member/ development	GDO Pilot	Plan Status
Colombia	PAHO	YES		**In development**
Comoros	AFRO			
Congo	AFRO			
Cook Islands	WPRO			
Costa Rica	PAHO	YES	YES	**Plan 2014-2024**
Côte d'Ivoire	AFRO			
Croatia	EURO	YES		
Cuba	PAHO	YES		**Plan 2016, National Mental Health Program (incl dementia), National Noncommunicable Disease Programe**
Cyprus	EURO			**Previous development, Strategy 2010**
Czech Republic	EURO	YES		**Plan 2016-2019**
Korea, DPR	SEARO			
DR Congo	AFRO			
Denmark	EURO	YES		**Plan 2009**
Djibouti	EMRO			
Dominica	PAHO			
Dominican Republic	PAHO	YES	YES	Mental Health plan 2006, Alzheimer's law 2013
Ecuador	PAHO	YES		
Egypt	EMRO	YES		**No dementia specific plan.** Constitution: Physical, Psychological, Social and Financial Care of the Elderly
El Salvador	PAHO	YES		
Equatorial Guinea	AFRO			
Eritrea	AFRO			
Estonia	EURO			
Ethiopia	AFRO	YES		
Fiji	WPRO		YES	
Finland	EURO	YES		**Plan 2012-2020**
France	EURO		YES	**Plan 2014-2019**
Gabon	AFRO			
Gambia	AFRO			
Georgia	EURO			
Germany	EURO	YES		**Regional plans 2015**
Ghana	AFRO	YES		
Greece	EURO	YES		**Plan 2016**
Grenada	PAHO			
Guatemala	PAHO	YES		**Plan in previous development 2014**
Guinea	AFRO			
Guinea-Bissau	AFRO			
Guyana	PAHO			
Haiti	PAHO			
Honduras	PAHO	YES		

Country	Region	ADI Member/ development	GDO Pilot	Plan Status
Hungary	EURO	YES	YES	
Iceland	EURO			
India	SEARO	YES		**Strategy in development,** National Programme for Older People (2018), NCD, Mental Health Act and National Palliative Care Programme
Indonesia	SEARO	YES		**Plan 2016**
Iran	EMRO	YES		
Iraq	EMRO			
Ireland	EURO	YES		**Plan 2011-2016**
Israel	EURO	YES		**Plan 2013**
Italy	EURO	YES	YES	**Plan 2014**
Jamaica	PAHO	YES		
Japan	WPRO	YES	YES	**Plan 2015**
Jordan	EMRO	YES	YES	**In development: Mental health**
Kazakhstan	EURO			
Kenya	AFRO	YES		In development
Kiribati	WPRO			
Korea, Republic of	WPRO	YES		Plan 2015
Kuwait	EMRO			
Kyrgyzstan	EURO			
Lao, PDR	WPRO			
Latvia	EURO			
Lebanon	EMRO	YES		
Lesotho	AFRO	YES		
Liberia	AFRO			
Libya	EMRO			
Lithuania	EURO			
Luxembourg	EURO	YES		
Macedonia, FYR	EURO	YES		
Madagascar	AFRO	YES		
Malawi	AFRO			
Malaysia	WPRO	YES		**In development 2018**
Maldives	SEARO		YES	**In development: Mental health/ Ageing**
Mali	AFRO			
Malta	EURO	YES		**Plan 2015-2023,** Dementia included in National Strategic Policy for Active Ageing 2014-2020
Marshall Islands	WPRO			
Mauritania	AFRO			
Mauritius	AFRO	YES	YES	**In development**
Mexico	PAHO	YES		**Plan 2014**
Micronesia, FS	WPRO			
Moldova	EURO			
Monaco	EURO	YES		

Country	Region	ADI Member/ development	GDO Pilot	Plan Status
Mongolia	WPRO			
Montenegro	EURO	YES		
Morocco	EMRO			
Mozambique	AFRO			
Myanmar	SEARO	YES	YES	
Namibia	AFRO	YES		
Nauru	WPRO			
Nepal	SEARO	YES		**No dementia specific plan.** Development Mental Health Policy1997
Netherlands	EURO	YES	YES	**Plan 2013-2020**
New Zealand	WPRO	YES		**Framework 2013**
Nicaragua	PAHO	YES		
Niger	AFRO			
Nigeria	AFRO	YES		**In development, Ageing**
Niue	WPRO			
Norway	EURO	YES		**2nd Plan 2015-2020,** Revision NCD plan to include dementia (2019). National Brain Strategy, Strategy for Elderly Persons.
Oman	EMRO	YES		
Pakistan	EMRO	YES		
Palau	WPRO			
Panama	PAHO			**In development: Mental health**
Papua New Guinea	WPRO			
Paraguay	PAHO			
Peru	PAHO	YES		**In development**
Philippines	WPRO	YES		Mental Health Act 2017
Poland	EURO	YES		
Portugal	EURO			**Previous development 2015**
Qatar	EMRO	YES	YES	**In development: Ageing**
Romania	EURO	YES		
Russian Federation	EURO	YES		
Rwanda	AFRO			
Saint Kitts and Nevis	PAHO	YES		
Saint Lucia	PAHO	YES		
Saint Vincent and Grenadines	PAHO			
Samoa	WPRO			
San Marino	EURO			
Sao Tome and Principe	AFRO			
Saudi Arabia	EMRO	YES		
Senegal	AFRO			
Serbia	EURO			

Country	Region	ADI Member/ development	GDO Pilot	Plan Status
Seychelles	AFRO			
Sierra Leone	AFRO			
Singapore	WPRO	YES		**Strategy, update 2018**
Slovakia	EURO	YES		
Slovenia	EURO	YES		**Plan 2016-2020**
Somalia	EMRO			
Solomon Islands	WPRO			
South Africa	AFRO	YES		
Spain	EURO	YES		**No dementia specific plan.** Neurodegenerative Diseases Strategy, Chronic Diseases Strategy
Sri Lanka	SEARO	YES		**In development**
Sudan	EMRO	YES		
South Sudan	EMRO			
Suriname	PAHO	YES		
Swaziland	AFRO		YES	
Sweden	EURO	YES	YES	**Possible development 2018,** allocated budget for persons with neuro-degenerative diseases
Switzerland	EURO	YES	YES	**Plan 2014-2019**
Syrian Arab Republic	EMRO	YES		
Tanzania, United Republic	AFRO			
Tajikistan	EURO			
Thailand	SEARO	YES		
Timor-Leste	SEARO			
Togo	AFRO		YES	
Tonga	WPRO	YES		
Trinidad and Tobago	PAHO	YES		**In development, Ageing**
Tunisia	EMRO	YES	YES	
Turkey	EURO	YES		
Turkmenistan	EURO			
Tuvalu	WPRO			
Uganda	AFRO			
Ukraine	EURO			
United Arab Emirates	EMRO	YES		
United Kingdom	EURO	YES		**Plan 2009**
United States of America	PAHO	YES		**Alzheimer's plan 2011, 2017 update**
Uruguay	PAHO	YES		**In development**
Uzbekistan	EURO			
Vanuatu	WPRO			
Venezuela	PAHO	YES		**Plan in previous development 2015**
Vietnam	WPRO			**In development**

Country	Region	ADI Member/ development	GDO Pilot	Plan Status
Yemen	EMRO			
Zambia	AFRO	YES		
Zimbabwe	AFRO	YES		

WHO regions as follows: AFRO: Regional office for Africa; PAHO: Pan American Health Organization (Americas region); SEARO: Regional Office for South-East Asia; EURO: Regional Office for Europe; EMRO: Regional Office for Eastern Mediterranean; WPRO: Regional Office for the Western Pacific.

Appendix B

List of WHO-GDO Pilot Countries by income group and plan status

Country	Region	Income group	Plan status
Australia	WPRO	HIC	Framework 2016-2020
Bangladesh	SEARO	LMIC	Development; Mental Health
Chile	PAHO	HIC	Plan 2017
Costa Rica	PAHO	HIC	Plan 2014-2024
Dominican Republic	PAHO	LMIC	Development
Fiji	WPRO	LMIC	
France	EURO	HIC	Plan 2014-2019
Hungary	EURO	LMIC	
Italy	EURO	HIC	Plan 2014
Japan	WPRO	HIC	Plans 2012, 2015
Jordan	EMRO	LMIC	Development; Mental Health
Maldives	SEARO	HIC	Development; Mental Health/ Ageing
Mauritius	AFRO	LMIC	Development
Myanmar	SEARO	LMIC	
Netherlands	EURO	HIC	Plan 2013-2020
Qatar	EMRO	HIC	Development; Ageing
Swaziland	AFRO	LMIC	
Sweden	EURO	HIC	Development
Switzerland	EURO	HIC	Plan 2014-2019
Togo	AFRO	LMIC	
Tunisia	EMRO	LMIC	

HIC: High income countries
LMIC: Low and middle-income countries

Appendix C

List of countries/territories with plans not directly represented at WHO, by income group and plan status.

Country/Territory	Income group	Plan status*
Bonaire	HIC	In development
Gibraltar	HIC	Strategy 2015
Macau SAR	HIC	Policy 2016
Northern Ireland	HIC	Regional Strategy 2011
Puerto Rico	HIC	**Plan 2015-2025**
Scotland	HIC	**Plan 2017-2020**
TADA Chinese Taipei	HIC	**Dementia Plan 2018-2025**, Long-term Care Plan 2.0, Patient Right to Autonomy Act, People with Disabilities Rights Protection Act, Mental Health Act
Wales	HIC	**Plan 2018-2022**

* Gibraltar, Northern Ireland, Scotland and Wales are represented at WHO by UK. Bonaire is represented by the Netherlands. Puerto Rico is represented by the USA. Macau SAR is represented by China.

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About ADI

Alzheimer's Disease International (ADI) is the international federation of Alzheimer associations throughout the world. Each of our 90 members is a non-profit Alzheimer association supporting people with dementia and their families. ADI's mission is to strengthen and support Alzheimer associations, to raise awareness about dementia worldwide, to make dementia a global health priority, to empower people with dementia and their care partners, and to increase investment in dementia research.

What we do

- Support the development and activities of our member associations around the world.
- Encourage the creation of new Alzheimer associations in countries where there is no organisation.
- Bring Alzheimer organisations together to share and learn from each other.
- Raise public and political awareness of dementia.
- Stimulate research into the prevalence and impact of Alzheimer's disease and dementia around the world.
- Represent people with dementia and families on international platforms at the UN and WHO.

Key activities

- Raising global awareness through World Alzheimer's Month™ (September every year).
- Providing Alzheimer associations with training in running a non-profit organisation through our Alzheimer University programme.
- Hosting an international conference where staff and volunteers from Alzheimer associations meet each other as well as medical and care professionals, researchers, people with dementia and their carers.
- Disseminating reliable and accurate information through our website and publications.
- Supporting the 10/66 Dementia Research Group's work on the prevalence and impact of dementia in developing countries.
- Supporting global advocacy by providing facts and figures about dementia, and monitoring as well as influencing dementia policies.

ADI is based in London and is registered as a non-profit organisation in the USA. ADI was founded in 1984, has been in official relations with the World Health Organization since 1996 and has had consultative status with the United Nations since 2012. ADI is partnered with Dementia Alliance International (DAI), a collaboration of individuals diagnosed with dementia providing a unified voice of strength, advocacy and support in the fight for individual autonomy for people with dementia.

You can find out more about ADI at www.alz.co.uk/adi

Alzheimer's Disease International:
The International Federation
of Alzheimer's Disease and
Related Disorders Societies, Inc.
is incorporated in Illinois, USA,
and is a 501(c)(3) not-for-profit
organization

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