

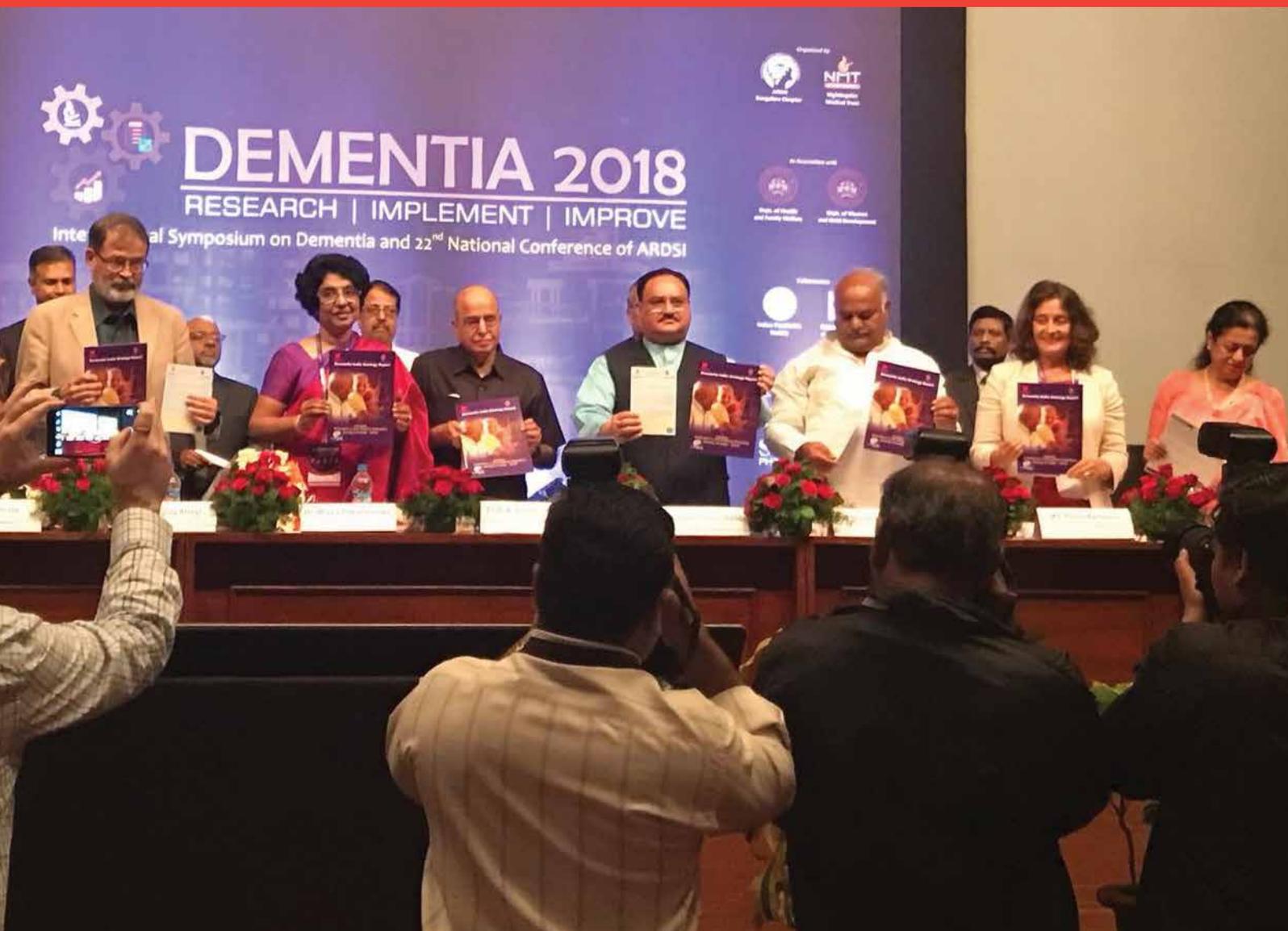


**Alzheimer's Disease  
International**

*The global voice on dementia*

# From Plan to Impact II

*The urgent need for action*



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Front cover image: Dementia 2018, International Symposium on Dementia and 22nd National Conference of ARDSI, Bangalore, September 2018, where the Minister of Health of India announced his commitment to a national dementia plan.



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## 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 action plan on the public health response to dementia.

## Foreword



**The thrust of this important report is that there is an urgent need for action.** We are still far from reaching the targets established two years ago. Only one national dementia plan has been published since our May 2018 report; that was in Qatar where energetic civil society leadership and real vision by the government inspired a solid plan. We need more and we need more now, as the crisis of dementia deepens - so many people with Alzheimer's and dementia and their families continue to struggle, often alone, with the multiple challenges presented by the condition.

On a positive note there is a great deal of good practice. There are many ideas of how to improve conditions for everyone across the board but, still, we need to ensure that these good practices and ideas are brought to those experiencing difficulties. Awareness raising is key but civil society can only do so much. So many of our member societies are staffed mainly by volunteers, especially in low- and middle-income countries.

National public health campaigns are crucial. It is becoming increasingly clear how in the absence of a pharmacological solution the message on risk reduction can be powerfully made as simple lifestyle interventions can reduce the risk, stave off or delay the development of dementia. In this, we really do share the agenda of the NCD community. On the other hand these messages, as well as diagnosis (and post diagnostic support), need to be available to end up firmly in the hands of primary care practitioners who act as first gatekeepers in most nations, and who all too often, still know too little about dementia to really make a real difference to for people with dementia and their families. Data gathering and sharing also needs to progress further. Given the relevance of the Global Dementia Observatory in this area, I invite you to read this chapter with great attention.

Finally, pharmacological and medical research is still led by a handful of committed and productive nations -- first and foremost the US, UK and Australia. In light of recent negative outcomes on drug discovery, it is our collective duty to keep encouraging young researchers to enter this difficult field. Given its evident success and effectiveness, it is also our duty as civil society to keep encouraging all areas of research into care and therapeutic interventions given their evident success and effectiveness.

When governments take responsibility for a plan and really bolster their vision and ambition, amazing things happen. I am thinking of Republic of Korea, now in the third iteration of its National Dementia Plan - a plan that must be commended as one of the best in the world in all areas bar research. Conversely, when nations take a step backward and bury a plan under more nomenclature, this may serve as a means to remove funding from this area; here, I am thinking of France.

We at ADI will continue to do the best we can. Our survey on attitudes around dementia, the largest ever commissioned in this area, will form the backbone of the World Alzheimer Report 2019 and will hopefully furnish us and our national members with more arguments to sharpen our advocacy tools. We need this, as many governments are still not considering dementia the priority and emergency that it is. There are still 50 million people and counting with dementia in the world. There is no doubt: we all need to do more.

**Paola Barbarino**  
Chief Executive Officer



**Around the world, there will be one new case of dementia every 3 seconds**

## Background and methodology

**In May 2017, the World Health Organization (WHO) adopted the Global action plan on the public health response to dementia 2017-2025.<sup>A</sup>**

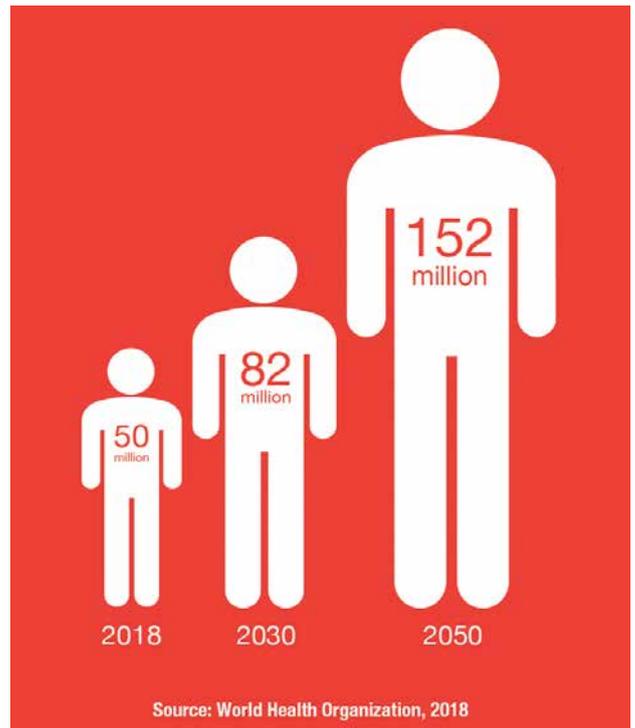
This report provides an overview of the current national responses to dementia around the world. Although ADI constantly monitors updates to national activity, for this report, we conducted a focused four-month scoping exercise in consultation with ADI members and other Alzheimer and dementia associations (including those on the Membership Development Programme) from January to April 2019.

The views and figures represented in the report are intended to represent an up-to-date and holistic view of progress towards the targets of the WHO Global plan. It presents the most accurate global view of the current policy landscape based on the included definition of a dementia plan. Where possible, efforts have been made to consider those governments that have made a significant inclusion of dementia in plans under other areas, such as ageing, neurology, mental health or non-communicable diseases. This approach does not, however, include information on all plans and strategies on dementia that may exist as part of broader frameworks or policies on age or health, as we advocate for standalone dementia plans in the belief that dedicated national plans are still the best tool available. We welcome feedback on these areas for future editions.

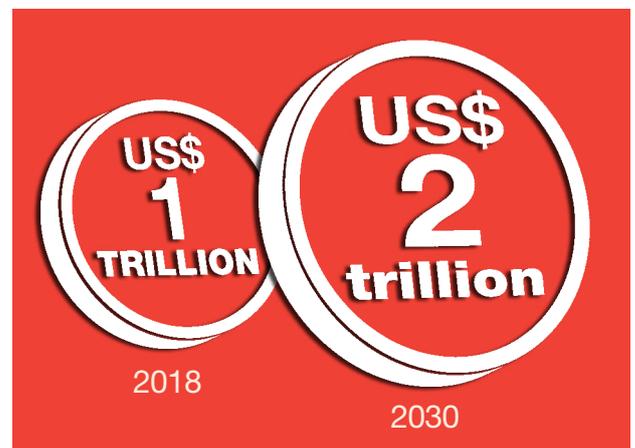
Data presented in this report reflects ADI's network of Alzheimer and dementia organisations in over 100 states, including the majority of ADI's members. There are 194 Member States represented by the WHO that form the basis for targets of the Global plan.

The governments of a small number of states, including some ADI members, that are not WHO member states, have developed or are in the process of developing responses on dementia, therefore are not included against the targets of the Global plan (See appendix B).

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 2019, from desk research on non-dementia policies and other frameworks and additional communication with Alzheimer associations and civil society groups from January to May 2019. 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 as it becomes available.



**Estimated growth in number of people with dementia 2018-2050**



**The total estimated annual worldwide cost of dementia in 2018 is US\$1 trillion. This figure will rise to US\$ 2 trillion by 2030**

A 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/](http://www.who.int/mental_health/neurology/dementia/action_plan_2017_2025/en/)

# Action Areas

Dementia as a public health priority



Dementia awareness and friendliness



Dementia risk reduction



Dementia diagnosis, treatment, care and support



Support for dementia carers



Information systems for dementia



Dementia research and innovation



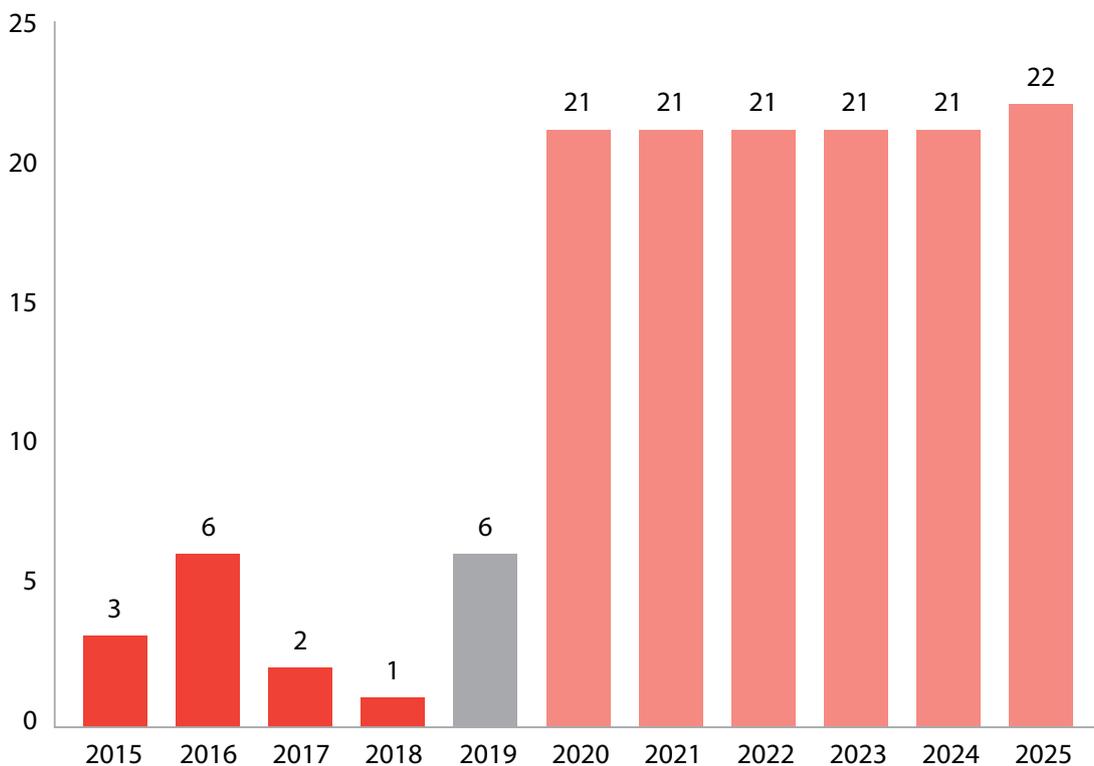
## CHAPTER 1

## 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.**

## Number of dementia plans adopted since 2015 – all states



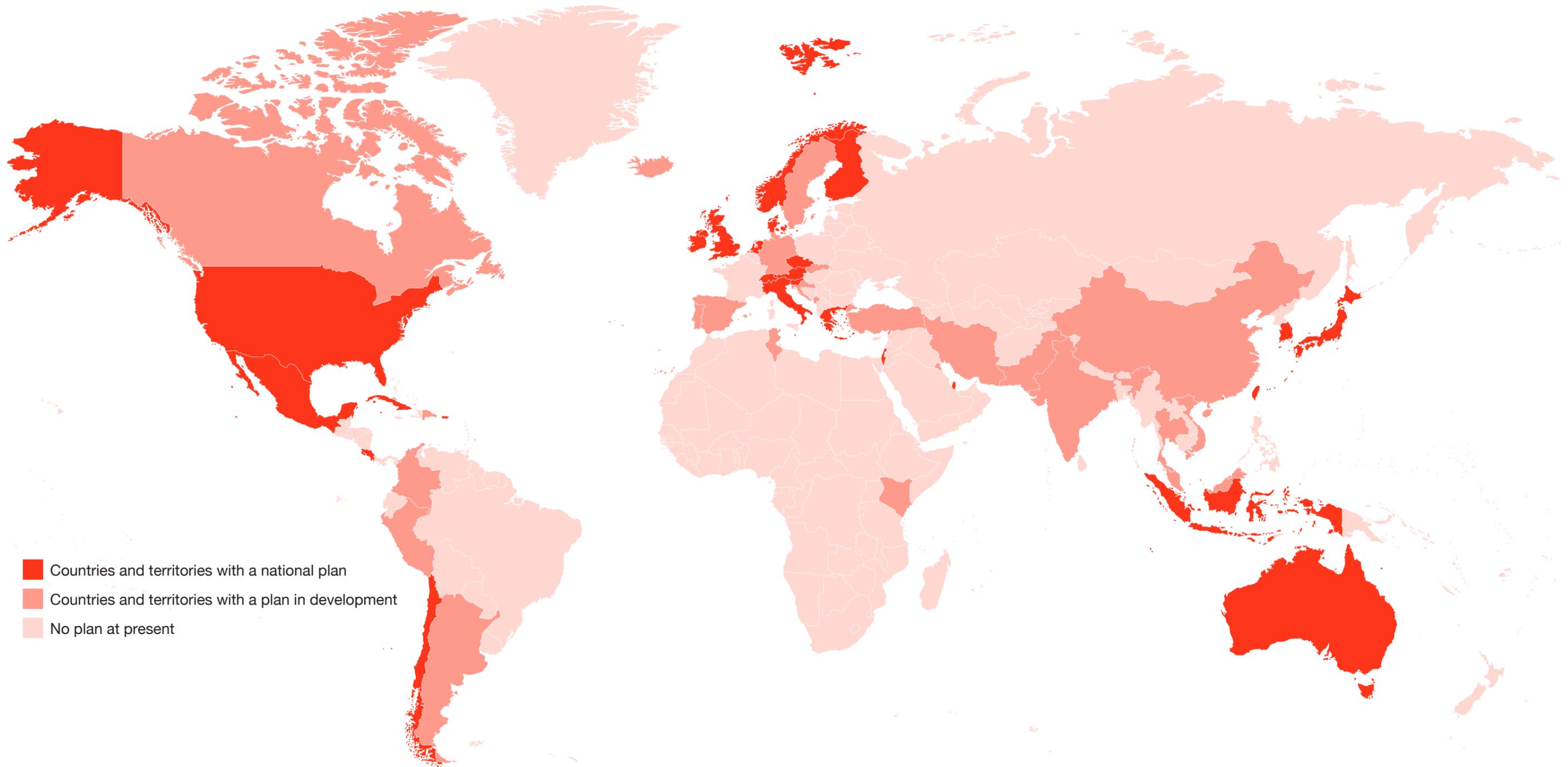
**Over 21 new plans needed every year from 2020 to cover 75% of countries by 2025. This calculation is based on the six national plans we expect to be finalised before 2020 (in Canada, Germany, India, Malaysia, Thailand and Turkey).**

**The target of the first strategic area of the Global plan sets the stage for governments of 146 countries to act on dementia. Two years into the action plan, 31 plans have been adopted, including 28 countries, 26 of which are WHO Member States - 18% of that target.<sup>1</sup> Upon the first interim review of the Global plan in 2021, it is likely that still less than half of the 146 countries target will have been met. As the title of this report suggests, there is an urgent need for action.**

We are now two years into plan implementation. The government of Qatar is the only one that has released a plan in the period since the previous edition of this report was published a year ago. Therefore, we have used this edition as an opportunity to delve deeper, with the assistance of our members, to produce a more detailed analysis of the stages that plans need to go through to be fully funded and adopted – stage 5 in our review. This staging will enable us to give a clearer indication of where countries and governments are; where there is progress, and where there are barriers.

<sup>1</sup> New Zealand and Costa Rica were moved to the “in development” category as a result of this updated scoping exercise.

## Countries with plans on dementia or in development in 2019



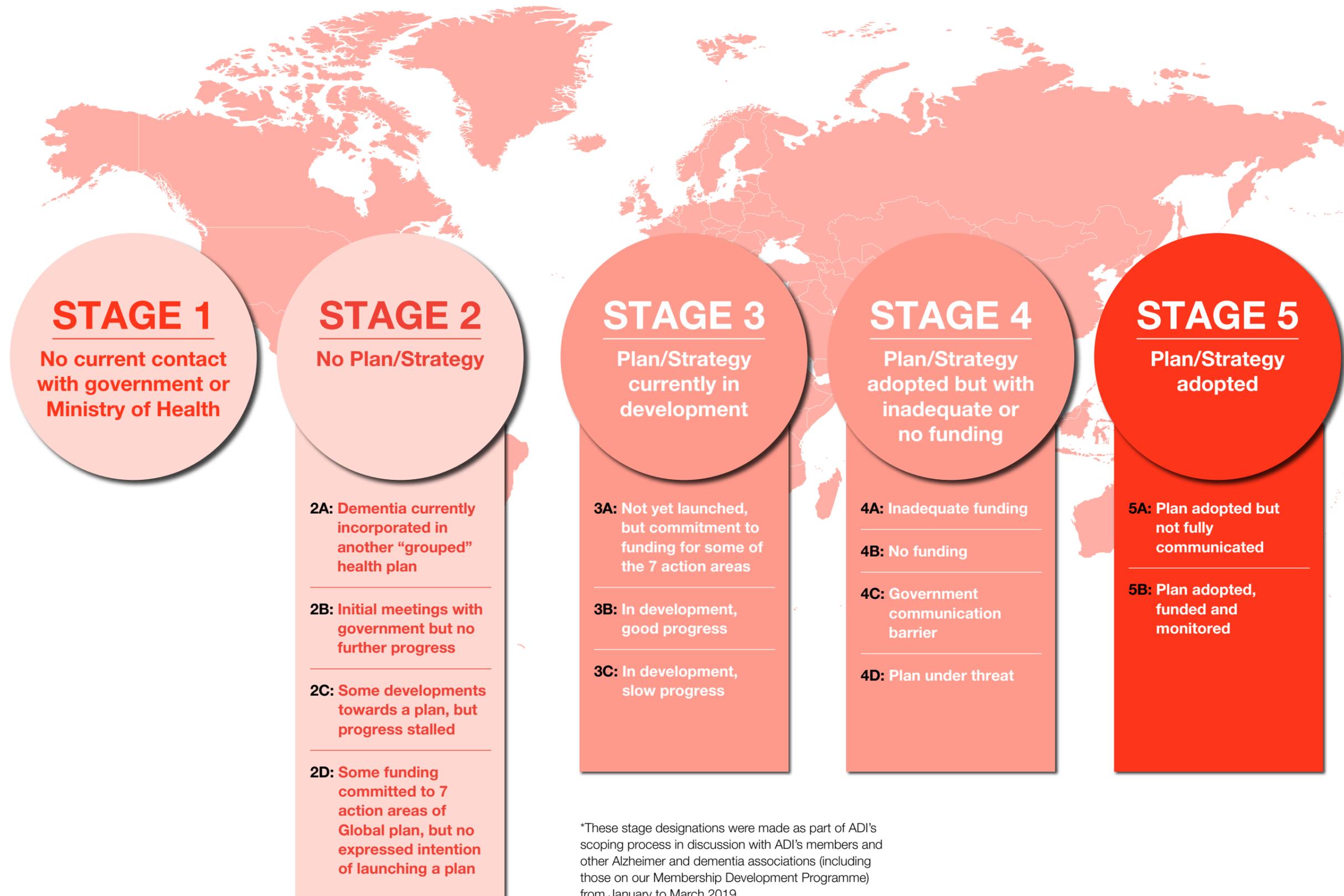
- Countries and territories with a national plan
- Countries and territories with a plan in development
- No plan at present

### Countries with national dementia plans

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

### Countries with national dementia plans in development

Argentina	China	Dominican Rep.	Kenya	Pakistan	Sweden
Barbados	Colombia	Germany	Kuwait	Peru	Thailand
Bonaire	Croatia	Iceland	Malaysia	Portugal	Tunisia
Brunei	Curacao	India	Mauritius	Spain	Turkey
Canada	Cyprus	Iran	Montenegro	Slovak Rep	Vietnam



**ADI believes strongly that dedicated national plans are still the best tools available to effect change, but any strategies incorporated in other areas should still have the targets and indicators that relate to the 7 action areas of the Global plan.**

ADI has a growing body of plans on our website for information and inspiration. The WHO has developed a useful guide on how to develop a national plan.<sup>2</sup>

One main area of focus is ensuring that plans are not only announced, but also funded, fully implemented and monitored. The planning, implementation and evaluation stages of national plans all require thoughtful consideration of the resources needed, of the department or functions of the government that may best meet the specific cost demands of each area, and of the roles other stakeholders may play.

Key areas that require dedicated budgets include training of healthcare professionals, investment in research, information dissemination and monitoring. Budgets are often a barrier, with many competing demands for government funds. There are other competing and important priorities such as disaster recovery, infectious disease control and unfortunately conflict. Innovative and solution-focused approaches are needed, as budgets are not limitless. In countries where budgets are a challenge and where governments are struggling even to start the development of a plan, we encourage decision and policy makers to identify action areas of the Global plan that are more achievable, for example national awareness raising campaigns.



## 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

## Dementia as a public health priority

A call for fully funded plans by ADI was a key element of the policy pack presented to Japanese Prime Minister Shinzo Abe in the build-up to the G20 leaders meeting and G20 Health Ministers' meeting which will take place later in the year under Japan's presidency.<sup>3</sup> We are encouraged by the response of the Japanese Ministry of Health, acknowledging the need for global leadership to tackle the escalating challenge of dementia; a sustained focus on national plans working towards the Global action plan on dementia; innovation in health and care systems, and continued development of dementia friendly initiatives. Global awareness such as this is vital following the G8 dementia summit in 2013 and the launch of the Global plan in 2017.

<sup>2</sup> World Health Organization, Towards a dementia plan: a WHO guide (2018)

<sup>3</sup> For more information about the G20 meeting, go to <https://www.g20.org/en/>



**Chris Lynch, ADI, and Noriyo Washizu, Alzheimer Association Japan, at C20 policy pack drafting session**

## WHO Member States with existing plans or other policies on dementia

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

## Spotlight on Africa

So far there are no national dementia plans in the sub-Saharan African region. This is concerning given that this is 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 key 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. More innovative approaches are sorely needed. We need regional bodies, starting from the WHO's African Regional Office, to devote time and effort to this task and raise awareness in the national governments. ADI's African members are making good steps to raise awareness in their governments but they need help and more influence.



Yet, there is hope. Alzheimer associations in Kenya, Lesotho, Madagascar, Mauritius, Namibia, Nigeria, Seychelles, South Africa, Tanzania, Togo, Uganda, Zambia and Zimbabwe are working hard to change the perception and experience of dementia in Africa. In addition, there are encouraging developments in the design of a national plan in Kenya. Partnership with these associations and other civil society groups offers extraordinary potential to realise real policy action in this region.

## CASE STUDY

## Senegal stage 2A: Dementia currently incorporated in another “grouped” health plan

A national plan is in the early stages of development in Senegal but has quickly gathered momentum thanks to the strong commitment of the government. Following a call with ADI staff, they have integrated dementia in their Mental Health Plan and are in the process of creating a national association to support people living with dementia. An office has also been created in the Ministry of Health, which deals with neurodegenerative diseases among other pathologies, and three individuals have been appointed within the government to communicate directly with ADI.

Paola Barbarino, ADI's CEO, said: *“We are delighted to see the great progress in Senegal as a result of our outreach to the Ministry of Health. The government has shown understanding and a strong commitment to pursue the integrated management of dementia and other neurodegenerative diseases within the health system. Other governments in Africa should be inspired by this example.”*

## CASE STUDY

## South Africa stage 2A: Dementia currently incorporated in another “grouped” health plan

Petra du Toit, Executive Director of Alzheimer's South Africa said: *“At present dementia is incorporated in parts of the Mental Health, Ageing and NCD plans.”*

*We have tried numerous times by email as well as in person to highlight the importance of a National Dementia Plan for South Africa with important figures in the field of Health, Mental Health and Social Development – without success. At both Strengthening Responses to Dementia in Developing Countries (STRiDE) meetings for South Africa, which included representation from National Departments of Health and Social Development, this fact was shared again, but still no response. The National Department of Health did follow up with an email after the STRiDE meeting in Cape Town that we need to discuss this matter, but no further action took place.”*

## CASE STUDY

## Namibia stage 2B: Initial meetings with government but no further progress

Berrie Holtzhausen, CEO of Alzheimer's Dementia Namibia (ADN), said: *“The deputy Minister of Health visited Alzheimer's Dementia Namibia (ADN)'s Dementia Care farm in 2017. They informed her about the National Dementia Health Plan and gave her a copy. She made a lot of promises. After a few months they wrote a letter to the Deputy Minister and the Minister of Health. The Deputy never replied, but the Minister did. In early 2018 they made an appointment with the WHO representative in Namibia. They informed her and gave her the same copy that they gave to the Deputy Minister but ADN never heard from her again.”*

ADN is busy, in collaboration with HU-Lab in Atlanta, USA, to work on a plan to gather data regarding Dementia in Namibia, which might have implications for the rest of Africa.



**Some ADN staff explaining Dementia and their non-pharmaceutical-care approach and the link between Witchcraft and Dementia to the Deputy Minister of Health, Juliet Kavetuna, during her visit to AND's Dementia Care Farm in December 2017**

#### CASE STUDY

### **Togo stage 2A: Dementia currently incorporated in another “grouped” health plan**

A staff member of an Alzheimer Association in Togo said: *“In Africa many countries have a real problem financing their national health policies and don’t have the budget to finance national dementia action plans. Togo is in this situation and could be classified as Stage 2 because it does not have a plan or a strategy to respond to dementia. Our contact within the Ministry of Health, Professor Mofou BELO, coordinator of the National Programme for the Control of NCDs, who is also the focal point for dementia in Togo, has informed us that the national plan for NCDs does include dementia. Therefore, in the absence of a stand-alone dementia action plan, Togo needs funding to implement an actionable plan against dementia that would result from the national plan for NCDs. In this case Togo could be classified as Stage 4.”*

#### CASE STUDY

### **Zambia stage 2B: Initial meeting with government but no further progress**

There is currently no mention of dementia in Zambia’s NCD national strategy. Dementia is also currently not visible in the health space in Zambia. A snap survey conducted by Alzheimer’s Disease and Related Dementias In Zambia (ADDIZ) to ascertain the levels of understanding of dementia by health personnel at all levels revealed that most health professionals have heard or come across the term dementia in their training, but know very little about the condition. From the survey, ADDIZ established an urgent necessity to compel the government to provide a policy direction on dementia.

Following a letter of support sent by ADI, ADDIZ met the Permanent Secretary, Ministry of Health, who pledged full support to the formulation and implementation of a National Plan on Dementia in Zambia. He said the Ministry of Health were excited that issues to do with dementia were brought to their attention by ADDIZ, supported by ADI. He added that he had only heard about dementia during World Health Assembly in Geneva and as such his office was going to provide total support to the activities of ADDIZ. He also committed to link the association to the relevant Ministry of Health departments to work in collaboration to develop a national plan and make dementia a health priority in Zambia.

## Dementia incorporated into a grouped health plan

**ADI believes strongly that dedicated national plans are still the best tools available to effect change, but any strategies incorporated in other areas should still have the targets and indicators that relate to the 7 action areas of the Global plan.**

### CASE STUDY

#### New Zealand stage 2A: Dementia currently incorporated in another “grouped” health plan

Dementia is mentioned as part of the 2016 Healthy Aging Strategy with two specific action items, but there is no specific dementia strategy or plan. The key issue is that the ageing population and dementia are not priorities for the current government (as they haven't been for successive governments). Alzheimers New Zealand continues to advocate strongly for ministers and senior officials to recognise and act on the impact of the aging population and conditions associated with aging, including dementia. Alzheimers New Zealand has proposed a six-step plan to provide a pathway to immediate improvement for people living with dementia.

## Upcoming plans

Through our desk-based research, we are anticipating six new plans to be launched in 2019. Below are some examples of these, which may provide some inspiration to other countries working to progress their plans, whilst also indicating what the barriers might be throughout this process.

### CASE STUDY

#### Canada stage 3A: Not yet launched, but commitment to funding for some of the 7 action areas

The Public Health Agency of Canada anticipates that Canada's dementia strategy will be publicly available in late May to early June 2019. In order to identify priorities for their national strategy, the Government of Canada has consulted a broad range of stakeholders, including people living with dementia, caregivers, healthcare professionals, researchers, advocacy groups, as well as provincial and territorial governments. These stakeholders were also engaged at their National Dementia Conference in May 2018<sup>1</sup> to provide input and share their perspectives on the areas of focus for the strategy.<sup>2</sup> A Ministerial Advisory Board on Dementia was created in 2018 to advise the Minister of Health. The launch of Canada's first National Dementia Strategy will meet one of the targets outlined in the WHO's Global Action Plan on Dementia (75% of Member States with a national plan by 2025) as part of its contribution to the international effort on dementia. The Minister will provide the first report to Parliament on the Strategy by June 2019 as required by the *National Strategy for Alzheimer's Disease and Other Dementias Act*.<sup>3</sup>

There has been a commitment through the federal budget in Ottawa of \$50 million over five years to support implementation of Canada's first National Dementia Strategy. Specifically, the funding is for \$3 million in fiscal 2019 and \$12 million in each of the following four years. The budget identified public awareness, stigma reduction, treatment guidelines, early diagnosis and collection and reporting of data as key priorities of the Strategy. This funding is in addition to the \$20 million over 5 years announced in the 2018 budget to support community-based projects that address the challenges of dementia. Budget 2019 provides a base upon which to build as the National Dementia Strategy becomes more fully developed and implemented.

1 Government of Canada, Conference report: National dementia conference (2018)

2 Government of Canada, What We Heard Report: Informing a dementia strategy for Canada (2019)

3 Parliament of Canada, Private Member's Bill C-233 (42-1) An Act respecting a national strategy for Alzheimer's disease and other dementias (2017)



The announcement event of Germany's national plan. Photographer: Herber Jennerich/BMFSF

#### CASE STUDY

### Germany stage 3B: In development, good progress

Work towards establishing Germany's national dementia plan officially commenced in January 2019. Work will focus on four fields of action: strengthening social participation of people with dementia; supporting people with dementia and their carers; further development of medical provision and care; and supporting excellent research. The input of stakeholders into the four action areas of the plan is good. Four working groups have met twice and will meet twice more in 2019. The German Alzheimer Association is co-chair of the Steering Committee; Chairs are the Ministry of Health and the Ministry for Family Affairs, senior citizens, women and youth.

Sabine Jansen, Executive Director of Deutsche Alzheimer Gesellschaft, said: *"The great challenge will be to prioritise measures and make a suggestion to the government. The ambitious aim is to finish the draft of the plan by the end of the year and get a decision from the government in spring 2020 – also containing a commitment to funding. Our advisory board of people with dementia has made suggestions what aims should be included in the plan at the beginning of the process in November 2018. The results of their workshop was given to the ministries and stakeholders during the kick-off. The advisory board will be kept informed and will discuss the process again in May 2019."*

#### CASE STUDY

### Bonaire 3B: In development, good progress

Fundashon Alzheimer Bonaire received an official letter from the Government of Bonaire in April 2019 informing of approval of funding and an agreement with Project Planners to write a National Dementia Plan, which should be available in three months. The process for the Government to approve the budget took longer than expected, but Fundashon Alzheimer Bonaire indicated that ADI's letter of support last year helped.

## CASE STUDY

**Turkey stage 3B: In development, good progress**

The Turkish Alzheimer Association drafted a national dementia plan in 2010 and created a committee to build the National Dementia Strategy. The second draft is almost finished and the committee expects to complete the whole document in May this year.

The Ministry of Health held a workshop to author the regulations for Day Care Centres for people with dementia and "define their disability type/level effectively". Additionally, a "Parliamentary Committee on Enquiry" was being assembled to include dementia day care centres with "special disabled care centre" status, so that governmental support can be provided, which should result in increasing number of centres. The Ministry of Family, Labour and Social Services has acknowledged the day care centres established by Turkish Alzheimer Association are "exemplary". They have approved the promotion of local collaborations with the branches of Turkish Alzheimer Association and local authorities for the purpose of enhancing and expanding Daily Care Services using the present centres as prototypes.

The first Council on Ageing was held in Ankara in February 2019 under the auspices of the Presidency of the Republic of Turkey. The main themes of the 1st Council on Ageing, as announced by the President, were "supporting active ageing" and "strengthening the rights of the elderly". Turkish Alzheimer Association participated in the commissions and study groups within the scope of the Council.

A challenge for the Turkish Alzheimer Association was the perception of government officials. Füsün Kocaman, Executive Director of Turkish Alzheimer Association, said: *"It took time to make them realise that neither the Elderly Care regulations nor the Regulations for Disabled Individuals wholly cover the needs of the people with dementia. Examples from other countries and the Global plan also helped in the planning. Funding has not yet been discussed, which may present issues in the future."*



**The President of the Republic of Turkey at the first Council on Ageing, 20-22 February 2019**

## CASE STUDY

## India stage 3A-3B: Not yet launched, but agreed to consider funding for some of the 7 action areas/In development, good progress

There are no specific policy, related schemes or treatment facilities available for dementia from the Ministry of Health and Family Welfare or Ministry of Social Justice and Empowerment. The Alzheimer's and Related Disorders Society of India (ARDSI) which has constant interaction and liaison with these Ministries, brought out the Dementia India Report in the year 2010, suggesting action areas for the Union Government to adopt to bring about a comprehensive policy for Dementia in India.

ARDSI held four regional consultative meetings in Bangalore, Kolkata, Mumbai and Delhi in 2017-2018 in order to stimulate the development of a strategy and budget for a national dementia plan. Accordingly, a comprehensive "Dementia India Strategy Report" with recommendations was prepared for the Union Health Minister for the Government of India at the annual conference of ARDSI in September 2018. After receiving the document, the Minister committed to do what was necessary to implement and fund a national plan and additionally promised to get dementia covered under the proposed new Insurance scheme and provide free medicines and treatment to persons with dementia.

Following up on his assurance, ARDSI staff took it up at the different levels of the Ministry of Health and Family Welfare. Since the requests made by ARDSI required special considerations, the Joint Secretary looking after Mental Health (under which dementia is presently listed) agreed to come up with an interim action plan and asked ARDSI to come up with action points. These included initiatives to improve diagnosis, training of primary healthcare workers, national awareness-raising materials and the formation of an expert committee to discuss a comprehensive policy. So far the Government has agreed, in principle, to consider from their national funds to support components 2, 4 and 5 out of the 7 action areas from the Global Dementia Action Plan, but there is a lack of clarity on the amount of funding that the government is committing and the confirmed services.

At the time of writing, India is facing Parliamentary elections, so progress has slowed. ADI are awaiting a written letter from India's Ministry of Health affirming their commitments and ARDSI will continue their efforts to advocate for the new plan.



**Dementia 2018, International Symposium on Dementia and 22nd National Conference of ARDSI, Bangalore, September 2018, where the Minister of Health of India announced his commitment to a national dementia plan.**

## Adopted plans

### CASE STUDY

#### Qatar stage 5: Plan/strategy adopted

Launched on 27th November 2018, Qatar is the first Arab nation to publish a dedicated dementia plan and is the only country in 2018 to publish its strategy. The plan is ambitious and aspirational; it sets out priority areas including addressing the stigma surrounding dementia, increasing the awareness of dementia, ensuring early diagnosis and intervention, and improving and responding to need to ensure services are responsive and appropriate. Proposals include the introduction of a dementia coordinator role to manage dementia care pathways, meaningful day care services and standardised triage and assessment processes.

The commitment to plan and prioritise dementia was first validated when Qatar agreed to become a pilot country in the WHO's Global Dementia Observatory (GDO) in May 2015. Following this, the country supported the World Innovation Summit for Health (WISH) to host a meeting where a select group of summit delegates discussed strategies to improve the care and monitoring of those living with dementia.

The development of the Qatar National Dementia Plan followed; the result of a lengthy consultation process with relevant stakeholders and interested parties. Multi sectorial stakeholder events were held. In addition, both people living with dementia and caregivers are widely consulted – including via a newly established Dementia Caregivers' Group - to understand the issues most pertinent to their needs along the dementia disease trajectory.

The overarching aim of the Qatar National Dementia Plan is to enhance the quality of life of individuals with dementia, their caregivers and family members. The Action Plan is built around the seven areas of the World Health Organization Global plan and the Global Dementia Observatory.

Dr Hanadi Al Hamad, focal point on dementia and Scientific Chair of Qatar Alzheimer's Society, said: *"Dementia is a multifaceted condition with multifaceted challenges. The seven action areas outlined by World Health Organisation set the framework for addressing the challenges as opportunities in Dementia care."*

The Ministry of Public Health has integrated the National Dementia four-year plan into a number of strategic objectives to improve care for people living with dementia and their carers. Each of these key objectives has an associated work stream tasked with achieving year on year improvements to deliver a four-year vision. The plan entails not only substantial human and financial commitments but also joint planning between different government entities, health and social care staff, individuals with dementia, their families and caregivers with the overall aim of improving the quality of life of those affected by dementia in Qatar.



**At the launch event of Qatar's National Dementia Plan, November 27, 2018, Dr Hanadi Al Hamad, Chairperson of Geriatrics, HMC-Qatar NHS-2 National Lead for Healthy Ageing**



**During the launch event of Qatar's National Dementia Plan. From Left: Dr. Mariam Ali Abdulmalik, Managing Director of PHCC-Qatar, Dr. Hanan Al Kuwari , Minister of Public Health, Dr. Salih Ali Al-Marri, Assistant Minister of Public Health**

#### CASE STUDY

### Chile stage 5: Plan/Strategy adopted

While a national plan is in place and the Pan American Health Organization (PAHO) may use Chile as a good example, the plan needs a push, to go beyond diagnosis, and geographically beyond the capital of Santiago. This year, Corporación Alzheimer Chile have partnered with professional associations, academics, and governmental and non-governmental organizations to galvanise the social pressure required to advance the national dementia plan, and to adopt public policies. In this context, there will be two national meetings for family caregivers that will bring together more than 800 family members with government agencies, Parliamentarians and civil society. Congress will launch a Policy Paper in June.

## CASE STUDY

## Republic of Korea stage 5: Plan/Strategy adopted

In South Korea, the first national dementia plan was prepared in 2008 by the Ministry of Health and Welfare. Based on the Dementia Management Act (DeMA) which was enacted in 2012, the second and the third national dementia plans were prepared in 2012 and 2016 respectively. In 2017, President Moon Jae-in announced the National Dementia Initiative that upgraded the national dementia plans from ministerial to pan-governmental agenda and strengthened the drive of national dementia plans.

The National Dementia Initiative emphasizes the following key strategies: 1) provide people with dementia with one-on-one tailored case management and support via 256 local dementia centers across the country; 2) increase the numbers of dementia-friendly convalescent hospitals and care facilities dedicated to people with dementia; 3) expand the beneficiaries of the National Long-term Care Insurance and the National Health Insurance for people with dementia; 4) expand public support services for people with dementia; 5) expand research and development investment for dementia, and 6) install a department dedicated to dementia policy in the Ministry of Health and Welfare.

Through the three national dementia plans and the National Dementia Initiative, South Korea established the national dementia service delivery system that consists of the National Institute of Dementia in the country, a Provincial Dementia Center in 17 provinces, and a Local Dementia Center in each city or county. The National Dementia Helpline has been in operation on 24/7 basis since 2013, and the Public Adulthood Guardianship Support Center began to provide services since 2018. The number of dementia partners surpassed the number of people with dementia. Korea is becoming more and more dementia-friendly through the national leadership and active participation of Korean people.

Paola Barbarino, ADI's CEO, said: "South Korea's plan and crucially the implementation of it is possibly the best in the world. They have devoted a lot of resources and work to implement Area 1 to 6 of the Global plan and that includes public health campaigning, implementation of a dementia friendly society, risk reduction mobile apps, programmes and even classes for citizens, a full dementia registry with integrated access to social services, a national helpline, and much more. I encourage you to read their national plan and try and delve deeper into the wealth of activity behind it."



**Korean National Institute of Dementia (KNID)'s National Dementia Helpline, which has now been running for over 6 years**

## CASE STUDY

**Norway stage 5: Plan/strategy adopted**

The Norwegian national plan was until recently at risk of being amalgamated under a grouped health plan. The government presented a national plan on “Old Living/Leve Hele Livet”. Nasjonalforeningen for folkehelsen, the national association, has started advocating for a continuation of this plan for 2020 – 2025, communicating directly with the Minister of Health and Ageing, and the Ministry of Health. Following this, the government launched a new strategy on public health, including a commitment to developing a new dementia plan after 2020. Work is now underway to develop the plan, which will be presented in the national budget in early October next year. Following a letter of support from ADI to the government, Nasjonalforeningen for folkehelsen also secured a meeting and dialogue with the health agency, who are conducting the evaluation of the dementia plan. At the time of writing, Nasjonalforeningen for folkehelsen is meeting with the Ministry about the next version of the national plan.

Regional meetings including people with dementia (and not only experts) had a huge impact whilst putting together the current plan - now national health plans are all developed the same way in Norway (National plan for Diabetes and “Old living/Leve Hele livet” for example). The Minister of Health of Denmark even came to Norway to learn about the process of developing the plan.

Municipalities have to follow the national plan, but do not get funding directly from the government. Some municipalities make local dementia plans, and the association thinks they are more “on track” in establishing sufficient care services. Quality across municipalities is different because they decide yearly budgets and local priorities separately. Working with dementia friendly societies, the association has adapted some work on universal design in public areas. From this they moved on to working with three dementia friendly hospitals. With these partners they want the next national dementia plan to include also have strategies on dementia friendly hospitals.

Siri Hov Eggen said on behalf of Nasjonalforeningen for folkehelsen: *“We are happy to find that the Norwegian government want to develop the third national dementia plan. Norway needs to prepare for more people with dementia in years to come. This includes all areas from timely diagnosis to a more dementia friendly society and healthcare. For the next plan we especially want to focus on more funding for research, health care and support. We look forward to developing the next dementia plan in partnership with the government, and we hope municipalities will be inspired to adopt local strategies for better care and dementia friendly societies.”*

## CHAPTER 2

# Dementia Awareness



***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 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.**

Current 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.

Reducing stigma is a fundamental objective of ADI. Relevant activities of ADI include the global coordination of World Alzheimer's Month, and holding 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 activities of many associations, partners and other institutions that increase the understanding of dementia around the world. In 2019 ADI will launch the World Alzheimer Report on global attitudes to dementia. This aims to be the biggest survey in the world on this key issue which will create a baseline for future measurements.

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 Silvia of Sweden, Queen Sofia of Spain and Luis Guillermo Solís Rivera, former President of Costa Rica, have joined ADI's global voice in 2017 and 2018.

### World Alzheimer's Month

Launched in 2012, 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 Day is on 21 September each year and acts as a focal point for global, regional and national action on dementia. ADI regularly schedules the launch of the World Alzheimer Report for World Alzheimer's Day. Other examples of action from around the world include memory walks, the illuminating of famous landmarks and buildings, conference and seminars, publications, campaigns and fundraisers.



**Ecuador - two walks in the cities of Quito and Guayaquil - over 4000 attendees**

World Alzheimer's Month is marked by associations and others in over 80 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. Support materials and key messages are developed by ADI, which can be translated, adapted and personalised for use globally.<sup>4</sup>



**Iran Alzheimer Association's World Alzheimer's Month Cyclists' Tournament**



**Virgin Islands Alzheimer's Association - Every 3 Seconds Walk to End Alzheimer's**



**Turkish Alzheimer Association - Football Players carried a 14x1 m banner whilst walking into the Stadium for the biggest derby match**



**Zimbabwe Alzheimer's and Related Disorders Association (ZARDA) - Breakfast in the Park**

The 2019 campaign will focus on stigma, awareness and attitudes to dementia under the theme of "Let's Talk about Dementia".

Training and information for professionals is an important area in which awareness can play a role in the response to dementia. WHO Mental Health Gap Action Programme (mhGAP) focuses on low and middle income countries and general health practitioners who have contact with people with dementia.

This year, ADI is working with the Pan American Health Organization (PAHO) on a regional awareness-raising campaign coinciding with World Alzheimer's Month. The campaign will use regionally-adapted materials and aims to engage with Ministries of Health to target their primary health and care workforce. The campaign comes in the final year of the PAHO regional plan and focusses on encouraging people to have that first, often very difficult conversation and then to seek out information, advice and support.

Dale Goldhawk, ADI Vice Chair, said: *"Increasing awareness of dementia, its symptoms and impact is vital for any meaningful policy action on dementia. Throughout my career as a journalist, as someone who has a lived experience of being a carer for a family member living with dementia, and as a Board Member of ADI, I have seen time and again myths and misconceptions about dementia being perpetuated, including by the media. We need concerted and sustained communications and awareness raising campaigns, like the World Alzheimer Month campaign, to help normalise the language around dementia; to dilute the fear; to help eradicate pre-conceptions; to establish the fact that it isn't a normal part of ageing; and that through timely diagnosis and planning people can better manage and even, for a time, live well with dementia. Campaigns need to engage governments and policy makers, but they must also win the hearts and minds of the public, which in turn gets the attention of the policy makers."*



## Dementia Alliance International – Peer-to-peer support groups

Dementia Alliance International (DAI), whose global membership is exclusively for people with a medically confirmed diagnosis of any type of dementia, continues to work on claiming Human Rights for all people with dementia. However, since the *World Health Organisation Global action plan on the public health response to dementia 2017-2025* was unanimously adopted, DAI members continue to report that little has changed for people facing a new diagnosis of dementia. DAI therefore implores governments and organisations to collaborate and co-operate with each other towards ensuring the rights of people with dementia are recognised and that changes relate to real life support and services. DAI provides online support through cafes, peer-to-peer support groups, regular blogs and educational webinars. Chair, CEO and Co-founder of DAI, Kate Swaffer, says: “unfortunately, many DAI members continue to report the DAI services are often the only support they receive, and ADI, ADI members and especially governments have the potential to ensure this changes”.



The World Health Organisation states, “*Dementia is one of the major causes of disability and dependency among older people worldwide*”, and we therefore need a new pathway of support to include disability support and assessment, and support including Community Based Rehabilitation. As founding members of the Global Rehabilitation Alliance, and Observer Members of the International Disability Alliance, DAI continues the pursuit of a disability rights-based approach to dementia, and they call on others to join them.

DAI hosts monthly educational webinars, attended by not only by their members and their families and friends, but by professionals working in the sector. The webinars cover topics such as driving and dementia, sex and intimacy, living more positively with dementia, dementia and rehabilitation as well as hosting an online art exhibition during World Alzheimer's Month. These types of



**DAI support group webinar**

activities positively support members to live with more purpose and allow for participation, without the need to travel, sometimes difficult for people with dementia following a diagnosis.

During World Alzheimer's Month in 2018, DAI hosted a daily blog series themed #Hellomynameis.<sup>5</sup> These was a series of written or video stories of members living with dementia and have continued on as a monthly blog. This series was not only informative and engaging, it led to dementia consultants and service providers using them in some of their training, to ensure care staff better understand the lived experiences of dementia. It was dedicated to the voices of people with dementia, where members shared their personal stories of being diagnosed with dementia. The hope is that these stories bring hope to others facing dementia, and that in sharing these stories they collectively support, inspire and educate about the negative and positive realities of living dementia.

The #Hello blog series was inspired by the late Dr Richard Taylor, one of DAI's co-founders, who was once asked, “What should I say to a person with dementia?” He answered by saying, “Try Hello.”

## Dementia Friendliness

Glenn Rees, Chair of the ADI Board, says: “*the commitment in the Global Dementia Action Plan to implement dementia friendly projects is one important strategy to help people better understand dementia and value the inclusion of people with dementia in their community. Through these projects we can work to improve the quality of life of people with dementia and their carers by reducing the social isolation many of them experience and to take the practical action necessary to assist them gain access to the services and activities we all enjoy. The great power of dementia friendly projects is to inspire communities whether small or large as well as*

<sup>5</sup> Dementia Alliance International, Hello: Our Voices Matter (2018): <https://www.dementiaallianceinternational.org/services/hello-our-voices-matter/>

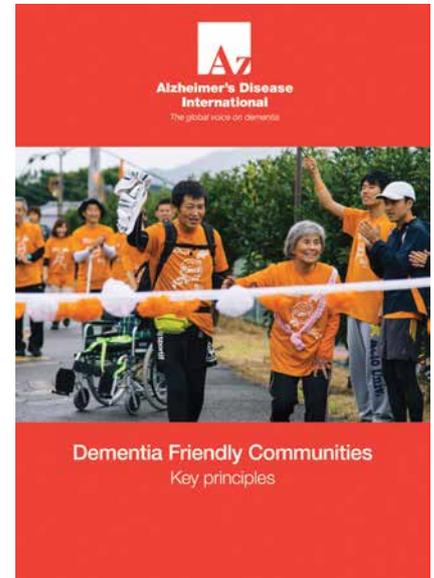
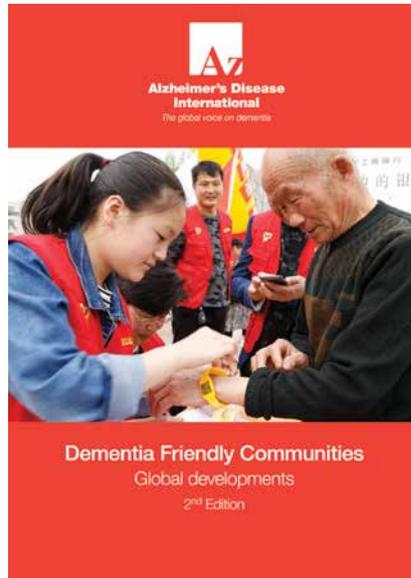
organisations in key sectors such as health, banks, retail and insurance to address the issues of most concern to people with dementia and their carers. We all have a part to play.”

Glenn was one of the authors of ‘The principles of dementia friendly communities’ report.<sup>6</sup>

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 16 million ‘Dementia Friends’ in almost 50 countries worldwide.<sup>7</sup> 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.



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

## Indonesia - Purple Troops Initiative

Alzheimer's Indonesia committed to support the government in implementing the National Dementia Plan in creating a dementia friendly community. In 2016, in collaboration with the local government of Jakarta, the Purple Troops program was launched, aiming to make Jakarta an elderly and dementia friendly city and to raise awareness on issues surrounding Dementia and Alzheimer's disease. The purple troops consist of health professionals (doctors and nurses) from the Primary Health Care Centers, social workers from the Department of Social Affairs and volunteers, including caregivers and students. The purple troops were trained and given information about dementia, how to communicate and interact with people with dementia, how to educate the community about the condition, and how to report if the community find a missing or abandoned elderly person on the street. In 2019, the purple troops programme has been adapted by the local government of Bali.

## Indonesia stage 5B: Plan adopted, funded and monitored

The Indonesian government committed a budget of \$105,000 in 2016 (when the plan was launched), but beyond then any funding commitment has been unclear. Further commitment is needed to make progress. Alzheimer's Indonesia Secretariat (ALZI) has initiated a few meetings with the Ministry of Health but progress and responses have been slow. Monitoring and evaluation have also been a challenge. The WHO Indonesia country office has expressed commitment to support the plan and is currently discussing things further with Alzheimer's Indonesia and the Ministry of Health.

6 Alzheimer's Disease International, Dementia Friendly Communities (2018): <https://www.alz.co.uk/dementia-friendly-communities>

7 Alzheimer's Society, Dementia Friends: Join the Global Dementia Friends movement (2019)

## Malaysia's first dementia friendly mall

In September 2017, during World Alzheimer's Month, Atria Shopping Gallery in Damansara Jaya, was established as the first dementia friendly mall in Malaysia. To mark the launch, Alzheimer's Disease Foundation Malaysia (ADFM) organised various risk-reduction activities, including an indoor Memory Walk and a dementia Treasure Hunt organised by professional treasure hunters. The first dementia-friendly community corner was launched, enabling anyone to walk in to receive information on dementia, sign-up with ADFM's National Caregivers' Support Network and receive preliminary advice on dementia. With a recorded 120,000 people living with dementia in Malaysia, and many more unrecorded cases, the work of ADFM is vital in raising awareness for people affected by dementia and their families. Jacqueline Wong, Board Member of ADFM said: *"I hope with this beginning of the first-of-its-kind collaboration with Atria mall and it will be the start of more organisations, large and small, to think about how they can become more dementia-friendly."*

## Malaysia stage 3C: In development, slow progress

The Ministry of Health have worked on the draft for the Revised Plan of Action for Elderly Health Care under the National Policy for Elderly Health Care with a component of the Management of Dementia included. ADFM met with the Ministry of Health in February 2019 in conjunction with a visit from ADI staff, Paola Barbarino and DY Suharya. The meeting resulted in the Ministry committing to studying and adopting the seven action areas of the Global plan into the Plan of Action for Elderly Health Care. ADFM will continue in its effort to work with Ministry of Health to realize a National Dementia Plan for the country.

## The first dementia-friendly bank in Hong Kong

Three out of five family members or care supporters in Hong Kong are worried that people living with dementia may not be capable of handling their finances by themselves.<sup>1</sup> In light of memory loss, problems communicating and difficulty processing information, managing banking affairs can be challenging for people living with dementia.

With the vision of enabling people living with dementia to manage their finances independently as far as possible, HSBC Hong Kong and the Hong Kong Alzheimer's Disease Association (HKADA) came together to establish measures and encouraging practices to move

- Providing information, training sessions and e-learning materials for HSBC staff to create awareness and learning on how best to support customers and families affected by dementia.
- Introducing 200+ Dementia Ambassadors equipped with the knowledge of how to better support customers with dementia with banking services across HSBC's branch network across Hong Kong.
- Launching a special account titled "Basic Banking Account with Independence" for customers with diminished cognitive capacity to maintain some control over their daily finances.
- Producing a guidebook entitled "Managing money when living with dementia", which provides tips on how to manage finances for customer and families living with dementia

We are not aware at present about any analysis or measurement of how successful the initiative has been so far but we will follow this up in the next year.

<sup>1</sup> Results from the October 2018 survey "How people living with dementia use banking services" conducted by the Hong Kong Alzheimer's Disease Association (HKADA).



**Mr Greg Hingston, Head of Retail Banking and Wealth Management, Hong Kong, HSBC (middle), Dr David Dai, Chairman, HKADA (left) and Ms Maggie Lee, Executive Director, HKADA (right) attended the press conference on “Building a Dementia-friendly Bank” held on 6 December 2018.**

## Argentina’s dementia friendly region

In Argentina, there has been plan development at three administrative levels, but progress has stalled. Firstly, there was a law establishing the National Alzheimer’s Plan. This was approved in December 2014 by the Chamber of Deputies. However, it was never discussed in the Senate, so the project never saw the light of day and was stalled. Secondly, a National Strategic Plan for a Healthy Brain, Alzheimer’s Disease and other Dementias was presented in November 2016 as part of the Comprehensive Medical Attention Programme (PAMI). However, its implementation has been discontinued due to economic reasons and funding of PAMI. The original project expires in 2019. At the same time, policy action has moved to the regional level, with some remarkable success. A law creating the Provincial Program to Fight Alzheimer’s Disease and other Dementias was approved in April 2017 by the Honorable Legislature of Tucumán Province. The provincial plan, will, however, require regulation to ensure its implementation. As of May 2019, the law has yet to be regulated: it has been passed by local congress, but the Executive branch has not approved its budget.

## Argentina 2C: Some developments towards a plan, but progress stalled

Diego Aguilar, Executive Director of Fundación León, said: *“In 2017, León, a non-profit Asociación de Lucha contra el Mal de Alzheimer (ALMA) partner, participated actively in the drafting of Argentina’s first provincial law on Alzheimer’s disease. For Tucumán – Argentina’s smallest province of over one million and a half inhabitants – Alzheimer’s disease is rapidly becoming an important health and social issue.*

*In 2016, Tucumán legislature invited Fundación León to a variety of forums, with other speakers: University, physicians and executive government offices. The need of a law was taken into consideration and León participated by contributing with ideas, revising drafts with carers and holding meetings to discuss the law. Finally, legislation was passed on 27 April 2017.*

*We highlight the importance and uniqueness of ALMA partners in legislation and policy making in Argentina, and its continuing role in pressuring government to regulate laws in the provincial and national levels.”* ADFM will continue in its effort to work with Ministry of Health to realise a National Dementia Plan for the country.



**“Café con Alma” in Tucumán - World Alzheimer’s Day 2018 in Plaza Independencia, Tucuman with ALMA founder Ana Bosio de Baldoni, Fundacion Leon Executive Director Diego Aguilar and volunteer Carmen Rosa Ibáñez**

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**Forum on Dementia mayo 2018 organized by Legislators Adela Estofan de Terraf and Jose María Canelada, authors of the Tucuman Alzheimer Law, with Diego Aguilar, Fundación León Executive Director**

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## CHAPTER 3

# Dementia risk reduction



***The relevant global targets defined in the Global action plan for prevention and control of noncommunicable diseases 2013–2020 and any future revisions are achieved for risk reduction and reported.***

**In the continued absence of a disease modifying treatment for dementia, initiatives 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 has been some excellent research to support this, including two studies which are being scaled up globally – the PREVENT<sup>8</sup> and FINGER<sup>9</sup> studies. Following ADI's World Alzheimer Report in 2014,<sup>10</sup> in 2017, a Lancet Commission study estimates that 35% of dementia cases could be prevented by targeting nine modifiable risk factors: education, midlife hypertension, midlife obesity, hearing loss, late-life depression, diabetes, physical inactivity, smoking, and social isolation.<sup>11</sup> 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 unmodifiable (level of education, inheritance of the ApoE4 gene).

The Global plan indicators for the target on risk reduction are not specific, instead they are 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).

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 has recently released guidelines on risk reduction of cognitive decline and dementia.

ADI's Chief Executive Paola Barbarino joined a panel of experts, including Professor Miia Kivipelto in January 2019 for the Global Better Health Webinar on dementia risk reduction. During the webinar, Paola highlighted ADI's own research on the topic.<sup>12</sup> The World Alzheimer Report 2014 '*Dementia and Risk Reduction: An analysis of protective and modifiable factors*' critically examines modifiable risk factors (for instance, controlling blood pressure) and distinguishes them from un-modifiable risk factors (for instance, genetic factors). Paola called on governments to investment in the training of primary care practitioners to better understand the specific needs of each patient in the acknowledgement that dementia is a complex disease and its development is difficult to predict. She said: "*Governments are not doing enough to keep their population informed on risk reduction activities they can do.*"

### 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

8 For more information, go to <https://preventdementia.co.uk/>

9 For more information, go to <https://thl.fi/en/web/thlfi-en/research-and-expertwork/projects-and-programmes/finger-research-project>

10 Alzheimer's Disease International (2014) World Alzheimer Report 2014: Dementia and Risk Reduction: An Analysis of Protective and Modifiable Factors

11 Livingston et al (2017) "Dementia prevention, intervention, and care"

12 For more information about Global Better Health, go to <https://www.globalbetterhealth.com/>

## 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<sup>12</sup>.

### Reduce your risk



Follow a healthy diet



Be physically active



Look after your heart



Challenge your brain



Enjoy social activity

## FINGER study

The Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER) trial was the world's first large multidimensional study of lifestyle interventions to delay cognitive impairment and disability in elderly at risk. The study highlights the need to address multiple dementia risk factors to effectively prevent or delay the onset of cognitive impairment and dementia.

Professor Miia Kivipelto, who is leading the project, said: *"Most of the earlier trials have been so-called single domain trials. Given that there are so many different risk factors and mechanisms behind Alzheimer's disease, we thought that probably you need to target several risk factors simultaneously, to get an optimal effect. Something I call multi-domain intervention, so we have the whole package. That's where we started, in 2009. At that time it was still quite a new area, to work in this way."*



**Professor Miia Kivipelto**

A notable finding of the study was that the lifestyle interventions had a clear effect among the APOE4 carriers (the most important genetic risk factor for Alzheimer's disease). There were also significant beneficial effects on functional decline and health related quality of life and the risk of other chronic diseases was reduced.

The FINGER pragmatic model is now being tested and adapted worldwide in different geographical, cultural and economic settings. Based on these collaborations, Professor Kivipelto has launched the World Wide FINGERS (WW-FINGERS) Initiative, a unique interdisciplinary network to share experiences, harmonize data, and plan joint international initiatives for maximal global scientific and clinical impact. 20 countries have already joined this initiative including the USA, China, Australia, Canada, Singapore, India and several European and Latin American countries. WW-FINGERS is the first global scale network of dementia prevention trials, and alignment and harmonization across the trials will allow maximal scientific and clinical impact. A rich biorepository will enable clarification of underlying mechanisms using 'big data'. First multimodal dementia prevention trials combining non-pharmacological and pharmacological approaches are currently being developed and tested within the WW-FINGERS.

Professor Kivipelto has been working with the World Health Organization (WHO) on their risk reduction guidelines. She wants to develop a multimodal dementia prevention "toolbox", to translate the research into

practical tools and support the next generation of Alzheimer's disease and dementia prevention trials and precision prevention approach.

## PREVENT study

In the absence of therapeutic treatments for dementia, prevention initiatives based on interventions targeting modifiable risk factors become essential to reduce dementia incidence. The success of these initiatives, however, depend on: (1) the accurate identification of individuals at higher risk of dementia; (2) the identification of effective interventions.

By the time symptoms emerge, brain pathologies have already developed. Hence, effective interventions to delay dementia onset and ultimately, prevent the disease, need to focus on asymptomatic individuals who are at high risk of developing the condition. This implies a shift towards the study of middle-aged individuals. PREVENT Dementia programme, a prospective study of individuals aged 40-59 at baseline in the UK, was designed under this premise<sup>13</sup>.

PREVENT Dementia Global (PDG) studies is a network of studies set up in low- and middle-income countries (LMIC)<sup>14</sup> that follow a design similar to PREVENT Dementia's. These studies respond to a need for further research on dementia prevention in LMICs, as projections indicate considerable increases of dementia incidence in these countries and because evidence generated from wealthy societies may not directly translate to other contexts where individuals transit through different life course experiences.



Although not consistent, some evidence is emerging about lifestyle factors associated with dementia and general brain health in older adults. These include, amongst others, engagement in physical and cognitive stimulating activities, smoking, alcohol consumption and the adoption of the Mediterranean diet. Ongoing research suggests that multimodal interventions targeting diet, exercise and cognitive training could improve cognitive function in at risk older adults<sup>15</sup>.

However, the relatively auspicious findings of these multimodal interventions may not translate directly to younger individuals. More importantly, it is not fully understood whether individuals living in LMICs have the capacity to adopt suggested lifestyle changes as heritage, economic contextual and environmental circumstance may preclude the adoption of (potentially) risk modifying lifestyle changes.

PDG studies will permit international comparisons of findings across settings, but notably, will generate knowledge about interventions that may be feasible in the context of each population where the local and personal capacity to adopt lifestyle changes.

However, the implementation of these studies is a challenging enterprise that also requires extensive research to adapt existing cognitive batteries or develop new ones that are sensitive enough to capture early signs of decline whilst being culturally unbiased and psychometrically comparable with tools used in other global efforts. The use of adequate testing tools becomes particularly important in contexts where the collection of clinically relevant data such as imaging or CSF (spinal tap) via invasive or expensive methods may not be possible to implement.

The success of initiatives in global dementia prevention such as the PDG studies necessitates important long-term efforts from national and international funding bodies and research communities to support local researchers who otherwise only have access to limited resources.

13 Ritchie and Ritchie (2012) "The PREVENT Study: A Prospective Cohort Study to Identify Mid-Life Biomarkers of Late-Onset Alzheimer's Disease."

14 So far work has been initiated in China, India, Uruguay and Argentina.

15 Ngandu et al (2015) "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."

## NCDs and dementia

Dementia is classified as a Non-Communicable Disease (NCD) and with that carries a strong risk reduction message.

2018 was a poignant year with the UN High Level Meeting (HLM) on NCDs and ADI actively engaged in the two-year road map process to the HLM, including participation in the WHO Civil Society Working Group on NCDs and as an active partner in the NCD Alliance (NCDA) ENOUGH. campaign.

NCDs: What have you had ENOUGH. of? This question reverberated globally in advance of the third United Nations High-Level Meeting on Noncommunicable Diseases, triggered by the launch of NCDA's thematic campaign, ENOUGH, in May 2018. Focused on six key advocacy priorities, the NCD movement mobilised digitally and in person, initiating the first Global Week for Action on NCDs and reaching millions of people in dozens of countries. People living with NCDs, high level champions and hundreds of advocates from NCDA's supporters, members and 55 national and regional alliances unified to demand "our health, our right, right now."

One campaign priority, reinforced by the actions and advocacy of the Our Views, Our Voices community, emphasised the need to put people first in the NCD response, urging governments to meaningfully involve civil society and people living with NCDs in national prevention and control of NCDs. This advocacy priority resulted in a paragraph in the political declaration on promoting meaningful engagement of civil society and people living with NCDs, the first time an outcome document of a High-Level Meeting on NCDs has included such language.

Although dementia was not specifically mentioned in the UN High-Level Meeting outcome document, the campaign supported the expansion of the NCD response to the '5x5' framework - including mental health and air pollution as core components of NCD prevention and control. The adopted political declaration's recognition of air pollution as a risk factor for many NCDs and the need to integrate mental health in the NCD response, is a significant achievement for civil society. This will have major implications for the 50 million people living with dementia globally; in the absence of a disease modifying treatment risk reduction will become an even more important policy tool. We have seen the life course and risk reduction messaging being extremely effective for other NCDs, and the inclusion of dementia in the WHO's 5 x 5 approach will hopefully unify these messages.

# 5X5

## DISEASES



**Cardiovascular Disease**



**Chronic Respiratory Diseases**



**Cancer**



**Diabetes**



**Mental and Neurological Conditions**

## RISK FACTORS



**Unhealthy Diet**



**Tobacco Use**



**Harmful Use of Alcohol**



**Physical Inactivity**



**Air Pollution**

**Non-communicable diseases – 5x5 Approach. Source: NCD Alliance (2018) 'A breath of fresh air: Acting on the UN mandate to tackle air pollution'**

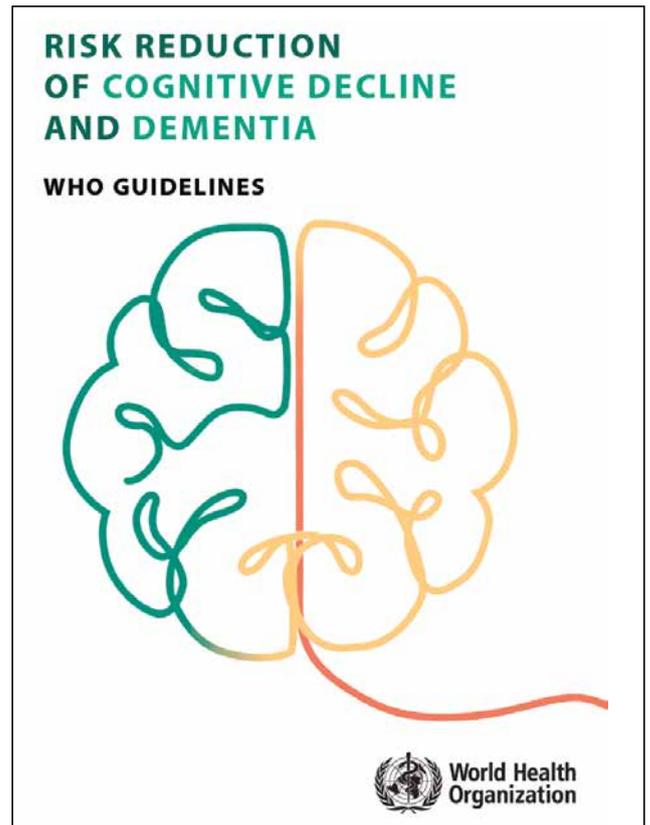
Source: NCD Alliance (2018) "A breath of fresh air: Acting on the UN mandate to tackle air pollution"

## WHO risk reduction guidelines

In May 2019 WHO launched guidelines on risk reduction of cognitive decline and dementia. ADI will actively promote and disseminate the materials, including hosting a global webinar in June.

Tarun Dua, WHO Programme Manager who has coordinated the development of the guidelines, said: *“More and more studies have shown a relationship between modifiable risk factors and cognitive decline and dementia. There are various lifestyle-related risk factors, including lack of physical inactivity, unhealthy diet, alcohol and tobacco use, and specific medical conditions such as diabetes, which if addressed can reduce your risk of dementia. These guidelines provide evidence and important actions for policy makers, health and care professionals, and individuals who are interested to find out what they can do to reduce their risk of dementia. Risk reduction interventions are cost-effective ways to reduce dementia at the population level and should be the priority of every government.”*

There is growing evidence for a strong call to action for governments to do more to increase awareness in their population of the strong links between certain lifestyle factors and dementia. We need to act now as there is no pharmacological solution yet.



## 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.***

**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 high income countries (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.<sup>16</sup>**

Achieving a diagnostic rate of 50% of those affected in both LMIC and HIC is an ambitious target that will require significant investment in capacity and training of health and social care professionals, innovative responses from health care systems, global awareness, and political will.

Healthcare system preparedness is also vital. A key goal is the introduction of a non-invasive, cost effective diagnostic breakthrough but if this becomes available it is equally essential that governments are prepared and can respond to an increased number of people being screened, evaluated, tested and treated<sup>17,18</sup>

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.<sup>19</sup> 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 48). Of the data currently available online from the Observatory, only 3 countries out of 21 pilot Member States have provided any data on diagnostic rates or other indicators.

National plans must heighten the prioritization and tracking of diagnosis in dementia. Diagnosis actions and targets are, however, present in just a little over half of countries where plans have been adopted, as reflected in a recent OECD report on care.<sup>20</sup>

## Diagnosis in OECD countries

A decade ago, dementia barely registered on the international agenda. Much has changed in recent years. Today, at least 23 members of the OECD have put in place national plans or strategies, up from less than half in 2013. But high-level commitments have not always translated into on-the-ground changes. Identifying dementia – including recognising key symptoms, receiving a high-quality diagnosis, and ensuring that an official diagnosis is properly communicated to health professionals in all relevant healthcare settings – is an essential component of good care. Yet the gaps are wide between best practice and reality. Virtually all countries that have developed national plans for dementia recognise in these plans the need to improve the diagnostic process and improve diagnosis rates. Nevertheless, only two OECD countries – Denmark and the United Kingdom – have actively set targets to improve diagnosis. And very few other countries currently have the capacity to monitor improvements in diagnosis rates, even if they wanted to. Just eight OECD countries are able to measure diagnosis rates for dementia on a national level.

16 Alzheimer's Disease International, Dementia in sub-Saharan Africa: Challenges and opportunities (2017)

17 Liu et al (2017) "Assessing the Preparedness of the U.S. Health Care System Infrastructure for an Alzheimer's Treatment"

18 Hlavka et al (2018) "Assessing the Preparedness of the Health Care System Infrastructure in Six European Countries for an Alzheimer's Treatment"

19 Alzheimer's Disease International, Dementia in sub-Saharan Africa: Challenges and opportunities (2017)

20 OECD, Care Needed: Improving the Lives of People with Dementia, OECD Health Policy Studies (2018)

Even where dementia diagnoses are made, it is far from assured that information is shared across relevant health settings. While 17 of 22 surveyed OECD countries reported that they could identify people with a diagnosis of dementia through administrative hospital data, just 8 of 21 OECD countries – including Austria, Canada, France, and the UK – reported that they could use primary care data to identify those with a diagnosis of dementia nationally. 10 of 22 surveyed OECD countries reported that they could link the information in a patient's primary care record – where many dementia diagnoses are currently made – with other parts of the health system. This means that even where a diagnosis has occurred, this important information is not necessarily shared with many parts of the health system where people with dementia seek care.

Some countries have taken steps to strengthen the data infrastructure for dementia. Dementia registries – such as SveDem in Sweden, the Danish Dementia Registry in Denmark, and efforts from health maintenance organisations (HMOs) in Israel – can help to link patient information from across care settings in the health system and provide a better overview of who is diagnosed and what care they receive. Information from registries is important both for the individual patient and the overall system of support for people with dementia. The development of dementia registries, however, is just one component of what should be systemic efforts to strengthen the health data infrastructure more broadly. Global efforts to outline framework conditions for increasing the availability of health data, including the Recommendation of the OECD Council on Health Data Governance, can serve as a useful blueprint for taking full advantage of national health data systems while minimizing privacy and security risks.



**ADI's CEO Paola Barbarino presenting HM Queen Silvia of Sweden with an award for becoming ADI's Global Ambassador, April 2019**

Countries must do more to improve the lives of people with dementia. Harnessing the power of data – within countries and across borders – is a critical element of ensuring that the ambitious goals of national plans are achieved. (See chapter 6 for further detail on data).

## **The importance of timely diagnosis and post diagnostic support**

### **Glenn Rees, Chair of ADI, reflected on post-diagnostic guarantee in Scotland**

Awareness of effective post diagnostic support can help to reduce the fear of seeking a diagnosis, especially in the absence of disease modifying treatments. Scotland was the first country to introduce a post diagnostic guarantee.

The impact of global target 4 in the Global plan in achieving improved support and care outcomes will depend on a well organised approach to post diagnostic care. Yet attention to post diagnostic support and the need for person centred coordinated support and advice after diagnosis of dementia is very variable in dementia plans.<sup>21</sup>

From the perspective of the person with dementia timely diagnosis is recognised as having the potential to remove uncertainty about what is wrong, assisting access to information and planning finances and support, including rehabilitation.

These benefits are unlikely to be fully realized unless priority is given to both diagnosis and post diagnostic support. What is needed is well-organised post diagnostic support which has the objective of helping people with dementia to continue living well in the community and delay admission to long-term residential care. The menu of support might include information, individual support, counselling, signposting, peer support, memory cafes, workshops, person centred planning and self-directed support. Equally important is a system of post diagnostic support that also recognises and supports the important role played by care partners.

The positive effect which flexible and personalized post diagnostic support can have on people's lives has been demonstrated in the pilot funded by the Scottish Government and delivered by Alzheimer Scotland

<sup>21</sup> Alzheimer Europe, Dementia in Europe Yearbook 2018 Comparison of national dementia strategies in Europe (2018)

(and post pilot including additional providers). The post diagnostic one-year guarantee introduced in Scotland responds to the human right of a person with dementia to know that support will be available. Currently in Scotland about 46 per cent of those diagnosed with dementia are offered post diagnostic support and work remains ongoing to ensure sufficient local investment so that every person with a diagnosis in Scotland receives the national guarantee.

How this is achieved in national dementia plans will vary according to different health and social service systems but primary care, mental health and aged care agencies, community health, multi-disciplinary teams and Alzheimer's and carers organisations may all have a role.

There are strategies to test including dementia coordinators and where to locate them, the duration of such support and achieving an approach that assists personal choice, builds on personal strengths and achieves individual outcomes.

In addressing action on global target 4 it is important to devote equal attention to improving care within settings and transitions across them.<sup>22</sup> This is particularly important in respect of diagnosis and post diagnostic care but the evidence base with regard to the effectiveness of various interventions is at best ambiguous and at worst weak.<sup>23</sup> Research projects are needed that address both diagnostic and post diagnostic strategies and provide an evidence base for policy makers. One such project is Cognisance, an EU Joint Programme for Neurodegenerative Disease Research (JPND) 3-year project working in five countries (Australia, Canada, Netherlands, UK, and Poland) whose focus will be on co-designing dementia diagnosis and post diagnostic care, including a toolkit and set of standards to ensure the diagnostic and post-diagnostic process and care are as positive as possible.<sup>24</sup>

In re-designing health and social service systems to be more responsive to the needs of people with dementia post diagnosis there are many issues to consider in respect of doctor and care staff training, the opportunities to use new technologies in tracking individuals and the care received and the costs and benefits of different approaches, including the extent to which there is a long-term impact in reducing and delaying the need for care services.

## Establishing clear care pathways

ADI's 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 approach to the planning, resourcing, and delivery of continuing care, and are a common component of care for other 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 that can be monitored. Within dementia care, the period of time in which an individual needs care may be difficult to define. For instance, although the course of dementia tends to be progressive, there may be 'plateau' periods. So, for dementia, monitoring care and support needs to be continuous, but particular activities may be needed at particular phases of the condition. Case management is needed to support coordination and integration of different elements and providers of diagnosis and care, including healthcare in the home.



**Dementia Friendly Spot opening at senior care home Ljubljana Vič-Rudnik with members of their band "Mambo Kicks" playing popular songs on balls like on drums**

22 Fortinsky et al (2014) "Optimizing Person-Centered Transitions In The Dementia Journey: A Comparison Of National Dementia Strategies"

23 Centre for Post-Diagnostic Support for People with Dementia and their Carers and National Dementia Office, Post-Diagnostic Support for People with Dementia and their Carers (2018)"

24 Alzheimer's Disease International, COGNISANCE Project awarded funding from JPND (2018)

## Award-winning care in Slovenia

Between 2017 and 2018, the first result of the Slovenian Dementia Strategy was the public tender of the Ministry of Health, which included community-based education programmes for healthcare professionals and formal and informal carers, supported by the national association, Spominčica. Over 10,000 formal and informal carers were included in the education programme, which was conducted across all regions of the country. The main challenges are raising awareness and addressing stigma.

This initiative is complemented by Spominčica's wider concept of Dementia Friendly Spots (DFS), a national awareness raising programme involving services providing organizations since 2016. Raising awareness of dementia is still one of the priorities of Spominčica and it is one of the major contributing factors for shifting the paradigm towards timely diagnosis and dementia friendly society.

The first DFS was opened in July 2017 at the Human Rights Ombudsman office after the training of employees. The opening was covered by national media, TV, radio and newspapers. A member of the European Working Group of People with Dementia (EWGPWD) presented his life with dementia after the diagnosis and stressed the importance of building dementia inclusive society. The programme is supported by the Ministry of Social Affairs and Ministry of Health. The education programmes for organizations covers the topics about dementia, and first signs, communication with persons with dementia, importance of timely diagnosis, post diagnostic support and rights of persons with dementia. At an official opening of a DFS, a cultural programme is organized, where all important stakeholders from local community are present, and it is covered by the media. The organization is presented with a DFS sticker, a certificate and put on a web map. Activities are evaluated, and training is periodically renewed. Spominčica has already opened more than 100 DFS in nursing homes, health centres, centres for social work, Red Cross, libraries, police and fire stations, hospitals, pharmacies, shops, hairdressers, etc. DFS are an innovative way of implementing a Dementia Management Strategy, adopted by the Ministry of Health in May 2016.

## Slovenia stage 4A: Plan/Strategy adopted but with inadequate funding

The Government has been working on the Long Term Care Act for a number of years. The current government supports the development and preparation of this legislation, but a lack of political will to adopt the Act is preventing further action. The next most important goals are timely diagnosis, access to treatment through a network of Memory Clinics and systematic approach for post-diagnostic support, including the development of domestic help services and community-based services for people living with dementia.



**Cultural programme at the opening of Dementia Friendly Spot at the Slovenian Red Cross Ljubljana, March 2018**

## Support services for people living with dementia in Guatemala

Asociación Alzheimer de Guatemala (ERMITA) has approached those within the Ministry of Health who are responsible for Elderly Care and Mental Health. However, 2019 is year of presidential elections, so changes will be forthcoming, confirming the lack of continuity in the public administration. ERMITA has presented a draft national dementia plan to the government in the past but there has been no progress towards this. The Minister of Health changes every two years in Guatemala, which makes it difficult to establish long-lasting contacts and continuity with regards to meetings. The Ministry of Public Health is developing policies on Elderly Care and Mental Health and had a first meeting to incorporate dementia into this health plan. They have therefore gotten closer to representatives in the Mental Health and Elderly departments. ERMITA will work on revising the strategic plan to present to the new government.

### Guatemala stage 2B: Initial meetings with government but no further progress

**In order to provide comprehensive dementia care, Asociación Grupo ERMITA provides a wide range of support services for people living with Alzheimer's disease and other dementias. These include:**

- Medical consultation with evaluation, diagnosis and monitoring of the disease.
- Physical therapy: through a partnership with Galileo University and Mariano Gálvez University, students come to train with ERMITA in caring for their patients.
- Psychology: supporting people with dementia who are referred by the doctor, to give a better diagnosis and also to attend the weekly support group for family members.
- Day Centre: ERMITA has a day centre open all day from Monday to Friday. At the centre, people with dementia participate in physical therapy, recreational therapy, music therapy, crafts, directed exercises, tai chi and basic care. The day centre also provides respite for the family caregivers.
- Diploma course of care for the elderly with emphasis on Alzheimer's and related diseases. ERMITA runs a diploma course designed to provide education, training and information for family caregivers. This course is now open to health professionals, nurses, and anyone with an interest in the training, and is run at Galileo University. Over 150 people a year complete the training. An online version of the diploma has been taken by 15,000 people. ERMITA's goal is to reach more and more people both in Guatemala and in Latin America, who have a need for this course.



**Training for caregivers in exercises and rehabilitation**



**Students and Lecturer Dr. Guillermo Gálvez in the Diploma of Care for the Elderly with a focus on Alzheimer's**

### Care training initiatives in Costa Rica

Costa Rica was the first country in Latin America to develop a National Plan for Alzheimer's Disease and related dementias in 2014. The plan was developed by the National Council of the Elderly and the Ministry of Health of Costa Rica and will run for 10 years up until 2024.

Its main feature is the rapprochement with local governments, the formulation of agreements with the Municipal Councils, and the accompaniment of the Costa Rican Association of Alzheimer and other Associated Dementia (ASCADA) as an NGO and representative of Civil Society before the Economic and Social Council of the UN.

Improving the quality of life of people living with dementia and their caregivers is the first area of action. This has improved access to diagnosis and forms of comprehensive care. Knowledge of research has also improved, through a 10/66 methodology project known as the Dementia Prevalence Study in Older Adults of the Community of Santo Domingo de Heredia, Costa Rica.

The government provides training on dementia and implements a workshop on the use of screening under a project called "Evaluators' Project". The entire general primary care physician workforce is provided with this training, covering 90% of the population.

The pilot plan was developed in schools and colleges thanks to the "Dementia Friends UK Costa Rica" initiative, which was successful and will now be implemented nationwide. Likewise, a community module was built in the district of Tirrases to continue developing a training centre called "House of the Caregivers" as the national innovation project in the care of Alzheimer's and other dementias.

### Costa Rica stage 5: Plan/strategy adopted

Costa Rica has approved the Inter-American Convention on the Protection of the Human Rights of Older Persons, which has decreed, as a priority, comprehensive attention and the right to health. It fosters international cooperation in the design of public policies, plans, strategies and legislation, and the exchange of capacities and resources, to implement health plans for the elderly and their active and healthy aging process, specializing in the protection of human rights.

## 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-specialist 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 condition 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.<sup>25</sup>

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25 For more information, go to [http://www.who.int/mental\\_health/mhgap/en/](http://www.who.int/mental_health/mhgap/en/)

## CHAPTER 5

# Support for dementia carers



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

**Just as groups of people living with dementia have formed (for instance, Dementia Alliance International, the European Working Group of People with Dementia, Scottish Dementia Working Group, and the 3 Nations Working Group), there is a need for carers groups to come together, to share and support but also to become advocates, to ensure the needs and rights of carers are fully met. Below are two examples of carer's groups which have formed for advocacy purposes - the National Dementia Carers Action Network (NDCAN), Scotland and, in the UK, there is Together In Dementia Everyday (Tide).**

### The National Dementia Carers Action Network (NDCAN)

The National Dementia Carers Action Network (NDCAN)<sup>26</sup> is a national campaigning and awareness raising group for carers of people with dementia in Scotland, supported by Alzheimer Scotland. NDCAN was formed in 2011. They meet regularly with the Minister for Mental Health, Health Improvement and Sport and other politicians and senior figures. They have been fully involved in all of Scotland's National Dementia Strategies, including work on testing models of community support, improving acute care in hospitals and the monitoring of better support for people newly diagnosed with dementia, as well as advanced illness / end of life. They have helped to develop a new framework of training for staff who work with people with dementia and carers; have spoken at a wide range of conferences in Scotland, the UK and internationally; and have developed new resources for carers on a range of subjects, including early onset dementia, continence and speech therapy.



Marion Ritchie provided the following quote on behalf of the NDCAN committee: *"A lone voice is too easily ignored, but collectively, in groups like NDCAN, we share our 'lived' experiences and expectations, and work together to help change things for the better now and for future generations."*

### Together In Dementia Everyday (Tide)

Together in Dementia Everyday<sup>27</sup> is a UK wide involvement network for carers of people living with dementia. Tide was launched in March 2015 as a grassroots movement to empower carers of people with dementia to assert their rights, raise awareness and change societal attitudes towards the impact of caring on carers as individuals. Tide believes that carers and former carers of people with dementia are powerful agents of change and they have a right for their voices to be heard and acted on.



Tide is investing in the personal development and leadership skills of carers, equipping and empowering them with knowledge, skills and confidence as well as providing them with varied opportunities to influence positive change from policy, research, practice, commissioning and education. Tide works across diverse communities including the deaf, LGBTI and ethnic groups within the UK and Northern Ireland; is also developing a systematic and sustainable model of involvement of carers of people with dementia; and has attracted interest in its model from overseas.

Anna Gaughan, CEO of the Life Story Network, which hosts Tide, said: *"As carers of people with dementia, individuals have to be strong and resilient, and through Tide, we are empowering carers, knowing that the collective voice is much stronger when we act and speak together."*

<sup>26</sup> For more information, go to <https://www.alzscot.org/ndcan>

<sup>27</sup> For more information, go to <http://www.tide.uk.net/>

## WHO iSupport program

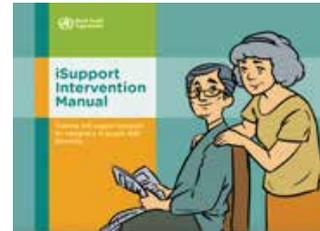
Action area 5 of the *Global action plan on the public health response to dementia 2017-2025* aims to see 75% of countries provide support and training programmes for carers and families of people with dementia by 2025.<sup>28</sup> To help countries achieve this global target, WHO developed iSupport, an online program that provides knowledge and skills training to carers of people with dementia. iSupport aims to prevent and/or decrease mental and physical health problems associated with caregiving and to improve the quality of life of those caring for people with dementia.



iSupport is currently available as an online program, accessible in English at [www.isupportfordementia.org](http://www.isupportfordementia.org). The program consists of five modules that are grounded in psychological interventions such as cognitive-behavioural therapy, psycho-education, cognitive reframing, behavioural activation and analysis, and relaxation/mindfulness. The five modules address the following topics: (i) general information regarding dementia; (ii) information related to being a carer; (iii) self-care; (iv) providing care for the person with dementia; and (v) addressing symptoms of dementia. Each of the five modules is organized into 1 to 10 lessons, depending on the topic.

WHO informs us that iSupport is currently being adapted in multiple countries including Australia, Brazil, China, India, Japan, Malta, Portugal and the Netherlands. The process for translating and adapting iSupport can be found on the WHO website.<sup>29</sup>

WHO has also developed a hardcopy manual of iSupport for carers of people with dementia to allow for a broader reach of the program, particularly in areas of the world with low internet bandwidth and/or connectivity. The manual includes all of the same modules and exercises featured in the online version of iSupport and can easily be printed, allowing users to complete the exercises by hand.



There are a growing number of examples of innovation in all areas of dementia support, which are vital in the continued absence of a disease modifying treatment. Training and development is an area that specifically requires innovative approaches. Here is one example which uses digital technology:

### Kate Swaffer, Chair, CEO and Co-founder of DAI, said:

*“DAI members regularly share or hear of the experiences of their families and care partners, and there is little doubt, just like our members, they do not receive enough support. Most are not equipped to support someone diagnosed with dementia, which is an extremely complex, chronic and progressive condition. At our webinars and cafes, and on the many online carer Facebook and other online support groups, they share their concerns of feeling abandoned by friends and families, and uncertain of how to best support the person in their care. They have little or no education in dementia, certainly less than health care professionals, which is also woefully lacking. Many speak of in home paid carers having no education or even awareness of how to support someone with dementia, and this transfers to a very poor experience for everyone. It also impacts a care partner’s willingness to use respite services. They all say they need more support, and through the Global action plan on dementia, they too have the same rights as people with dementia.*

*DAI has been asked for the last five years, to provide online peer to peer support groups for carers, as we already provide weekly for our members, and this year, we hope this goal will be realised, with the support of two care partners willing to commence hosting their own groups. DAI cannot do it alone, as we barely have the resources to support our members, but we are providing the software for them to run their own. The levels of poverty we hear of, due to lost employment, high medical costs, alongside the social isolation and inability to participate in civil society like everyone else, is unacceptable, and we need governments and service providers, including advocacy organisations to provide more tangible supports and services, not only for people with dementia, but for our families and carers, and, if we have younger onset dementia, also for and children.”*

28 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/](http://www.who.int/mental_health/neurology/dementia/action_plan_2017_2025/en/)

29 World Health Organization, WHO iSupport: E-programme for Carers of People Living with Dementia (2017)

## Swedish Care International

Swedish Care International (SCI) is a Stockholm-based organization that develops, packages and exports Swedish elderly and dementia care practice to the world. SCI strives to disseminate learning about good elderly care and dementia practice widely, and one way they have done so is via their mobile applications for smartphones. By working with global partners and using digital technologies, SCI initiates and leads projects such as these applications to support healthcare professionals, family members and people with a dementia diagnosis alike.

Two of their most relevant smartphone tools are:

### Dementia Support app

The Dementia Support app was created for relatives and caregivers of people with a dementia diagnosis. It contains information, inspiration and advice on how to increase the quality of life of both the person with the diagnosis and the caregiver. The information is updated regularly with expert partners.



### Memory Box

This engaging, conversational aid is used to inspire dialogue between relatives and caregivers with those living with dementia. This app contains visual, musical and topical tips for conversations and act as a memory support of famous events and occurrences throughout the last century.

## Dementia care as a public health priority in Sweden

The Swedish National Board of Health and Welfare works in line with the WHO on many health care issues. With inspiration from the WHO, that the Swedish National Dementia Strategy consists of key areas: cooperation between health-care and social services; staff-quality, competence building; evaluation and follow ups; care-givers; the civil society; digitalisation and technique as part of the care-process for persons with dementia.

Chair of Alzheimer Sverige Krister Westerlund said: *“Alzheimer Sweden are happy that Sweden finally takes responsibility for the caregiving to people with Alzheimer’s disease and other dementias. The Swedish Dementia Strategy is a step in the right direction towards a dementia friendly and inclusive society. We believe that the announcement that HRH Queen Silvia has become a Honorary Ambassador of ADI will have a great impact on the society of Sweden to increase the knowledge of these diseases.”*

## Sweden stage 3B: Dementia strategy

On 24 May 2018, in Stockholm, the Swedish Minister for Children, the Elderly and Gender Equality, announced the Swedish Government’s decision to launch a national dementia strategy for Sweden with the overall ambition of equality in care for persons with dementia. There is, however, no targeted funding. The Dementia Strategy is a ‘work in progress’ by the Swedish National Board of Health and Welfare until 2022. When the plan is finished it should be presented to the current Swedish Government and then rolled out across the country. The Dementia Strategy is financed by taxpayers through the health budget.

There have, however, been some political challenges. Sweden has recently formed a new government. Although the Dementia Strategy is not affected by the new government, the work has been put on hold by the Swedish National Board of Health and Welfare during the months it has taken for the Swedish government to form after the election. It has been challenging for Alzheimer Sverige to get through to the Ministry of Health and Social Affairs and the Swedish National Board of Health and Welfare 2018, but all questions have been answered in an accountable manner. There are concerns that further delays might happen, and that the new government might give too much focus to costs and IT, decreasing attention on crucial activities such as staff training and care-giver support activities in all 290 communities. It has been decided that private healthcare providers are to be further introduced into the Swedish health system. Internet doctors are very popular in Sweden and that may affect the Dementia Strategy overall, regarding distribution of care resources.

## Dementia Care Skills training in Indonesia

There are several training programs for domestic workers, family caregivers and health professionals in Indonesia. ADI Dementia Care Skills (DCS) training is regularly held in collaboration with the local government, university and health care service providers. This training programme is delivered by Alzheimer's Indonesia and focuses solely on giving skills on dementia care.

### Indonesia stage 5B: Plan adopted



**Dementia Care Skills training conducted in Indonesia since 2016 resulting in 20 lead trainers and 200 family caregivers and care workers**

## Dementia Care Skills training in Malaysia

Alzheimer's Disease Foundation Malaysia (ADFM) regularly conducts Dementia Care Skills (DCS) training, which is gaining traction among caregivers and care workers. A training session was conducted in Pahang for the first time at the request of Lions Clubs Malaysia. The training, which took place over one and a half days, attracted more than 100 participants. The regular DCS training conducted by ADFM, which is free of charge, has helped many caregivers to understand and develop the skills in caring for persons with dementia.

ADI's report with the Karolinska Institute '*Global estimates of informal care*' revealed the number of people globally that provide informal care for people living with dementia. In 2015 informal carers provided 82 billion hours of care for people living with dementia. This is the equivalent of more than 40 million full time workers – and will increase to 65 million full time workers by 2030. ADI is calling on policy makers to consider innovating in the area of employment to consider flexible approaches to employment, particularly for carers, and for people living with dementia, to help mitigate challenges of loss of income, interruption or cessation of careers and self-worth and achievement. Employers benefit too, not losing their investment in hiring and training and no doubt engendering more loyalty.

### Malaysia stage 3C: In development, slow progress

## CHAPTER 6

# Information systems for dementia



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

Last year our Plan to Impact report 2018 had only limited information on action area 6 as we were waiting for countries to populate the Global Dementia Observatory (GDO). But this area is of key importance; it is the foundation for the whole Global plan.

This year we know that 21 pilot countries have contributed data to the GDO. Approximately 60 more countries are in the process of collecting and submitting data. Currently, on the GDO site, the data is from the first 21 countries, which equates to about 11% of the total countries in the WHO. The target is 50% so we are slowly on our way. Looking at the GDO data for this area in particular it is also quite clear that many countries fall short in the areas monitored.

ADI and its members look forward to being able to analyse further the data as it becomes available.

The Republic of Korea's K-Dreams dementia database is an example of how national monitoring can help in strengthening dementia systems. But what is particularly remarkable about K-Dreams is that it aims not only to register and monitor people living with dementia in the country but also to connect them with all the healthcare services available in their area for their specific condition. In that way K-Dreams really attempts to fulfil one of the main points of area 6: *“sharing the health and administrative data of each encounter of a person with dementia with the health and **social care** system.”*<sup>30</sup> As part of the Republic of Korea's plan to develop a national strategy, they are in the process of completing the GDO based on their national database.

The Global plan also mentions the importance of data registries. We really do need to point out that there is a lot still a lot to do in this area. Only a few nations have registries or are planning to set them up. The USA, UK, Netherlands and Australia are the main ones. But the type and quality of registries vary hugely and the way that people living with dementia can access them and the way their medical professionals can point them out to them vary too.

Even the definition of registries can be confusing to the general public and non-specialist healthcare professionals. Some are registries of people willing to undertake research, but the term ‘registry’ is also applied to datasets per se, like cohorts of a given research study. Also, registries are hosted by very different types of institutions and it is still unclear where should they best reside. Continued maintenance of the data included in the registries also seems to be a major issue.

More coordination and sharing of data are necessary, but given the variations mentioned above it is easy to see how lack of harmonization is a real obstacle. There has not really been much visible progress from the call to action in an OECD report<sup>31</sup> published in 2016. There is a need for a few countries to come together to lead and pave the way for harmonization and collaboration<sup>32</sup>.

Finally, the Global plan also calls for the involvement of people with dementia, their families and carers in the collection, analysis, and use of data on dementia. This is still a challenge for many institutions. Whilst we have seen much good practice, e.g. The Banner Alzheimer's Institute's Alzheimer's Prevention Registry, there is still a

30 National Institute of Dementia, Ministry of Health and Welfare (2019) Presentation material, International Conference on Global and National Strategies against Dementia (ICSAD)

31 OECD Science, Technology and Industry Policy Papers No.31: Global Action to Drive Innovation in Alzheimer's Disease and Other Dementias, 2016.

32 Whilst the opinions expressed are ADI's I would like to thank Prof. Piers Kotting, Prof. Henry Brodaty and Dr. Eric Reiman for conversations on this subject.

lot of misunderstanding and apprehensions in the general public about data. The recent examples uncovered in our own Clinical Trials Webinar series reveal how people living with dementia and their families are still finding it very difficult to find out about trials, enrolling and feeling in charge of their own data throughout the process. In addition, access to trials in low- and middle- income countries is slowly getting better but much more needs to happen.

## WHO's Global Dementia Observatory

Action area 6 of the global dementia action plan focuses on activities to improve monitoring and health information systems for dementia on a national and global level.

The Global Dementia Observatory (GDO) is WHO's online data and knowledge exchange platform. The GDO includes country data on policy, service delivery, information and research on dementia using comparable indicators. This information will help monitor global targets and track progress over time. The GDO has two main functions which complement each other: the GDO data portal and the knowledge exchange platform.

### The GDO data portal

GDO data is collected using 35 indicators which are in line with the seven action areas of the global action plan. The GDO also links to other databases or data collection efforts (e.g. WHO Global Health Observatory, Mental Health Atlas, OECD, STRiDE, JPND) to help unify information and prevent duplication of work. Once countries submit their data it is analysed to see how countries are addressing the challenges on dementia, in line with the seven action areas and then uploaded to the GDO data portal, where information from different countries can be compared.



The GDO data portal was launched in December 2017 and at the time of publication of this report data from 21 pilot countries<sup>33</sup> have started to upload data. WHO informs us that 80 countries are now engaged and that newly submitted data is currently being prepared to upload. Governments are tasked with providing data but it is vital that this data is examined by experts in each field, including by civil society in each country. ADI members thus have a crucial role in both encouraging governments to provide data but also in checking and validating data. In the next edition of this report (May 2020) we should be able to comment more specifically on the data being uploaded and also include some case studies.

Collecting GDO data can also be a catalyst for countries to start conversations on their approach to dementia. For some countries, GDO data collection became the foundation for the development or update of a national dementia strategy. GDO data collection also provides the opportunity to create cross-sector working groups to discuss the provision of services and legislation on dementia in their country as it often brings together stakeholders from government offices, health services, civil society (Alzheimer Societies), academia, and other national bodies.

One such example is Qatar: Under the leadership of the multisectoral dementia working group that was responsible for GDO data collection in Qatar, the team used this information as a foundation and decision tool, leading which led to the development of the Qatar National Dementia Plan 2018-2022.<sup>34</sup>

### GDO knowledge exchange platform

The GDO knowledge exchange platform contains key resources to support the implementation of the global dementia action plan and enhance countries' response to dementia. It provides a space for all relevant stakeholders to share resources (e.g. good policy, guidelines and practice examples for dementia) to facilitate mutual learning and promote the exchange of good practices in the area of dementia.



**How it works:** All resources are submitted by users of the platform. Resources will be mapped to at least one of the strategic action areas of the global dementia action plan.

33 World Health Organization, GDO peer reviewer registration form (2017)

34 Ministry of Public Health, Qatar National Dementia Plan 2018-2022 Summary (2018)

Automated filters will further allow users to search for country-, region- or language-specific resources, narrow down their searches by types of resources (e.g. policies, trainings, tools, practice examples) or explore settings and target audiences on which the resources focus.

WHO is introducing a standardized peer-review process that aims to support quality assurance of the platform. Peer reviewers are invited to become part of this community by completing this registration form.<sup>35</sup> The official call for resource submissions will start later in 2019 and we will report on progress in 2020.

### Wendy Weidner, ADI's Research and Policy Project Lead said:

*"While conducting situational analyses in the STRIDE countries, we realised we had a great opportunity to collaborate with colleagues at WHO and to contribute to their Global Dementia Observatory (GDO) collection of important baseline data. After consultation with WHO, we incorporated the GDO data questions into the STRIDE situational analyses and are working with country focal points to share these data through the GDO. By identifying gaps in policy, research, and the health and care systems, we can engage with local stakeholders and WHO colleagues in productive discussions around policy change. I am hopeful that we can continue this process when STRIDE is scaled up in more countries worldwide."*



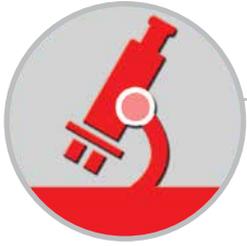
### Dr Maëlénn Guerchet, The Global Observatory for Ageing and Dementia Care, King's College London, said:

*"The Global Dementia Observatory can contribute to provide harmonised and detailed data on the dementia burden by following good practice principles which would ensure high-quality and accurate information. Efforts to access data published in any language and from low-and-middle income regions should be made in order to avoid bias in reported data. Additionally, careful consideration needs to be given to countries where data is not available or very limited: modelling of sparse regional data into estimates for individual countries could lead to misleading information with a potential impact on policymaking and prioritization. There is no substitute for real data."*

35 <https://extranet.who.int/dataform/456967?lang=en>

## CHAPTER 7

# Dementia research and innovation



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

Perhaps the most frequently asked questions of the ADI team are about research: Where are we now? What are the barriers to drug development? What is happening in care research? Thus, in 2018 ADI commissioned a journalist to interview 21 of the world's leading dementia researchers and asked them to discuss not only their own work, but for their views on dementia research in general; the barriers, the breakthroughs, the hopes and frustrations. The report was written in an accessible style to appeal as much to the general public as to governments, policy makers, academics and other researchers.



**Webinar 1 panellists (left to right) Piers Kotting, National Institute for Health Research; Dr Gayle Madden, Dementia UK; Professor Craig Ritchie, University of Edinburgh; Alison Searle, Roche; Paola Barbarino, ADI; Eileen and Dubhglas Taylor.**

The World Alzheimer Report 2018 looks at what causes dementia (the basic science), plus the challenges of diagnosis.<sup>36</sup> There is a key focus on drug discovery and when there may be a breakthrough. Risk reduction research and care research also feature.

A key finding of the report is that fact that the global ratio of publications on neurodegenerative disorders to cancer is an astonishing 1:12. More research is evidently needed but we also need to attract more researchers to this sector.

Over the last 2 years there have been a number of disappointing and high profile negative results in clinical trials. The lack of a disease modifying treatment breakthrough, in over 15 years, is frustrating but Professor Bart de Strooper (UK Dementia Research & University College London) sums up the hope:

*"We need to believe in ourselves. We need to believe that scientific approaches to this problem are going to help. The brain is an organ. It's a very difficult organ, a very fascinating organ, but it's made from the same components as all other body parts, and it's governed by the same principles. So, if you can find drugs for cancer, if you can find drugs for heart disease and diabetes, etc., then you should find it for brain disorders, too."*

<sup>36</sup> Alzheimer's Disease International, Patterson, C., World Alzheimer Report 2018 The state of the art of dementia research: New frontiers (2018)

A key call to action of the World Alzheimer Report is for governments to dedicate 1% of the societal cost of dementia to research. This is a call to action that needs to be amplified if we are to make the breakthroughs we all hope for

## ADI dementia research webinar series

Since November 2018, ADI's global webinar series 'Let's Talk About Dementia Research', has explored various topics surrounding dementia research and clinical trials. The aim of the series was to open up a dialogue between the general public, Alzheimer and dementia associations, people living with dementia, carers of people with dementia, health and social care professionals, as well as companies involved in dementia research and clinical trials, and to bridge gaps in understanding with information. As far as we are aware, no other webinar series has provided such 'public to professional' direct engagement before.

Webinar one provided an overview of what dementia research is: why clinical trials and research are important; the practicalities for clinicians; and the personal experience of taking part in a clinical trial, which was shared candidly by Eileen and Dubhglas Taylor. As a result of this direct feedback, at least one pharmaceutical company changed its training techniques to better support the needs of people living with dementia and their care partners.

Polls conducted throughout the webinar revealed that while 80% of participants would take part in dementia research; lack of knowledge on research and clinical trials, lack of access, fear, mistrust of the pharmaceutical industry and stigma played a role in preventing participation.

The second webinar compared the research available in high income countries as opposed to low-and middle-income countries (LMICs), and the barriers, enablers, and opportunities surrounding this global gap. There was a perceptible increase in registration numbers between the webinars. Participants came from 52 countries, and notably during the second webinar, over half of these were from LMICs, demonstrating the keen interest in opportunities for dementia research in LMICs.

The final webinar, which is upcoming at the time of writing, will address why some clinical trials are discontinued and what are hopes for the future.

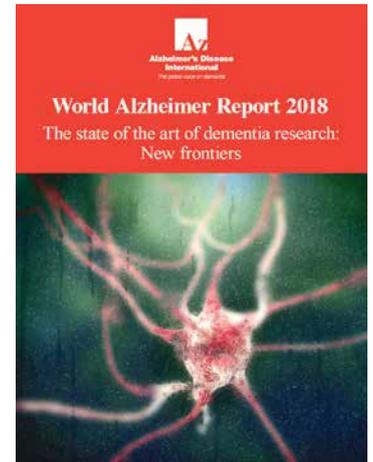
At the end of the first webinar, Eileen Taylor's take-home message was: *"Hope. Hope for my sons and my grandkids. Listening to this has given me hope that things might change."*

## STRiDE

Strengthening responses to dementia in developing countries (STRiDE) is a four-year (2018–2021) project to build capacity in dementia research in seven developing countries, led by the London School of Economics and Political Science (LSE), the University of Cape Town, Brighton and Sussex Medical School, Alzheimer's Disease International and Dementia Alliance International.<sup>37</sup> The aim of the project is to contribute to improving dementia care, treatment and support systems so that people living with dementia are able to live well, as well as preventing care partners from incurring excessive costs, which may put them at risk of poverty or negatively impact their own health. The project will initially focus on seven pilot countries: Brazil, India, Indonesian, Jamaica, Kenya, Mexico, and South Africa. The project comprises 10 major work packages. Work package 8, led by ADI and ADI members in each of the seven countries, will directly address the WHO Global plan by providing recommendations for national dementia plans across all seven countries.



**STRiDE Launch event, London, March 2018**



**World Alzheimer Report 2018**

37 STRiDE (2019): <https://www.stride-dementia.org/>



**STRiDE meeting in Cape Town, March 2019**

## Dementia research investment in the US: a case study

Second to insufficient research funding, recruiting and retaining clinical study participants is the greatest obstacle to developing the next generation of Alzheimer's treatments. Why is this?

To find out, the Alzheimer's Association and National Institutes on Aging (NIA) at the National Institutes of Health (NIH) brought together experts and collected insights from government, private, academic and industry stakeholders, as well as from individuals with Alzheimer's and other dementias, caregivers and study participants. The two-year effort culminated in 2018 with the National Strategy for Recruitment and Participation in Alzheimer's and Related Dementias Clinical Research.

The strategy recognizes the unique barriers to participation in Alzheimer's clinical research, including the need for a study partner in many trials and for asymptomatic participants for some studies. An important insight discussed at the first National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers, held at the NIH in 2017, is that people with Alzheimer's who are recruited into clinical trials want to feel like they are more than just participants. They want to be more involved. For example, some want to be included in the development of the study, from the earliest feasible point. Others want to serve in an advisory capacity to researchers and to clinical research staff who have the hands-on role of conducting cognitive tests and interacting directly with volunteers throughout the study. Yet others are interested in being members of clinical study steering committees. *"The message is clear,"* says Maria Carrillo, chief science officer at the Alzheimer's Association. *"Participants want to feel that they have a voice. They want to be included."*

As diagnosis moves earlier and earlier in the disease continuum, a growing proportion of people will live with Alzheimer's disease knowing the health trajectory that awaits them. *"Just as it is imperative that we understand the needs of clinical study participants, it's critical that we undertake research to examine the needs and wants of individuals in the earlier stages of the disease,"* comments Carrillo. These may include support systems similar to those now in place for people with Alzheimer's dementia and their families. Or perhaps support systems for this unique group will be quite different. Only through research can these needs be identified.

Individuals living with Alzheimer's and their families are also increasingly active in advocacy, helping to shape policy and advance research, care and support services. Working with the Alzheimer's Association and its advocacy arm, the Alzheimer's Impact Movement (AIM), advocates began in 2010 to successfully urge the U.S. Congress to order the creation of a national Alzheimer's plan. That plan set a goal of having prevention and treatments by 2025. Following recommendations of an expert workgroup convened by the Alzheimer's Association, the NIH — the agency that funds medical research — developed a timeline and series of milestones to reach the 2025 goal. To ensure the funding was adequate to meet the timeline and milestones, Association/AIM advocates successfully lobbied Congress to require scientists to submit an annual budget on how much money was needed to maintain progress toward the 2025 goal.



In addition to advocates, the research community is mobilized in the fight against Alzheimer's. As the National Institute on Aging, part of the NIH, began submitting its annual budget request to Congress, the Alzheimer's Association/AIM mobilized tens of thousands of grassroots advocates, solicited the testimony of researchers, provided a platform for the voices of those with the disease and their caregivers, and cultivated policy makers directly.

This resulted in Congress more than quadrupling annual funding for Alzheimer's research in the last four years. In 2019, the Alzheimer's research investment will total \$2.3 billion. This dramatic increase was the result of a multi-year, multi-pronged effort by the Alzheimer's Association and Aim to end two decades of stagnant budgets. And while these increases have been historic, the scientists say more is needed to reach the 2025 goal. The Alzheimer's Association/AIM is continuing to work to secure additional funding, advocating for a \$350 million increase in funding for fiscal year 2020.

*"The work we do to support and advance dementia science domestically has great impact on the global research community. The Alzheimer's Association is currently investing \$165 million in active research in more than 450 projects spanning 25 countries," says Carrillo. "Many researchers who receive grants from us go on to receive additional support from the NIA, which strengthens the research pipeline. For individuals living with Alzheimer's and their families, we continue to be relentless in pursuit of our vision — a world without Alzheimer's disease."*

## Conclusion and recommendations

The opportunity offered by the adoption of the WHO's *Global action plan on the public health response to dementia 2017-2025* by all its 194 Member States in 2017 is yet far from being realised. Two years into the implementation of the plan, there are large gaps in global coverage, leaving many of the more than 50 million people currently living with dementia without adequate information, services and support including in the key areas of awareness and friendliness; risk reduction; diagnosis, treatment, care and support and support for carers. In the continued absence of a disease modifying treatment we also need much more research in all areas. At an academic level there



is some focus on health care system preparedness, but this is an area that needs much more attention at a policy level. A diagnosis or treatment breakthrough is a global goal, but even if it was realised, national systems would not be prepared to deal with it, and this would leave many people living with dementia behind.

Only one plan was launched in 2018. Based on our calculations, more than 21 new plans a year are needed after 2020 to achieve the targets of the *Global action plan on the public health response to dementia 2017-2025* (Global plan). However, this is only part of the picture. Unless national plans are fully implemented, funded and monitored, they are merely documents with good intentions. Our research reveals that funding and prioritisation issues are key barriers to developing and implementing plans.

There have been some encouraging developments since 2017. This report has outlined some of the progress and momentum and has highlighted some key examples for inspiration. The Republic of Korea plan is good example, only lacking in the area of research. Alzheimer Scotland has worked closely with Scottish Government across the full spectrum of the disease, from diagnosis, to advanced illness and is now turning to risk reduction. There are some excellent examples of regional progress, including Tucumán Province in Argentina, responding regionally as a reaction to the lack of progress with a national plan. There are more and more groups of people living with dementia being set up, giving a powerful advocacy voice to all aspects of dementia from plan development to advising health care development. We have also highlighted some examples of carers groups (NDCAN and Tide), bringing the invaluable experience of carers and past carers forward.

Dementia friendly communities and initiatives keep evolving. This is a dynamic and innovative area and one of the action areas of the Global plan where partners, including national dementia associations, really can make a difference. Examples include the dementia-friendly shopping mall in Malaysia; dementia-friendly banks in Hong Kong and the UK; a growing network of dementia friends programmes, including over 11 million people trained in Japan, where it all started.

Going forward the WHO's Global Dementia Observatory (GDO) will be an extremely important tool for governments when preparing their health and social care systems for the forecast increases in numbers of people living with dementia. ADI urges the 194 governments that have signed the Global plan to actively engage in providing robust data for the GDO and to work with the Alzheimer and dementia associations in their countries, alongside researchers, to ensure that up to date data is available for the first interim reporting cycle of the plan in May 2020. We also welcome the WHO's Dementia Knowledge Exchange initiative to ensure adequate reviewing of the data contained in the GDO.

From a research perspective, there are some robust research projects exploring the relationship between modifiable risk factors and dementia, such as the FINGER and PREVENT studies. ADI encourages the global transposition of such studies. 2018 was an important year for risk reduction, with the UN High Level Meeting on NCDs and the announcement of the WHO's '5 x 5' approach, which is a huge opportunity to highlight the role of dementia within NCD response. Tools such as the WHO's risk reduction guidelines should provide evidence and concrete policy actions for policy-makers.

Overall, ADI continues to call strongly for all governments to dedicate a minimum of 1% of the societal cost of dementia to research. It is only through research that we will ultimately make the breakthroughs in prevention, treatment and cure that we all strive for.

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## Appendix A

Table of states represented by countries/territories, ADI status, plan stage and status				
Country/ Territory	Region	ADI member / development	Plan stage	Plan status
Afghanistan	Asia Pacific		-	
Albania	Europe	YES	-	
Algeria	Africa		-	
Andorra	Europe		-	
Angola	Africa		-	
Antigua and Barbuda	Caribbean		-	
Argentina	Americas	YES	STAGE 2C	Proposed national strategy 2016, <b>regional plan</b> in Tucumán province
Armenia	Europe	YES	-	
Aruba	Caribbean	YES	-	
Australia	Asia Pacific	YES	STAGE 4A	<b>National Framework on Dementia 2015-2019</b> , but inadequate funding; GDO pilot
Austria	Europe	YES	STAGE 4A	<b>Plan 2015</b> , but inadequate funding
Azerbaijan	Asia Pacific		-	
Bahamas	Caribbean		-	
Bahrain	Middle East		-	
Bangladesh	Asia Pacific	YES	STAGE 1	<b>No plan</b> , though ageing and NCDs are Government priorities; GDO pilot
Barbados	Caribbean	YES	STAGE 3B	<b>In development</b> , news on progression expected soon
Belarus	Europe		-	
Belgium	Europe	YES	STAGE 2D	No plan, but <b>regional dementia plans</b> in Flanders and Wallonia
Belize	Americas		-	
Benin	Africa		-	
Bermuda	Caribbean	YES	-	
Bhutan	Asia Pacific		-	
Bolivia	Americas	YES	-	<b>In development</b> , but 2019 is election year
Bonaire	Caribbean	YES	STAGE 3B	<b>Plan in development</b> , expected in 2019
Bosnia and Herzegovina	Europe	YES	STAGE 2	Plan previously in development, but waiting on a new Ministry of Health
Botswana	Africa		-	
Brazil	Americas	YES	STAGE 1	Plan previously in development, renewed commitment announced in April 2019 that STRiDE Brazil was working with the government on a national plan
British Virgin Islands	Caribbean	YES	STAGE 2B	New Minister of Health committed to dementia (as a founding member of the association)
Brunei	Asia Pacific	YES	STAGE 3B	<b>Plan in development</b> , expected in 2020
Bulgaria	Europe	YES	STAGE 2D	Plan being drafted by association. National strategy on long-term care and a Plan for action for 2018-2021 for the implementation of the National strategy
Burkina Faso	Africa		-	
Burundi	Africa	YES	-	
Cambodia	Asia Pacific		-	
Cameroon	Africa		-	

Country/ Territory	Region	ADI member / development	Plan stage	Plan status
Canada	Americas	YES	STAGE 3A	<b>In development</b> , expected by June 2019; funding committed
Cape Verde	Africa		-	
Cayman Islands	Caribbean	YES	-	
Central African Republic	Africa		-	
Chad	Africa		-	
Chile	Americas	YES	STAGE 5	<b>Plan 2017</b> , but plan needs a push, to go beyond diagnosis, and geographically beyond limited geographical coverage; GDO pilot
China	Asia Pacific	YES	STAGE 3A-3B	<b>Plan in development</b> , expected in 2019
Colombia	Americas	YES	STAGE 1	<b>No plan</b> , association developing connections with Ministry of Health
Comoros	Africa		-	
Congo	Africa		-	
Cook Islands	Asia Pacific		-	
Costa Rica	Americas	YES	STAGE 5	<b>Plan 2014-2024</b> ; GDO pilot
Côte d'Ivoire	Africa		-	
Croatia	Europe	YES	STAGE 3A	<b>Plan in development</b> , progress in palliative care, education, raising awareness, stigma
Cuba	Caribbean	YES	STAGE 5	<b>Strategy 2016</b> , but not yet introduced uniformly across the country
Curacao	Caribbean	YES	STAGE 3	<b>Plan in development</b>
Cyprus	Europe	YES	STAGE 3C	Plan previously in development, currently undergoing changes to Ministry of Health
Czech Republic	Europe	YES	STAGE 4B & 4D	<b>Plan 2016-2019</b> , but no concrete budget for all areas of the plan; new plan in development
Democratic Peoples Republic of Korea	Asia Pacific		-	
Democratic Republic of the Congo	Africa		-	
Denmark	Europe	YES	STAGE 4A	<b>Plan 2009</b> , but only partially funding and the country is undergoing major reform of health system and upcoming elections
Djibouti	Africa		-	
Dominica	Caribbean		-	
Dominican Republic	Caribbean	YES	STAGE 3B	<b>In development</b> , GDO pilot
Ecuador	Americas	YES	STAGE 2	<b>No plan</b> , but association in discussion with Ministry of Health
Egypt	Africa	YES	STAGE 2B	
El Salvador	Americas	YES	STAGE 1	Draft national plan from 2017 to be reactivated, but Governmental changes
Equatorial Guinea	Africa		-	
Eritrea	Africa		-	
Estonia	Europe		STAGE 2D	<b>No plan</b> , but Dementia Competence Centre established in 2018, with funding until 2021
Ethiopia	Africa		-	
Fiji	Asia Pacific		-	GDO pilot
Finland	Europe	YES	STAGE 4D	<b>Plan 2012-2020</b> , but funding insufficient and recent Governmental changes have threatened the plan

Country/ Territory	Region	ADI member / development	Plan stage	Plan status
France	Europe		STAGE 2A	<b>No plan</b> , but a Neurodegenerative diseases Plan 2014-2019; GDO pilot
Gabon	Africa		-	
Gambia	Africa		-	
Georgia	Europe	YES	STAGE 2B	<b>No plan</b> , but Ministry of Health expressed interest in developing a plan
Germany	Europe	YES	STAGE 3B	<b>Plan in development</b> , working groups being consulted
Ghana	Africa	YES	-	
Gibraltar	Europe	YES	-	<b>National Vision and Dementia Strategy for Gibraltar 2015</b>
Greece	Europe	YES	STAGE 5	<b>Plan 2016</b>
Grenada	Caribbean		STAGE 2B	<b>No plan</b> , but association in discussion with Ministry of Health
Guatemala	Americas	YES	STAGE 2B	Plan previously in development in 2014; Governmental changes
Guinea	Africa		-	
Guinea-Bissau	Africa		-	
Guyana	Africa		-	
Haiti	Caribbean		-	
Honduras	Americas	YES	STAGE 2	National health emergency
Hong Kong SAR	Asia Pacific	YES	STAGE 1	<b>No plan</b>
Hungary	Europe	YES	STAGE 2B	<b>No plan</b> , but association in discussion with Ministry of Health; GDO pilot
Iceland	Europe		STAGE 3B	<b>Plan in development</b> , expected in 2019
India	Asia Pacific		STAGE 3A-3B	<b>Plan in development</b> , funding committed to Action Areas 2, 4 and 5 out of the 7, but Governmental changes
Indonesia	Asia Pacific	YES	STAGE 5B	<b>Plan 2016</b> , but has not been fully communicated
Iran	Middle East	YES	STAGE 3A	<b>Plan in development</b> , pilot expected in 2019 but Governmental changes
Iraq	Middle East		-	
Ireland	Europe	YES	STAGE 5	<b>Strategy 2011-2016</b>
Israel	Europe	YES	STAGE 4A	<b>Plan 2013</b>
Italy	Europe	YES	STAGE 4B	<b>Plan 2014</b> , but funding challenges; GDO pilot
Jamaica	Caribbean	YES	STAGE 1	No contact with Ministry of Health; STRiDE team initiated and participates in a Jamaica Global Dementia Observatory Oversight Committee
Japan	Asia Pacific	YES	STAGE 5A	<b>Plan 2015</b> ; GDO pilot
Jordan	Middle East	YES	STAGE 2	GDO pilot
Kazakhstan	Asia Pacific		-	
Kenya	Africa	YES	STAGES 2A-3A	<b>In development</b> , Ministry of Health drafting plan; dementia incorporated into grouped health plan
Kiribati	Asia Pacific		-	
Korea, Republic of	Asia Pacific	YES	STAGE 5	<b>Plan 2015</b>
Kuwait	Middle East		STAGE 3	<b>In development</b>
Kyrgyzstan	Asia Pacific		-	
Lao People's Democratic Republic	Asia Pacific		-	

Country/ Territory	Region	ADI member / development	Plan stage	Plan status
Latvia	Europe		-	
Lebanon	Middle East	YES	STAGE 2B	<b>No plan</b> , but association in discussion with Ministry of Health; Governmental changes
Lesotho	Africa	YES	STAGE 2B	<b>No plan</b> , but association in discussion with Ministry of Health
Liberia	Africa		-	
Libya	Africa		-	
Lithuania	Europe		-	
Luxembourg	Europe		-	<b>Plan 2013</b>
Macau SAR	Asia Pacific	YES	STAGE 5A	<b>Policy 2016</b> , but has not been fully communicated, including on funding
North Macedonia	Europe	YES	-	
Madagascar	Africa	YES	STAGE 2A	<b>No plan</b> , but dementia mentioned once in the Mental Health Strategic Plan; association in discussion with Ministry of Health
Malawi	Africa		-	
Malaysia	Asia Pacific	YES	STAGE 3C	<b>No plan</b> , but progress towards Plan of Action for Elderly Health Care containing elements of the Global plan
Maldives	Africa		-	GDO pilot
Mali	Africa		-	
Malta	Europe	YES	STAGE 5B	<b>Strategy 2015-2023</b> , but no guarantee of funding in future
Marshall Islands	Asia Pacific		-	
Mauritania	Africa		-	
Mauritius	Africa	YES	STAGE 2B	<b>No plan</b> , but association in discussion with Ministry of Health; GDO pilot
Mexico	Americas	YES	STAGE 4A	<b>Plan 2014</b> , including funding for some activities, but not adequate for the whole plan
Micronesia, FS	Asia Pacific		-	
Moldova, Rep. of	Europe		-	
Monaco	Europe	YES	-	
Mongolia	Asia Pacific		STAGE 2A	Dementia incorporated into <b>National Strategy Programme for Healthy Ageing and Health of Older Persons 2014-2020</b>
Montenegro	Europe		STAGE 3C	<b>Plan in development</b> , dementia a priority for Ministry of Health in 2019
Morocco	Africa	YES	STAGE 1	<b>No plan</b>
Mozambique	Africa		-	
Myanmar	Asia Pacific	YES	STAGE 2B	<b>No plan</b> , but association in discussion with Ministry of Health; GDO pilot
Namibia	Africa	YES	STAGE 2B	<b>No plan</b> , but association in discussion with Ministry of Health
Nauru	Asia Pacific		-	
Nepal	Asia Pacific	YES	-	<b>No plan</b> , but development of Mental Health Policy reported in 2018, will include dementia, Government committed \$1000/per person with dementia for diagnosis and treatment support
Netherlands	Europe	YES	STAGE 5B	<b>Plan 2013-2020</b> , with substantial funding; GDO pilot

Country/ Territory	Region	ADI member / development	Plan stage	Plan status
New Zealand	Asia Pacific	YES	STAGE 2A	<b>No dementia-specific plan</b> , but 2016 Healthy Aging Strategy has 2 specific action items on dementia
Nicaragua	Americas	YES	STAGE 1	Political challenges preventing action
Niger	Africa		-	
Nigeria	Africa	YES	-	<b>No plan</b> , but ageing plan in development reported in 2018
Niue	Asia Pacific		-	
Norway	Europe	YES	STAGE 5B	<b>Plan 2015-2020</b> , Ministry of Health committed to continuation of plan for 2020-2025
Oman	Middle East	YES	STAGE 2A	<b>No plan</b> , but dementia incorporated into National NCD Action Plan 2018
Pakistan	Asia Pacific	YES	STAGE 3B	<b>Plan in development</b>
Palau	Asia Pacific		-	
Panama	Americas		-	<b>No plan</b>
Papua New Guinea	Asia Pacific		-	
Paraguay	Americas		-	
Peru	Americas	YES	STAGE 2B	<b>No plan</b> , but Law for the Prevention and Treatment of Alzheimer's Disease and Other Dementias 2018 and National Plan for the Strengthening of Community Mental Health Services 2017-2021; changes in government
Philippines	Asia Pacific	YES	STAGE 2B	<b>No plan</b> , but Mental Health Act 2017
Poland	Europe	YES	STAGE 2A	<b>No plan</b> , but dementia incorporated into treatment and care system dedicated to elderly people
Portugal	Europe		STAGE 3B	<b>Health Strategy for Dementia 2018</b>
Puerto Rico	Caribbean	YES	STAGE 4	<b>Plan previously reported 2015-2025</b> , progress stalled
Qatar	Middle East	YES	STAGE 5	<b>Qatar National Dementia Plan</b> launched in November 2018; GDO pilot
Romania	Europe	YES	STAGE 2A	<b>No plan</b> , but dementia incorporated into Project Mental Health
Russian Federation	Europe	YES	STAGE 2A & 3B	<b>Plan in development</b> , expected in 2019; dementia incorporated into grouped ageing plan
Rwanda	Africa		-	
Saint Kitts and Nevis	Caribbean	YES	STAGE 2B	<b>No plan</b> , but association in discussion with Ministry of Health
Saint Lucia	Caribbean		-	
Saint Vincent and the Grenadines	Caribbean		-	
Samoa	Asia Pacific		-	
San Marino	Europe		-	
Sao Tome And Principe	Africa		-	
Saudi Arabia	Middle East	YES	-	
Scotland	Europe	YES	STAGE 5	<b>Strategy 2017-2020</b>
Senegal	Africa		STAGE 2A	<b>No plan</b> , but neurodegenerative diseases incorporated into national plan of action of the Ministry of health and social action
Serbia	Europe		-	

Country/ Territory	Region	ADI member / development	Plan stage	Plan status
Seychelles	Africa		STAGE 2B	<b>No plan</b> , but association in discussion with Ministry of Health
Sierra Leone	Africa		-	
Singapore	Asia Pacific	YES	STAGE 5A	<b>Strategy</b> , updated 2018
Sint Maarten	Caribbean	YES	-	
Slovak Republic	Europe	YES	STAGE 3B	<b>Plan in development</b>
Slovenia	Europe	YES	STAGE 4A	<b>Strategy 2016-2020</b> ; Long Term Care Act in development
Solomon Islands	Asia Pacific		-	
Somalia	Africa		-	
South Africa	Africa	YES	STAGE 2A	<b>No plan</b> , but dementia incorporated into incorporated in parts of the Mental Health, Ageing and NCD plans
South Sudan	Africa		-	
Spain	Europe	YES	STAGE 3B	<b>National Alzheimer's Plan 2019-2023 in final stages of development</b>
Sri Lanka	Asia Pacific	YES	STAGE 2B	<b>No plan</b> , but possibility of integrating dementia into Mental Health Action Plan
Sudan	Africa		-	
Suriname	Americas	YES	STAGE 2B	<b>No plan</b> , but association conducting stakeholder meetings to initiate plan development
Swaziland	Africa		-	GDO pilot
Sweden	Europe	YES	STAGE 3B	<b>Dementia Strategy 2018-2022</b> , but Governmental changes; GDO pilot
Switzerland	Europe	YES	STAGE 4B & 4D	<b>Plan 2014-2019</b> , but lack of funding; GDO pilot
Syrian Arab Republic	Middle East	YES	STAGE 1	
Tajikistan	Asia Pacific		-	
Tanzania, United Republic of	Africa	YES	STAGE 2B	<b>No plan</b> , but association in discussion with Ministry of Health
Chinese Taipei	Asia Pacific	YES	STAGE 5B	<b>Dementia Plan 2018-2025</b> , Government committed \$300 million budget
Thailand	Asia Pacific	YES	STAGE 2D	<b>No plan</b> , but Comprehensive Dementia Care Project contains funding for Action Areas 2, 4, 5 and 7
Timor-Leste	Asia Pacific		-	
Togo	Africa		STAGE 2A	<b>No plan</b> , but association in contact with Ministry of Health and dementia incorporated into grouped health plan; GDO pilot
Tonga	Asia Pacific		STAGE 2B	<b>No plan</b> , but association making contact with Ministry of Health; Government working on Long Term Care Plan and interested to discuss dementia plan
Trinidad and Tobago	Caribbean	YES	-	National Ageing policy development previously reported in 2018
Tunisia	Africa	YES	STAGE 3C	<b>Plan in development</b> , but Governmental changes; GDO pilot
Turkey	Europe	YES	STAGE 3B	<b>National Dementia Strategy in development</b> , expected in 2019
Turkmenistan	Asia Pacific		-	
Tuvalu	Asia Pacific		-	

Country/ Territory	Region	ADI member / development	Plan stage	Plan status
Uganda	Africa	YES	STAGE 2B	<b>No plan</b> , but association in discussion with Ministry of Health
Ukraine	Europe		-	
United Arab Emirates	Middle East	YES	STAGE 2B	<b>No plan</b> , but association in discussion with Ministry of Health
United Kingdom	Europe	YES	STAGE 5	<b>Plan 2009</b>
United States of America	Americas	YES	STAGE 5	<b>Plan 2011, 2017 update</b>
Uruguay	Americas	YES	STAGE 1/2	<b>No plan</b> , Governmental changes
Uzbekistan	Asia Pacific		-	
Vanuatu	Asia Pacific		-	
Venezuela	Americas	YES	STAGE 3A	<b>Plan in development</b> , but political challenges
Vietnam	Asia Pacific		STAGE 3B	Recently received funding to develop national plan
Yemen	Middle East		-	
Zambia	Africa	YES	STAGE 2B	<b>No plan</b> , but Ministry of Health expressed commitment to developing a plan
Zimbabwe	Africa	YES	STAGE 2B	<b>No plan</b> , political challenges

## Appendix B

List of countries/territories with plans not directly represented at WHO, by income group and plan status.				
Country/ Territory	Region	ADI member / development	Plan stage	Plan status
Bonaire	Caribbean	YES	STAGE 3B	In development
Curacao	Caribbean	YES	STAGE 3	In development
Macau	Asia Pacific	YES	STAGE 5A	Policy 2016
Northern Ireland	Europe			Regional Strategy 2011
Puerto Rico	Caribbean	YES	STAGE 5	Plan 2015-2025
Scotland	Europe	YES	STAGE 5	Strategy 2017 - 2020
TADA Chinese Taipei	Asia Pacific	YES	STAGE 5B	Dementia Plan 2018-2025
Wales	Europe		STAGE 5	Plan 2018-2022

\*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



## **Alzheimer's Disease International**

*The global voice on dementia*

### **About ADI**

Alzheimer's Disease International (ADI) is the international federation of Alzheimer associations throughout the world. Each of our 94 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.

You can find out more about ADI at [www.alz.co.uk/adi](http://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  
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**Alzheimer's Disease  
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