



**Alzheimer's Disease
International**

The global voice on dementia

From Plan to Impact III

*Maintaining dementia as a priority
in unprecedented times*



Authors

Paola Barbarino, Chris Lynch, Annie Bliss, Laura Dabas, Alzheimer's Disease International (ADI)

Contributors

Professor Emiliano Albanese, Head of the Division of Public Mental Health and Aging, Université de Genève

Kielan Arblaster, Policy Officer, Alzheimer's Society

Professor Henry Brodaty, Professor of Ageing and Mental Health, Director, Dementia Centre for Research, Collaboration and Co-Director, Centre for healthy Brain Ageing, University of New South Wales, Sydney, Australia and Honorary Vice-President, Alzheimer's Disease International

Maria C. Carrillo, PhD, Chief Science Officer, Medical & Scientific Relations, Alzheimer's Association

Dr Christopher Chen, Director, Memory Ageing and Cognition Centre, National University Health System, Singapore

Adelina Comas-Herrera, Assistant Professorial Research Fellow at the Care Policy and Evaluation Centre (CPEC) at the London School of Economics and Political Science (LSE)

Dr. Tricia Cowan, Assistant Professor, Department of Nursing, Bemidji State University

Dr. Jeffrey Cummings, MD, ScD, Translational Science Lead Advisor, Shanghai Green Valley Pharmaceuticals

Sam Fazio, PhD, Senior Director of Quality Care and Psychosocial Research Care and Support, Alzheimer's Association Home Office

Daniela Fernandez Gomora, (former) Senior International Officer, Alzheimer's Society

Rickard Forsman, CEO, Geras Solutions

Anna Gaughan, Chief Executive, tide – together in dementia everyday and Life Story Network

Lorène Gilly, France Alzheimer et maladies apparentées

Melissa Gong Mitchell, Executive Director, Global Coalition On Aging

Dr. Aliaa Ibnidris, Doctoral Assistant, Università della Svizzera italiana

Priya Kanayson, Policy and Advocacy Manager, NCD Alliance

Jinhe Li, PhD, CEO, US Green Valley Pharmaceuticals

Professor Gill Livingston, Professor of Psychiatry of Older People, Division of Psychiatry, Faculty of Brain Sciences, University College London

Raj Long MBPs MSc, Independent Expert; (prior) Vice-Chair of the World Dementia Council; (prior) GAAD Lead, Integrated Development, UK Department of Health

Joost Martens (prior) Regional Director for the Americas, ADI

Dr. José Luis Molinuevo MD, PhD, Scientific Director of the Alzheimer Prevention Program at BarcelonaBeta Brain Research Center (BBRC)

Graciela Muniz Terrera, Senior Lecturer in Biostatistics and Epidemiology, Centre for Clinical Brain Sciences, University of Edinburgh

Haza Newman, (prior) Chief Executive Officer, Geras solutions

Jim Pearson, Director of Policy, Alzheimer Scotland

Princess Nouf bint Muhammed bin Abdullah Al-Saud, CEO, King Khalid Foundation

Glenn Rees, Chairman, Alzheimer's Disease International and former CEO, Alzheimer's Australia

Nina Renshaw, Policy and Advocacy Director, NCD Alliance

Professor Craig Ritchie, Chair, Psychiatry of Ageing at the University of Edinburgh and Director, Centre for Dementia Prevention

Dr. Bernadette Rock, Policy and Research Manager, Alzheimer's Society of Ireland

Ella Robinson, Senior Policy Officer, Alzheimer's Society

Sam Savin, Associate Director, Global Coalition On Aging

Professor Bart de Strooper, Director, UK Dementia Research Institute

DY Suharya, Regional Director, Asia Pacific Regional Office, Alzheimer's Disease International

Kate Swaffer, Chair, Co-Founder and CEO, Dementia Alliance International

Dr. Noriyo Washizu, Alzheimer's Association Japan

Wendy Weidner, Research and Policy Project Lead, Alzheimer's Disease International

Masahiko Yamamoto, Office Manager, Asahi Shimbun Social Welfare Organization, Osaka

ADI members

Acknowledgements

We would like to thank all the national Alzheimer associations and other organisations, including Alzheimer Europe and Dementia Alliance International, that have provided the information for this report. We would like to thank the Department of Mental Health and Substance Abuse, World Health Organization (WHO) dementia team – Tarun Dua, Katrin Seeher, Neerja Chowdhary and Stefanie Freil.

ADI would like to thank our corporate partners and donors:

Anonymous Foundation

Helen Daniels Bader Fund, A Bader Philanthropy

Biogen

Boehringer-Ingelheim

Eisai

International Federation of Pharmaceutical Manufacturers & Associations (IFPMA)

Janssen

Roche

Otsuka America Pharmaceutical, Inc.

Mary Oakley Foundation

The Van Otterloo Family Foundation



**Alzheimer's Disease
International**

The global voice on dementia

Contents

Foreword.....	4
Background and methodology	6
Action areas.....	7
CHAPTER 1: Dementia as a public health priority.....	12
CHAPTER 2: Dementia awareness and friendliness.....	24
CHAPTER 3: Dementia risk reduction	33
CHAPTER 4: Diagnosis, treatment, care and support.....	41
CHAPTER 5: Support for dementia carers.....	54
CHAPTER 6: Information systems for dementia.....	62
CHAPTER 7: Dementia research and innovation.....	65
Summary and conclusion.....	74
Bibliography	75
Appendix A – Table of states represented by countries/territories, ADI status, plan stage and status.....	77
Appendix B – List of countries/territories with plans not directly represented at WHO, by income group and plan status.....	82

Foreword



It is impossible to imagine a more different world now to the one I was writing about for this report in 2019. Everything has changed since COVID-19 became the biggest global pandemic in several generations.

The virus's higher mortality rate in those over 65, in those with underlying conditions (and in particular non communicable

diseases), and – more chillingly – among residents of care facilities, has brought into sharp focus how those we advocate for are one of the most vulnerable groups globally. And also, one of the least valued groups. As reports started pouring in – from the Philippines and Italy first and then from all over the world – of the triage decisions doctors were forced to make when admitting patients to intensive care units, we watched in disbelief. The UK NICE guidelines recommended the use of the Clinical Frailty Scale, which was updated to specifically include dementia (not included anywhere else as far as we know). However, this still encouraged blunt decisions made on an age basis, crystallising what we had always known in our heart of hearts, that age discrimination is still considered perfectly acceptable. In all other countries these bedside life or death decisions were left in the hands of overworked and courageous doctors, nurses and paramedics – wherever the bedside might have been.

But this novel coronavirus has hit hundreds of thousands of families, and behind each of these families there have been individual stories of loss and grief; of not being able to talk to loved ones at home, in hospitals, in care homes; of not being there to hold hands, to hold and attend funerals. And social distancing has resulted in compromised mental and physical wellbeing for so many in the “at risk” categories who

had never had to shelter before. In a way, the lockdown has brought to many the experience that people with dementia feel from diagnosis onward. In the words of Kate Swaffer, one of the most preeminent dementia advocates:

“In 2020, the rest of the world suddenly experienced what people with dementia and their families experience on a daily basis after diagnosis, such as isolation, distancing (from many family and friends), fear, anxiety and stigma.”

Carer burnout has also emerged as a huge issue. In the words of one carer who wishes to remain anonymous:

“I have given up a well-paid job to care for my husband Keith 2 years ago. He is 56 years old and has suffered early onset dementia for the past three years. As a result of COVID-19, his dementia deteriorated at pace. I left him in a wheelchair in the car park of a care home and haven't seen him for 4 weeks. It was all so sudden! Almost immediately all our benefits stopped – and our family income has been reduced from £1000 a month to £400. I have only £113 to live on per week. I feel that I have just been dropped into the middle of an ocean! As carers of people with early-onset dementia – we are forgotten and the impact is seismic.” **Carer**

And let us not forget that the virus has hit everyone in the world but questions have been raised in many countries about mortality rates among ethnic minorities. Similarly, marginalised groups are often disproportionately impacted by dementia, as they are often poorer and disadvantaged wherever they are.

There are other topics crowding our minds and workspaces at ADI.

- The possible interruption of clinical trials – this of all years when we had finally started to hope for a pharmacological breakthrough. What will this mean for a sector that was timidly allowing itself

“In my lifetime I have learnt that memory of epochal events is short, but I think people will be remembering this for a longer time than usual. And if not, we are here to make sure these memories won't be forgotten because we need now more than ever to make sure we can use this example in our future advocacy. This must never happen again.” **Paola Barbarino**

“In 2020, the rest of the world suddenly experienced what people with dementia and their families experience on a daily basis after diagnosis, such as isolation, distancing (from many family and friends), fear, anxiety and stigma.” *Kate Swaffer*

to be dreaming of a solution, which whilst not the answer to all our problems was certain to galvanise investment and research in an area where so much biopharma had given up?

- The interruption to diagnosis, as families are too scared to attend primary care facilities or as the provision of diagnostic and specialist care has been interrupted. Nothing is stopping dementia, it continues to be one of the biggest killers of the 21st century and one of the most undiagnosed diseases in the world. What will happen to all those families and people living with dementia who will have no capacity to prepare themselves for what is coming or receive the post-diagnostic support they need now more than ever.
- The interruption to care, social or other. When will these face-to-face services resume, if ever? More and more people are being left alone to battle with what feels like an unsurmountable obstacle.
- More worrying than anything else is the possibility that governments, already reluctant to own up to the dementia crisis in their country, may use the pandemic as an excuse to delay it forever. At three years since the approval of the WHO Global dementia action plan, progress (and funding!) is still so slow – to make the many of us who advocate for it cry in frustration. But, as COVID-19 has demonstrated, at the scale we are talking about – over 50 million people with dementia globally – only governments can find solutions.

As ever, from difficulties also come opportunities. The rise of telemedicine is one: there are still many sceptics and more studies are needed but COVID-19 has accelerated this process and forced the unconverted to consider it. Insofar as I had only seen it applied in lower income countries where the absence of specialist geriatricians, psychiatrists and neurologists make it a necessity; but who knows, this could now be a way to increase diagnostic capacity globally.

The delivery of support groups like memory cafés online has also been heartening to see. Further, it has reminded us of the many who do not yet have the access that makes it possible to join these activities. But these gatherings of carers and people with dementia have been a lifeline during this difficult period.

There we go: there have been some positive things coming out of this, but we owe it to the hundreds of thousands who have died not to let governments ever forget how unprepared they were to deal with their older populations.

In my lifetime I have learnt that memory of epochal events is short, but I think people will be remembering this for a longer time than usual. And if not, we are here to make sure these memories won't be forgotten because we need now more than ever to make sure we can use this example in our future advocacy. This must never happen again.



Paola Barbarino
Chief Executive Officer

Background and methodology

In May 2017, the World Health Organization (WHO) adopted the Global action plan on the public health response to dementia 2017–2025.¹

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 six-month scoping exercise in consultation with ADI members and other Alzheimer and dementia associations (including those on the Membership Development Programme) from January to June 2020.

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, consideration has been made to 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.

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.

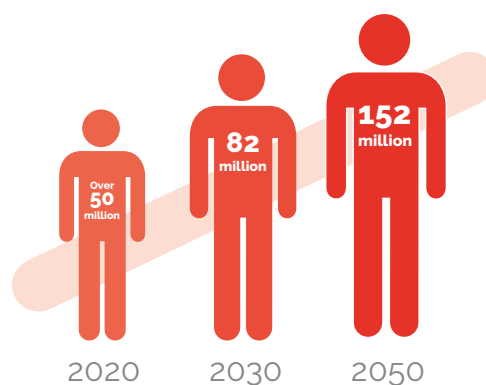
The governments of a small number of states, including some ADI members, that are not WHO member states, have developed or are in the process of developing responses on dementia, therefore are not included against the targets of the Global plan (See appendix B).

The report reflects current information provided by Alzheimer associations in each country, key stakeholders, researchers and policy makers. Data used in the report includes that collated and sourced from the WHO Global Dementia Observatory between December 2017 and May 2020, from desk research on non-dementia specific policies and other frameworks and additional communication with Alzheimer associations and civil society groups from January to June 2020. 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.

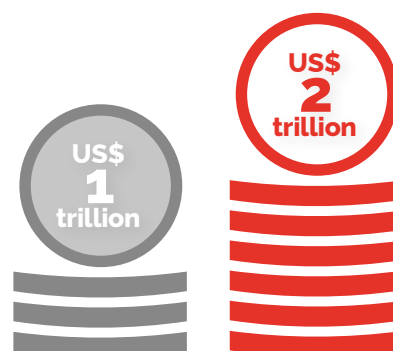
Due to the large number of external contributions to this report, some sections appear in first person, but mention of the author is made where appropriate.



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



Estimated growth in number of people with dementia 2020–2050



The total estimated annual worldwide cost of dementia in 2020 is over US\$1 trillion. This figure will rise to US\$ 2 trillion by 2030

7 action areas

1 Dementia as a public health priority



2 Dementia awareness and friendliness



3 Dementia risk reduction



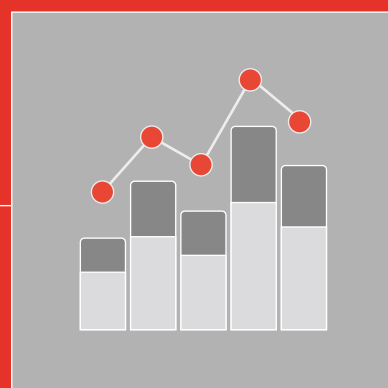
4 Diagnosis, treatment, care and support



5 Support for dementia carers



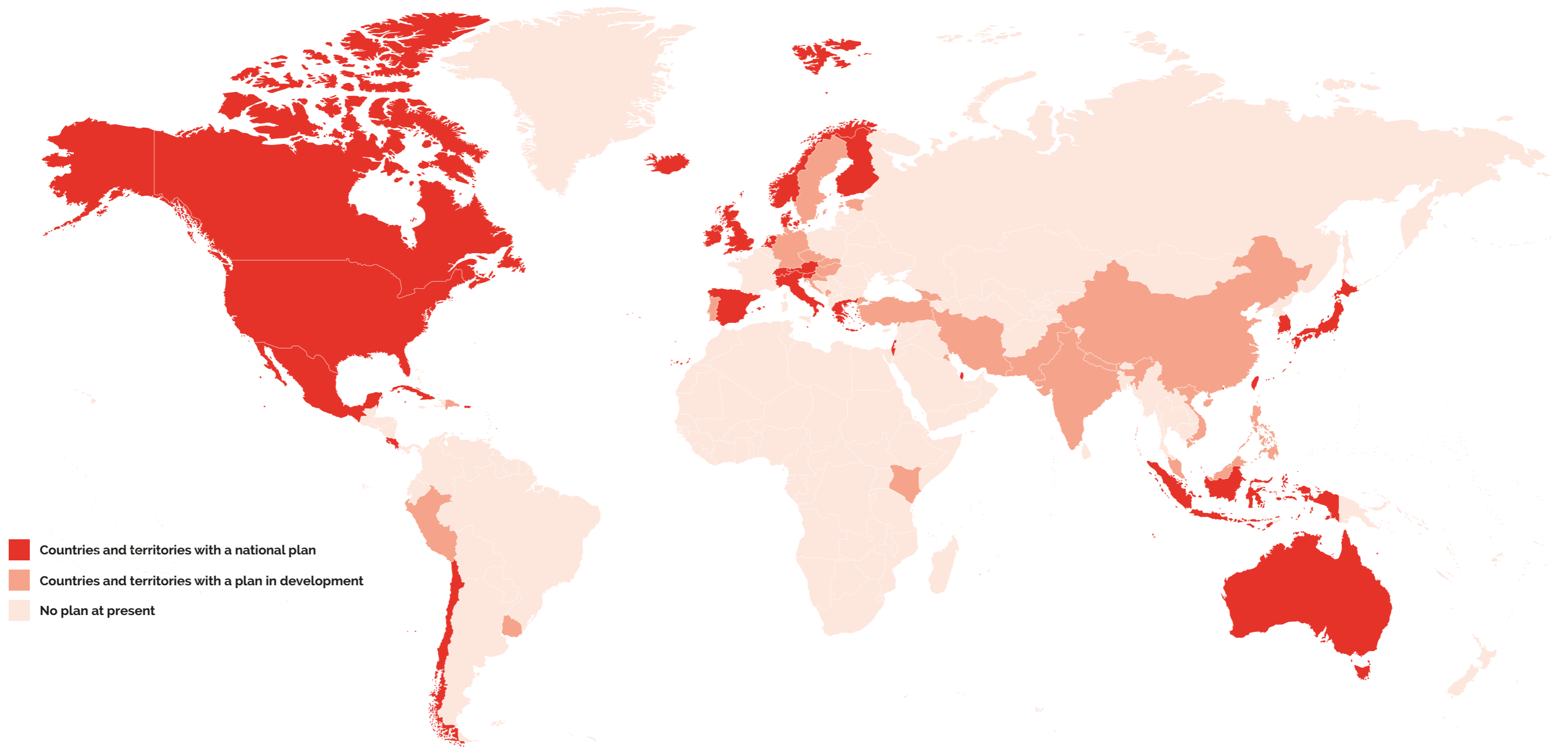
6 Information systems for dementia



7 Dementia research and innovation



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

Countries with national dementia plans in development					
Barbados	Cyprus	Germany	Kenya	Pakistan	Turkey
Brunei	Czech Republic	Hungary	Kuwait	Philippines	Uruguay
China	Dominican Republic	India	Malaysia	Portugal	Vietnam
Croatia	Estonia	Iran	Montenegro	Slovak Republic	
Curacao	Georgia	Jordan	Nepal	Sweden	



*These stage designations were retained from last year's report based on a consensus of ADI's members and other Alzheimer and dementia associations (including those on our Membership Development Programme).

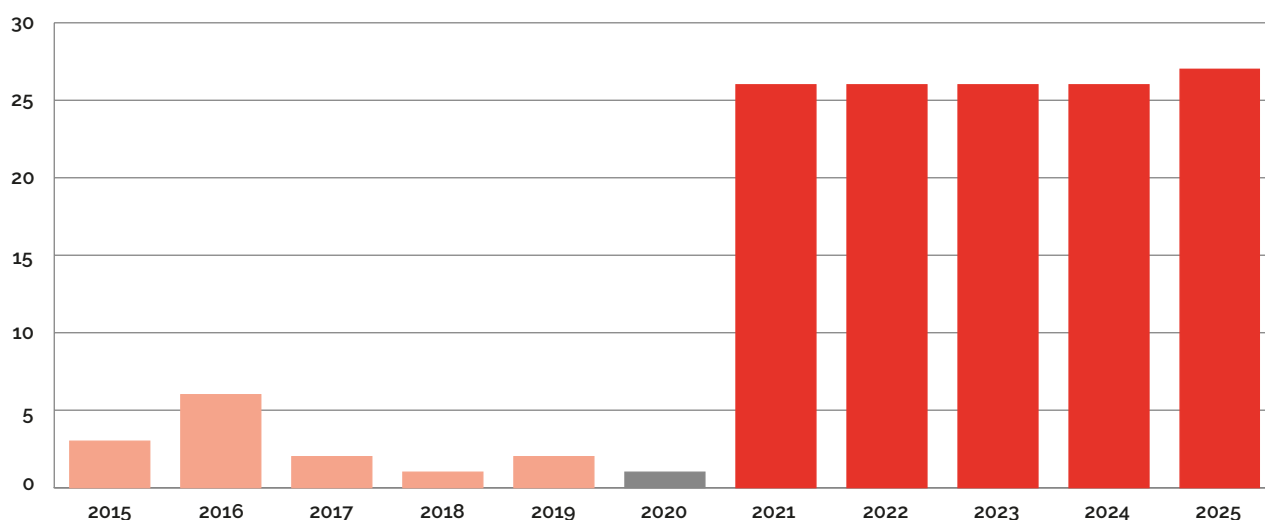
Chapter 1

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 26 new plans needed every year from 2020 to cover 75% of countries by 2025. This calculation is based on information available as of June 2020 and an assumption of no additional plans launching this calendar year – potentially influenced by the impact of COVID-19

The target of the first strategic area of the Global plan sets the stage for governments of 146 countries to act on dementia. Three years into the action plan, 31 plans have been adopted, including 27 WHO Member States – just 19 per cent of that target. 2020 marks the first interim review of the Global plan, and still far less than half of the 146 countries target has been met. There is still so much to be done to ensure the millions of people affected by dementia globally have access to adequate support and services, which centre their views and experiences.

We are now three years into plan implementation. The governments of Canada, Gibraltar and Spain are the only three to have released plans 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 and other partners, to uncover the ongoing challenges and barriers that persist globally. Throughout the report, we retain the five stages measurement of plan development from this report's previous edition, while recognising that this is an evolutionary measurement given the complexities and grey areas inherent in measurement of governmental policy.

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

ADI believes 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.²

A key advocacy priority is ensuring that plans are not only announced, but they are progressed into a fully implemented, funded, and monitored plan. 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 of other stakeholders in complementing these efforts. They require a strong long-term political commitment to dementia.

ADI believes 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.

Towards a dementia plan: a WHO guide



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. Now more than ever, during the global COVID-19 pandemic, it is clear that there are other competing and important priorities such as disaster recovery, infectious disease control and unfortunately conflict. ADI, our members, partners and the global dementia community must be mindful of this and be adaptable to meet changing policy landscapes. Innovative and solution-focused approaches are needed, as budgets are not limitless. For countries struggling to dedicate funds to start the development of a plan, we encourage decision and policy makers to assign a budget to action areas of the Global plan that are identified as being more achievable, for example national awareness raising campaigns.

Dementia as a public health priority

G20 dementia strategy: leading by example

Early in 2019, Chris Lynch, ADI's Deputy CEO and Director of Policy, Communications & Publications, joined Noriyo Washizu, Alzheimer's Association Japan (AAJ), with the aim to make dementia a G20 global health priority under Japan's presidency. Japan is the most aged country in the world and has been developing dementia care and policy for over 40 years, giving hope that this leadership could be shared globally.

Chris and Noriyo attended C20 planning sessions and the C20 Summit in Tokyo, plus cross parliamentary group meetings and a press conference in the build-up. This, alongside working with remote partners from NCD Alliance and HelpAge International, ensured that healthy ageing and dementia were explicitly recognised in the policy pack presented to Prime Minister Abe and in the G20 Summit declaration.

More important, however, was how to take this momentum forward to the G20 Health Ministers Meeting (HMM) in Okayama in October 2019. Through a series of letters to the G20 Ministers of Health, ADI specifically sought to have six key areas of the global dementia strategy given priority and leadership by the G20 in the meeting declaration. In the build-up to the HMM, CEO Paola Barbarino conducted a series of media interviews and cross parliamentary meetings in Japan. The culmination of the strategy was the specific inclusion of six dementia-related articles in the outcome document, with a specific focus on committing to the WHO Global action plan for the development of national dementia plans. In addition, there were a series of commitments to healthy ageing including a focus on disability and the UN Convention on the Rights of Persons with Disabilities (CRPD).³

"The immediate and long term impacts of COVID-19 on the health and well-being of people living with dementia need to be monitored, and we need to find ways to mitigate the added challenges facing this community caused by how we are trying to deal with COVID-19. To this effect, it is incumbent on our world leaders to prevent or reduce secondary negative impacts of this disease on access to, for example: routine health services, adequate nutrition, social services and support." **Princess Nouf bint Muhammad bin Abdullah Al-Saud, Chair of C20 2020**



Paola Barbarino (ADI) and Noriyo Washizu (Alzheimer's Association Japan) with members of The National Diet of Japan

With our partners, ADI's aim was to keep this impetus going with the changeover of G20 presidency from Japan to Saudi Arabia in 2020. Although ADI worked with the C20 team under the leadership of Princess Nouf bint Muhammad bin Abdullah Al-Saud, frustratingly, dementia and healthy ageing were not continued as priority areas in 2020. However, we engaged with the process through the C20 group and with our links at the G20 Health Development Partnership, with a specific focus on patient safety. The programme for the G20 in 2020 has rightly been revised to focus on the global COVID-19 response but because of the high risk and impact of the coronavirus on the ageing population, and by default on those living with dementia, especially in care environments, we are reassured that under the Italian presidency in 2021 healthy ageing and dementia will once again be a G20 priority and ADI has already had some initial engagement with the Sherpas for 2021.

ADI's member in Japan, AAJ, was instrumental in the process, as was Asociación Lucha contra el Mal de Alzheimer (ALMA), our member from Argentina, in passing the baton on from the 2018 presidency. AAJ continue to work across the country, with local and national governments and with other civil society organisations, towards Japan's dementia plan.



Noriyo Washizu (Alzheimer's Association Japan) with Her Highness Princess Nouf bint Muhammad bin Abdullah al-Saud at the handover of C20 from Japan to Saudi Arabia

Global awareness such as this is vital following the G8 dementia summit in 2013 and the launch of the Global plan in 2017.

CASE STUDY

Japan STAGE 5A

Japan has for decades been a pioneer in many areas surrounding dementia, including friendliness, risk reduction, health and social care, research, and innovation. They developed their first dementia plan. The Orange Plan was established in 2013, and the New Orange Plan was established in 2015. However, to meet the rapid increase in the number of people living with dementia and to meet all stakeholder

needs, the National Framework for Promotion of Dementia Policies (Cabinet decision) was announced in June 2019, and a new legislative bill for dementia has been submitted to the Diet.

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

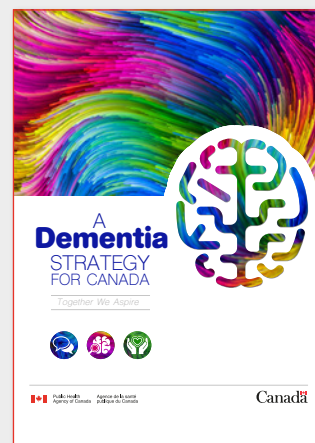
- Australia
- Austria
- Canada
- Chile
- Costa Rica
- Cuba
- Czech Republic
- Denmark
- Finland
- Greece
- Iceland
- Indonesia
- Israel
- Italy
- Japan
- Korea, Republic of
- Luxembourg
- Malta
- Mexico
- Netherlands
- Norway
- Qatar
- Singapore
- Slovenia
- Spain
- Switzerland
- UK
- USA

*See Appendix B for a full list of national plans or strategies not directly represented at WHO

CASE STUDY

Canada STAGE 4A

Canada's first national dementia strategy, A Dementia Strategy for Canada: Together We Aspire, was launched on June 17, 2019.⁴ The Government of Canada also committed funding of \$50 million over five years in Budget 2019 to support implementation of key elements in the strategy. The federal Minister of Health presented the First Annual Report to Parliament in June 2019, as required by the National Strategy for Alzheimer's Disease and Other Dementias Act. Most of Budget 2019 funding will be administered through the Dementia Strategic Fund (DSF) and focus on efforts to raise awareness of dementia. The Public Health Agency of Canada has invited interested stakeholders to submit applications for strategy-related activities.

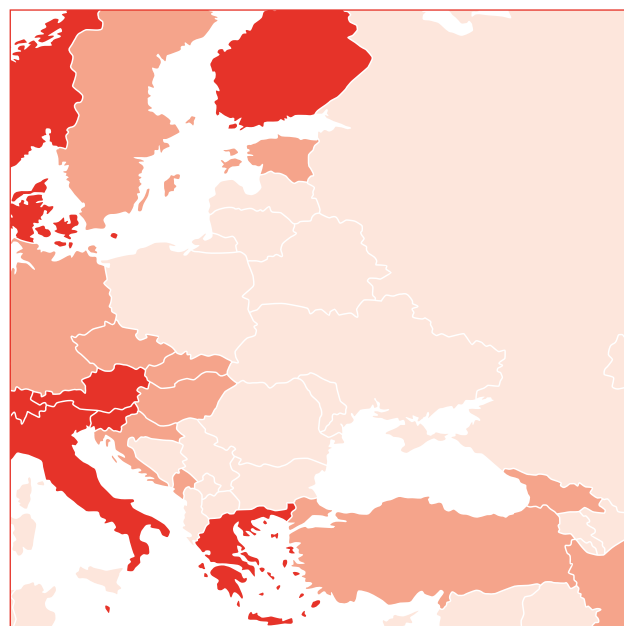


Spotlight on Eastern Europe

Eastern Europe represents an area of the map which has realised sporadic progress towards the WHO's Global action plan. Three plans or strategies exist in the Czech Republic, Slovenia, and Russia, but they are not without their challenges. In Slovenia, the Dementia Strategy Action Plan Working group was not able to conclude its work in due time and the goals set in the current strategy did not meet its targets. The current Slovenian Dementia Strategy will conclude this year, and work must be done to plug these gaps in the new strategy. In the Czech Republic, the National plan 2016–2019 has expired and there has been slow progress on the new plan. Russia has a national plan – but it has not been published or made publicly available.

Plans are in development in Croatia, Cyprus, Estonia, Georgia, Montenegro and the Slovak Republic, but in many of these countries there has been difficulty in maintaining the momentum needed to ensure dementia is high on the political agenda and receives funding. In Belarus, dementia, within the auspices of mental health, is not included in the mainstream State health program and there are currently no plans to develop a national dementia plan.

Several other Eastern European countries, including Bosnia and Herzegovina, Latvia, Lithuania, Poland and



Montenegro, have seen some progress towards a plan, but there needs to be a concerted focus by Eastern European states, with ageing societies, on providing long term care and support for their older populations, many of whom have NCDs like dementia.

Table of Eastern European countries and their plan stages

Country	Plan stage	Plan status
Belarus	STAGE 2	No plan/strategy
Bosnia and Herzegovina	STAGE 2	No plan/strategy
Croatia	STAGE 3A & 3B	"Strategy in development, commitment to funding for some of the 7 action areas"
Cyprus	STAGE 3B	Plan in development, good progress
Czech Republic	STAGE 3C	Plan 2016–2019 expired. Slow progress towards new plan
Estonia	STAGE 3A	"No plan, but commitment to funding for some of the 7 action areas"
Georgia	STAGE 3C	Plan in development, but slow progress
Latvia	STAGE 2A	Dementia grouped under Mental Health Care Developments plan 2019–2020
Lithuania	STAGE 2B	Initial meetings with government but no further progress
Montenegro	STAGE 3C	Plan in development, but slow progress
Poland	STAGE 2C	Some developments towards a plan, but progress stalled
Russian Federation	STAGE 2A	National plan, but it has not been published
Slovak Republic	STAGE 3C	Plan in development, but slow progress
Slovenia	STAGE 4D	Plan in development, but under threat

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

France STAGE 2A

Since 2014, in France, dementia has been grouped with neurodegenerative diseases in a 5-year plan. The "Plan maladies neurodégénératives 2014–2019" has now come to an end and its evaluation is expected soon. It may result in developments towards a standalone national dementia plan. France Alzheimer and other associations (Parkinson's and multiple sclerosis in

particular) have actively provided inputs into this process. Due to the impact of the current pandemic crisis on people with dementia and their families' wellbeing and healthcare pathway, the association is also strongly advocating to raise their voices and make sure their needs are taken into account in the current government's work to reform the healthcare system.

CASE STUDY

Kenya STAGE 2A and 3A

In Kenya, issues surrounding dementia cut across two departments: mental health and non-communicable diseases (NCDs). Currently dementia is included in the country's mental health plan. However, Alzheimer's & Dementia Organisation Kenya (ADOK) and the Kenya team of Strengthening responses to dementia in developing countries (STRIDE) have been working closely with the Ministry of Health to draft a national dementia action plan, which would be the first of its kind in Sub-Saharan Africa. The Ministry of Health has also dedicated a team to continue progress towards a national plan. The team is working towards organising an online meeting to get views from stakeholders.

Dementia is not given the attention it requires due to competing challenges. A Mental Health Taskforce has been set up by the Ministry of Health and a Memorandum of Understanding has been finalised with ADOK. ADOK has been given the opportunity to present their views on the draft strategy, including what they felt were the gaps not addressed.



Stakeholders including Alzheimer's & Dementia Organisation Kenya during their meeting with the Mental Health Taskforce on dementia

Securing sustainable funding for the plan will be a major barrier. ADOK is therefore working collaboratively with other civil society organisations to secure allies within the Ministry of Finance to ensure there is funding for dementia as budgets are being allocated. The WHO has also committed to fund the plan through the Ministry of Health. The Director of Mental Health has alluded to the fact that Kenya contributes to the Global Dementia Observatory and he has assigned a contact person on the issues of dementia who is working towards this.

CASE
STUDY

New Zealand STAGE 2C

In May 2020, Alzheimers New Zealand, along with the New Zealand Dementia Cooperative and Dementia New Zealand, released a Dementia Action Plan. The Plan, which involved the voices and input of over 300 individuals and groups, has now been shared with the Minister of Health and opposition politicians in the hope that it will be supported by Government following the upcoming General Election. This would be a huge step towards New Zealand adopting a national dementia plan, and shows the power of sector-wide collaboration in advocating for dementia policy.



Upcoming plans

The global COVID-19 pandemic has understandably impacted on developments towards national dementia plans. Below are some examples of plans which are expected to launch in the near future, 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

India STAGE 2B and 3A

Steady progress has been made in developing a national dementia plan for India, a country which has a population of over 1.3 billion.

The Alzheimer's and Related Disorders Society of India (ARDSI) developed a Dementia India Strategy document and handed it over to the Union Health Minister for adaptation. He promised to do so, however, due to elections and change of the Health Minister, no further progress was made. ARDSI has presented the document to the new Minister, Dr. Harsh Vardhan, and also held discussions with Ministry officials, who have asked ARDSI to present

a Project Implementation Plan for the diagnosis of dementia to be included as part of the District mental health programme under the National Health Mission. Letters have been sent to 15 state health mission heads, with a draft proposal seeking the establishment of memory clinics. The main challenge is that no concrete action has been taken despite lots of meetings and persuasion. There are many other programmes under which health related issues leading to dementia are addressed and which policy makers could cite them as provisions to be considered.

CASE STUDY

Bonaire STAGE 4

On 20 November 2019, the Commissioner of Public Health and Social Welfare issued a press release announcing that the Government was developing the National Dementia Plan for Bonaire. The plan will address risk factors; prevention and awareness; care facilities and informal care; nursing homes and day care; and care skills training. The document called for a 5-year implementation plan to be set up, now that sufficient data is collected and needs have been mapped.

Fundashon Alzheimer Bonaire's Board wrote to the Island Government of Bonaire asking about the next steps and establishment of an Implementation Committee for the plan. After some follow up from Fundashon Alzheimer Bonaire and ADI, the Island Council of Bonaire clarified that they have included the dementia plan in their 2020 programme and during the first quarter of 2020 the Public Health department head would approach Fundashon Alzheimer Bonaire to start with the next steps of the implementation of the Plan. There has been further communication in the meantime, and approval from the Public Health department is now pending for

Fundashon Alzheimer Bonaire to propose candidates for the Implementation Committee.

Once the COVID-19 pandemic is over, the development of this policy will provide crucial support to people living with dementia, their families and carers in Bonaire, and demonstrates how small island economies can take on the issue of dementia, which for them is as relevant as anywhere else.



Pictured from left to right: Commissioner of Public Health and Social affairs Mrs Nina den Heyer, Head Public Health Department, Mrs Alcira Janga-Jansen, Chair of Fundashon Alzheimer Bonaire, Mr. Evert L. Piar and Mrs Serodjenie van Rhijn-Nandoe, the writer of the Plan

CASE STUDY

Suriname STAGE 2B

Stichting Alzheimer en Overige Dementieën Suriname has been conducting stakeholder meetings to initiate the development of a national dementia plan. However, meetings planned for March 2020 have been cancelled, in large part due to the general election. Following the ADI regional meeting in Jamaica in 2019, the PAHO country office seemed very motivated to organise the stakeholder

meeting, although progress in this regard has been slow. The association continues to plan and seek collaborations with third parties in the hope that if the awareness in the country is increased the pressure on the government to act will become greater. ADI's engagement with the PAHO headquarters in Washington has resulted in greater attention and collaboration from the country office.

Responding to the challenges of COVID-19

CASE STUDY

China STAGE 3B

As the country first affected by the COVID-19 pandemic, many countries can learn from China's response. With respect to people living with dementia, ADI's member in China, Alzheimer's Disease Chinese (ADC), was quick to share the lessons learned from the initial outbreak period. Dr Huali Wang, Executive Vice President of ADC, prepared a presentation, based on her first-hand experiences of the challenges and responses to dementia care during the spread of the novel coronavirus.⁵ The presentation, which was widely shared by ADI, outlined best practice information around safety, management of Behavioural and Psychological Symptoms of Dementia (BPSD), Mental Health and Psychosocial Support (MHPSS), medication, carer support and stress management,

among other topics. The advice was tailored to people with dementia in hospitals, care homes and in assisted living facilities, as well as carers. ADC has since participated in ADI's public webinars⁶ and released several other supporting documents, including on China's Mental Health and Psychological Support for Older Adults during the Outbreak of COVID-19.⁷

China is the country experiencing the greatest overall increase in numbers of older people in the world, with the population aged 60 or above projected to reach 490 million by 2050.⁸ Dementia is integrated in a national health plan in China, but ADC has been actively advocating for China to have a separate policy document for dementia.

CASE STUDY

Iceland STAGE 5

Work towards establishing Iceland's national dementia strategy began in late 2018 and a draft was ready in mid-2019 following consultations with major stakeholders. In the midst of the global COVID-19 pandemic, on 8 April 2020, the Ministry of Health launched the national dementia strategy and action plan.

The plan establishes several important initiatives: dementia friendly societies; effective consultation with people with dementia and their carers; the role of the Icelandic Alzheimer Association in implementing the plan; and enshrining the right to timely diagnosis.

It has been heartening to see such huge commitment to developing effective dementia policy during a time of global crisis.



Minister of Health, Svandís Svavarsdóttir, who published the National Plan last April

Spain was hit hard by the COVID-19 outbreak, announcing a state of emergency in mid-March 2020. This resulted in the country's over 300 dementia associations being forced to cease their specialised services and support, resulting in many professionals temporarily losing their jobs and people living with dementia and their families being left without support. The Spanish Confederation of Alzheimer's and other Dementias (CEAFA) responded by establishing an official information access alert system, a dedicated COVID-19 website, and a resource for sharing knowledge and best practice.

In October 2019 the Spanish Ministry of Health, Consumption and Social Welfare adopted the National Alzheimer's Plan 2019–2023. The plan has four axes along which the actions of the plan are based: (1) sensitisation, awareness and transformation

of the environment; (2) the person at the centre of social and health care: prevention, diagnosis and treatment; (3) rights, ethics and dignity of the person; (4) and research, innovation and knowledge. A key focus of the plan is improving diagnostic capacities of the health system, which is crucial for improved access to services, and for reaching the WHO target of a diagnostic rate of 50 per cent of those affected. CEAFA will continue to work closely with the Ministry of Health, Consumption and Social Welfare, as well as the State Dementia Group and the General Secretariat of Health, to ensure the plan achieves its objectives and achieves real, measurable progress for those affected by dementia in Spain. Despite the plan being approved, funding for implementation of the plan is yet to be secured.



Photo credit: Wonsung Jang

CASE STUDY

Italy STAGE 4B

Italy has been one of the countries earliest and worst affected by COVID-19. Alzheimer Italia has increased its support services via their telephone helpline "Pronto Alzheimer" and online, producing a handbook of practical advice for carers to support them during periods of isolation at home with their loved ones.⁹ Italy was also one of the first countries to report the damaging effects of scarcity of healthcare resources resulting in triage protocols being used.

While Italy has had a national dementia plan since 2014, funding remains a challenge, as does the lack of participation of all regions in the dementia roundtable at the Ministry of Health. Together with ADI, in January 2020, Alzheimer Italia have been asked to give feedback and input on a Bill to protect carers.

What we have done and what we're doing

- our work is to **bringing together** news, resources, stories, advice and **support** for anyone affected by dementia around Italy. We gathered them in our FB page will be updated on a regular basis.
- Our **help line** is on available to support, encourage and help
- We have also shared nationally with the media, family caregivers, operators and on our Facebook page, a **handbook of practical advice** dedicated to the caregivers to help them better face the period at home with their loved ones.
- many of our **associations and Dementia friendly communities** have organized delivery of groceries and food, meals on wheels, small associations reactivated local helplines, gym classes online, towns that gathered around the most fragile people delivering medicines
- In this moment we are concerned about the possibility that in some **residential care unit** the necessary protection for people with dementia has not been guaranteed. For this reason we sent an institutional letter to our health minister and regional ones to rings the alarm about discriminatory practices in intensive care and to investigate in depth about residential care situation.

Mario Possenti, CEO of Alzheimer Italia, sharing their response to the COVID-19 pandemic on ADI's public webinar

CASE STUDY

Germany STAGE 3B

Progress towards Germany's national dementia plan has been ongoing since January 2019. Many stakeholders have been involved in the development of the plan, including the federal states and local governments, Deutsche Alzheimer Gesellschaft as patient organization, health and long-term care providers, public and private healthcare payers, and several research institutions.

The four main priorities of the plan include: building dementia-inclusive communities; improving support for people with dementia and carers; improving medical and long-term care for people with dementia; and promoting research and innovation.

The outbreak of the COVID-19 pandemic delayed the original schedule, but the federal government will continue to prioritise the implementation of a national strategy on dementia.

Index Finds Cities Play Essential Role in Promoting Innovation Readiness and Advancing National Progress on Dementia

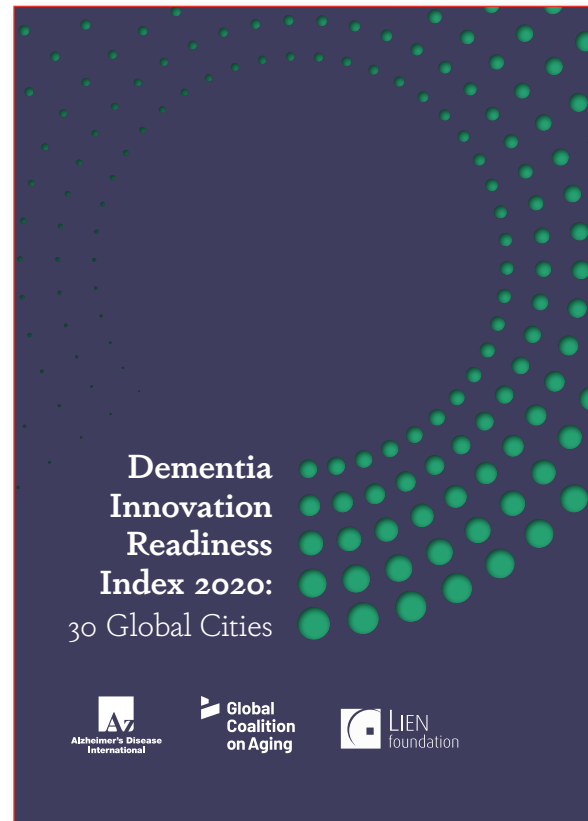
Cities play a critical role in preparing for innovations in the treatment, prevention and risk reduction, and care of dementia, as highlighted in a new report, *Dementia Innovation Readiness Index 2020: 30 Global Cities*. The report was developed in a partnership among the Global Coalition on Aging (GCOA), ADI, and the Lien Foundation, and it evaluates dementia innovation readiness in 30 cities around the world—from Singapore to London to Buenos Aires.

The Index is the third evaluation of dementia innovation readiness from GCOA and ADI and the first report of its kind to focus on the unique opportunities and challenges of dementia innovation in cities. Due to the global trends of ageing and urbanisation, cities are home to more than half of people aged 60+ worldwide – and growing. It's at this local level that national dementia plans are translated into everyday services and solutions, making the city a key focus point for effective strategies. Age- and dementia-friendly principles provide a starting point, but every city can do more to support people with dementia, their families, and communities.

To help inform leaders in cities around the world about opportunities to promote innovation readiness, the Index brings together insights from approximately 100 global experts and more than a thousand hours of research. Its key findings include:

- **Cities must be empowered and funded to enact local responses to dementia, with support from national and regional governments.** While national dementia policies can provide a framework and funding, cities have invaluable local expertise, networks, and services. Cities must ensure dementia efforts are tailored for the specific needs and opportunities of local communities, moving from high-level plan to real-world impact.
- **The local level is essential to early detection, post-diagnostic support, and community-based care.** Dementia support services are most effective when designed with a hyperlocal approach. Therefore, cities should organise, deploy, and ensure access to population-specific messaging, screening tools, post-diagnostic support, community-based care, and other resources that are most relevant and useful for its citizens.
- **Dementia associations, community organisations, and non-profits are key stakeholders for city responses to dementia.** These third-sector groups provide services to people with dementia, advocate for policy changes, and provide dementia training at the local level. City leaders should integrate them into dementia responses, turning to their established networks and expertise to elevate the success of dementia strategies.
- **Cities can cultivate innovation and new advances against dementia.** Cities are engines of innovation. Leaders can feed this innovation and direct it towards dementia with city-supported efforts like accelerators and incubators, mentorship programs, and knowledge-sharing resources and networks.

The full Index provides detailed findings across a number of dementia innovation categories, in-depth scores for each of the 30 cities, and promising practices from across the globe.



Chapter 2

Dementia awareness and friendliness



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

Increased awareness of the impact, symptoms and relevance of dementia is essential to provide a foundation for other targets of the Global plan to 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 workplaces, 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.

The World Alzheimer Report 2019¹⁰ revealed a startling lack of global knowledge around dementia. The report analysed results of the largest attitudes to dementia survey ever undertaken, with almost 70,000 people from 155 countries and territories completing the survey. The report revealed that two thirds of the general public still believe the disease is a normal part of ageing rather than a neurodegenerative disorder. Worryingly, this misinformation is evidently reinforced by the health system, with 62 per cent of healthcare practitioners sharing this view. Also concerning was the finding that 35 per cent of carers globally have hidden the diagnosis of a person with dementia. As illuminated in Chapter 5, carers must receive adequate services and support to enable them to carry out their caring responsibilities. Moreover, while 78 per cent of people are *concerned* about developing dementia at some point in their life, only 1 in 4 believe there is something you can do to prevent it. ADI will continue

to disseminate the growing body of research on risk reduction (See chapter 3) to ensure it reaches the public consciousness. The report establishes an important baseline from which future measurements of behavioural and attitudinal change can be drawn.

The survey findings are complemented by expert essays and case studies which contextualise the stigma and negative attitudes surrounding dementia. To quote one of the respondents living with dementia: *"Shunned by hundreds in my home town. People would sooner have stage 4 breast cancer than my diagnosis. [They] couldn't look me in the eye."* Quotes such as this are testament to the great amount of work which still needs to be done in this area. The consequences of stigma on individuals are complicated and can undermine participation in meaningful life activities and generally lower well-being and quality of life. At the societal level, structural stigma and discrimination can influence levels of funding allocated to care and support. One of the central recommendations of the report was targeted public health awareness campaigns, which is the subject of the remainder of this chapter.

Currently, all countries with national dementia plans run awareness campaigns. In addition, other governments have 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.



2 in 3 people still think that dementia is caused by normal ageing



62% of healthcare practitioners still believe that dementia is part of normal ageing



35% of carers globally have hidden the diagnosis of a person with dementia

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. The conference regularly attracts over 1,000 delegates and is unique for the broad global audience it commands among policy makers, leading academics and scientists, carers and care organisations, healthcare professionals, people living with dementia and their families.

Throughout the year, ADI publishes new information on dementia, hosts regional campaigns and 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.

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. ADI's Global Ambassador programme consists of three High profile ambassadors, Queen Silvia of Sweden, Queen Sofía of Spain and Luis Guillermo Solís Rivera, former President of Costa Rica. Such high-level support is crucial for ensuring the global transformation of awareness, science and care for the millions of people affected by dementia worldwide.

World Alzheimer's Month

Launched in 2012, World Alzheimer's Month is the international campaign led by ADI and Alzheimer and dementia 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, often marking the launch of a new World Alzheimer Report. Other examples of action from around the world include memory walks, the illuminating of famous landmarks and buildings, conferences and seminars, publications, campaigns and fundraisers.

World Alzheimer's Month is marked by associations and others in over 90 countries each year and provides a unique opportunity for governments, in partnership with these associations and people with dementia, to garner attention around dementia, contributing directly towards 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.¹¹

The 2020 campaign will focus on stigma, awareness and attitudes to dementia under the theme of "Let's Talk about Dementia" and will provide guidance on how to adapt the campaign in line with social distancing measures.

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 primary healthcare practitioners who have contact with people with dementia.

In 2019, ADI worked with the Pan American Health Organization (PAHO) to deliver a joint dementia

World Alzheimer's Month September 2019

Let's talk about dementia

#LetsTalkAboutDementia
#WorldAlzMonth @AlzDisInt
www.worldalzmonth.org

Alzheimer's Disease International
The global voice on dementia

World Alzheimer's Month septiembre 2019

Hablemos de demencia

#Hablemosdedemencia
#WorldAlzMonth @AlzDisInt
www.worldalzmonth.org

Alzheimer's Disease International
The global voice on dementia

World Alzheimer's Month Septembre 2019

Parlons de la démence

#Parlonsdeladémence
#WorldAlzMonth @AlzDisInt
www.worldalzmonth.org

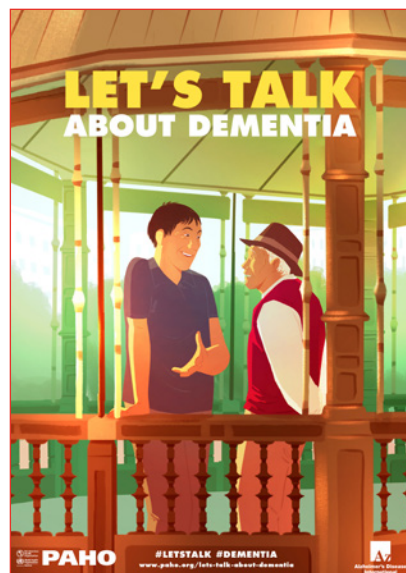
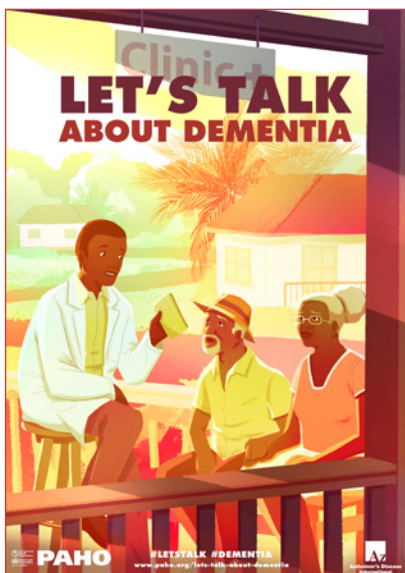
Alzheimer's Disease International
The global voice on dementia

Materials from World Alzheimer's Month 2019

awareness campaign for the Region of the Americas between September and November, coinciding with ADI's annual World Alzheimer's Month campaign. ADI and PAHO took this opportunity to work collaboratively during the final year of the PAHO regional plan of action on dementia (2015–2019). The campaign shared the tagline of World Alzheimer's Month, 'Let's talk about dementia', emphasising that talking about dementia helps tackle the stigma, normalises language and encourages people to find out more information, advice and seek help and support. A series of regionally-adapted graphics, interactives and other materials were developed in order to emphasise the importance of that often difficult 'first conversation' and the follow-on conversations between an individual, family members, friends and colleagues and extending to conversations

with health and care professionals. They were hosted on a dedicated campaign website.¹²

Different factors played a role in the success of this campaign, and can be reflected in the number of visits to the campaign site, as well as how often the materials were downloaded, the feedback that was received on the materials, the media attention and the social media use. Moreover, and in line with the regional collaboration between ADI and PAHO, the country level relations between the PAHO Country Offices and the Alzheimer's association stood out. However, measuring the impact of awareness campaigns is complex and requires strong indicators of behaviour change which can take time to diffuse.



Materials from the joint ADI-PAHO awareness raising campaign

CASE STUDY Dominican Republic STAGE 3B

ADI's regional awareness raising campaign for the Americas 'Let's talk about dementia', enabled Asociacion Dominicana de Alzheimer to foster closer relations with the Pan American Health Organization (PAHO) and the Ministry of Public Health. This has contributed to establishing the 'Plan de Respuesta a las Demencias en la Republica Dominicana 2020–2025'. The plan is still in development and was socialised among stakeholders in February 2020 by Asociacion Dominicana de Alzheimer, the Ministry of Health and PAHO.



A meeting between Asociacion Dominicana de Alzheimer, the Pan American Health Organization (PAHO) and the Ministry of Public Health

CASE STUDY

Puerto Rico STAGE 4B

Similarly to Asociación Dominicana de Alzheimer, excellent relations were established between Asociación de Alzheimer y Desórdenes Relacionados de Puerto Rico, the Ministry of Health, and PAHO as a result of the ADI/PAHO campaign. Although a national plan was established in 2015, this has never

been properly implemented. An interdisciplinary group, together with AARP (the American Association of Retired Persons), continues to work on this, and the association has been invited to participate.

Dementia Alliance International

Dementia Alliance International (DAI) is the global voice of dementia, their membership comprising exclusively of people with a medically confirmed diagnosis of dementia.

Although ADI and DAI, and many others, continue to work on claiming Human Rights for all people with dementia, since the World Health Organization's *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. Members are still being told to "get their end of lives in order", and are not well supported to live positively, nor provided with disability assessment or proactive post-diagnostic services such as rehabilitation.

Furthermore, even since the WHO risk reduction guidelines, which were launched last year, little attention has been given so far by governments or health care providers to promoting lifestyle factors such as improving diet and exercise, to improve quality of life, or even potentially reduce the speed of the progression of dementia. The ADI and Pan American Health Organization (PAHO) campaign in 2019 did focus attention on risk reduction but there needs to be equal emphasis on post-diagnostic risk reduction too. DAI therefore continues to implore governments and organisations to collaborate and co-operate with each other more, towards ensuring the rights of people with dementia are recognised. *"We ask that we all work towards these changes, to ensure they relate to real life support and services."*



Speakers at DAI's Side Event at the COSP on the CRPD in New York

DAI strongly stresses that dementia must be managed as a condition causing acquired disabilities, and not to do so ensures what the World Health Organization says, that *dementia is the leading cause of disability and dependence in older persons*. It is imperative we all work towards changing this and that people living with dementia are not only provided with equal access to universal health coverage, but equal access to post-diagnostic support that improves quality of life and wellbeing, and reduced dependence and disability, rather than a pathway that ensures it.

To further the work on claiming the rights of people with dementia, in June 2019, DAI hosted a Side Event at the Conference of State Parties on the Convention (COSP) on the Rights of Persons with Disabilities (CRPD) at the UN in New York. They focused on dementia as a disability, and it is the first time in the history of the COSP that dementia has been represented in a Side Event. DAI were delighted that Ms. Catalina Devandas Aguilar, UN Special Rapporteur on the rights of persons with disabilities, accepted their invitation to open the session. Read DAI's statements, and watch their Side Event, *Dementia: the leading cause of disability*, on their website.¹³

During World Alzheimer's Month in 2019, DAI once again highlighted a #HelloMyName¹⁴ is blog series. They continue to be informative and engaging, and always lead to other action, including dementia

consultants and service providers using them in some of their training. It often encourages them to invite people with dementia to participate in education sessions with staff as well, and by doing so, they ensure care staff and other health care professionals better understand the lived experiences of dementia. These stories bring hope to others facing dementia, they encourage others to live more positively, whilst still sharing the difficulties of a diagnosis. In sharing stories, DAI collectively provide each other with strength to face the unknown together and educate others about the realities of living with a diagnosis of any type of dementia – both positive and negative.

Dementia does not discriminate what age a person can be diagnosed, nor does it discriminate in terms of race, culture, career or socio-economic status. However, people with dementia are still being discriminated against, and experiencing isolation and stigma. DAI's members regularly report experiencing these and work hard to advocate for the much-needed change. Dementia changes lives, of that there is no doubt; people living with dementia now need people without dementia to ensure that at every single opportunity, there is nothing about us without us, so that one day, there will be a world full of compassion and a deeper understanding of the vast differences in the lived experience of everyone with dementia, and a world that is free from loneliness, isolation, stigma and discrimination.

Dementia Friendliness

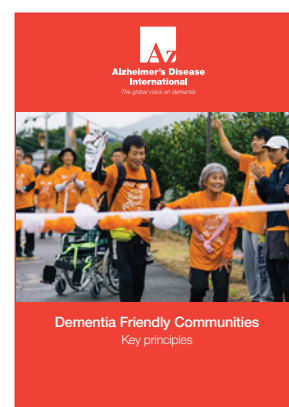
The concept of dementia friendliness has gained global prominence among consumers, policy makers and researchers over the past decade. These groups have demonstrated innovation in the many iterations of dementia friendly initiatives and communities across the world, from dementia friendly cafés in Europe and South America, to dementia friendly malls, businesses, cinemas and banks all over Asia and Europe, and even dementia friendly regions in Latin America. At its core, it holds the power to change the way we all think about living with dementia. It extends to areas such as language, improvements in social support, health and dementia services, and the physical environment.

The concept has two different, but complementary, objectives: Firstly, to reduce stigma and promote awareness (i.e. the lived experience); and secondly, to empower people living with dementia to take decisions about their own lives (i.e. the rights approach). ADI's Board Chair, Glenn Rees, has written and spoken extensively on the topic, including authoring ADI's 'The principles of dementia friendly communities' report and a piece with Dr Linda Barclay from Monash University in the World Alzheimer Report 2019.¹⁵ This latter piece provides a reconceptualization of dementia friendliness,

encouraging caution when considering how much awareness and dementia friendliness on their own can do to tackle stigma and how dementia advocacy can be part of the broader disability rights movement.

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.

COVID-19 has demonstrated again the importance of community networks. The voluntary effort in providing transport and food to older people stranded in their homes has been critical and possibly the difference between life and death. Continued advocacy for Action area 2 within the Global plan is critical to fostering inclusion of people with dementia.



Dementia Friends

Inspired by the models in Japan and the UK, there are now 67 Dementia Friends programmes launched or in development in 56 countriesⁱ and almost 19 million Dementia Friends worldwide (11 million of those in Japan). Dementia Friends aims to transform the way people think, act and talk about the condition. It is about learning more about dementia and the small ways that everyone can help. Dementia Friends 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. According to a survey by Alzheimer's Society, 83 per cent of countries reported feeling part of a global dementia-friendly movement and that they were benefitting from the experience of other countries.

Although we were informed that the Global Dementia Friends Programme developed by the UK Alzheimer's Society was no longer being supported, we are confident national programmes will continue to develop and strengthen.



Amigos na Demencia, Portugal

Are now working in partnership with shopping centres in Portugal. Inspired by the "in sickness and in health" vow, a campaign was launched with celebrities under the banner "Friends in Health and in Dementia" to support the Dementia Friends programme.

Dementie Vriendelijk, Netherlands

In 2019 more than 140,000 persons registered as a Dementia Friend of whom 56 per cent followed an online training. The program reached by the end of 2019 a total of 280,000 Dementia Friends (equal to the number of people living with dementia in the Netherlands) and therewith achieved almost their program goal of 310,000 Dementia Friends by the end of 2020. One of the highlights was a campaign with the Dutch railway (NS) and a bus company (Connexxion) that was launched by the Deputy Prime Minister and the CEOs of the companies and kicked-off in Utrecht's central station (200,000 daily-travellers). The campaign includes a campaign movie and stories from bus drivers and train conductors demonstrating that being dementia friendly is relevant for everyone.



In 2019 more than 140,000 persons registered as a Dementia Friend of whom 56% followed an online training.

ⁱ Note the difference in number of programmes vs countries is due to classifications of countries (UN Member State, yet a Member State may comprise of more than one country or territory).



Dementia Friends Mexico

The programme launched in 2019 exceeding expectations. In less than a year, 3,500 Dementia Friends were created. There has been a strong interest in the program by the medical sector. Rosa Farers president of FEDMA, said:

"The impact that the programme has had in young doctors has been very positive. It has not only allowed them to see the condition from a different perspective but has given them the tools to better engage with people with dementia and their families."

Dementia Friends Hong Kong

Public hospitals have been engaged in promoting dementia friendly communities by organising Dementia Friends Information Sessions for their staff members and setting up an exhibition to raise public awareness. The Hong Kong Alzheimer's Disease Association has worked with one local public hospital to deliver training for staff on the wards and modify the environment and functional designs of the geriatric ward as to cater the needs of patients living with dementia.



Dementia Friends Northern Ireland

Adults with learning disabilities across Belfast were keen to access information about dementia. Together with a Dementia Support Worker they have worked hard to set up an innovative, collaborative working partnership. Service users from four Day Centres across the Belfast Health & Social Care Trust have taken part in adapted Dementia Friendly Communities workshops; 68 adults with learning disabilities have attended Dementia Friends sessions for people with learning disabilities. They now have the skills and confidence to support those affected by dementia.

Not only have they become Dementia Friends but nine of them have also trained to become Dementia Friendly Communities (DFC) Champions and now deliver the sessions to their peers with learning disabilities.

Communities workshops; 68 adults with learning disabilities have attended Dementia Friends sessions for people with learning disabilities.

Dementia friends sessions for college students' and community members' in the USA

Provided by Dr. Tricia Cowan, Bemidji State University

A study in the USA examined whether Dementia Friends could affect attitudes toward people with dementia.¹⁶ Negative attitudes toward dementia can delay care and diagnosis and promote stigmatisation. This study used the Dementia Attitudes Scale¹⁷ to measure participants' attitudes toward dementia before and after participating in a one-hour Dementia Friends session. The scale measured attitudes through two distinct factors: dementia knowledge and social comfort. Participants included members from the community and college students. Of the 80 participants who completed a pre-test and post-test, overall scores indicated a statistically significant improvement in attitudes toward dementia after participating in a Dementia Friends session. Providing information about dementia, including early signs and symptoms, can increase knowledge and awareness. In this study, 79 per cent of the participants reported having experience with persons living with Alzheimer's disease or related dementias. Despite this majority, participants reported a statistically significant

increase in dementia knowledge after participating in a Dementia Friends session. Likewise, participants reported a statistically significant increase in social comfort around people living with dementia. Feeling more comfortable around people living with dementia can reduce stigma and foster friendly communities where positive attributes of people living with dementia are celebrated.

These findings suggest that participation in a Dementia Friends information session can positively affect participants' attitudes towards dementia. Dementia Friends can be offered to persons of all ages and in most settings and can be adapted to be culturally relevant for many populations. Further research with larger and more diverse samples using Dementia Friends as an intervention to affect attitudes toward dementia should be undertaken. As more communities across the globe implement interventions to raise awareness and foster dementia-friendly environments, government support and community partnerships are paramount. Research on the efficacy of interventions used is also vital.

Masahiko Yamamoto, Office Manager at Asahi Shimbun Social Welfare Organization in Osaka shared his views on The First Stirrings of a Dementia Friendly Community

The phrase "Building Dementia Friendly Communities" has often been used among welfare providers in Japan for at least the past 10 years. Indeed, this phrase has been in use in Japan earlier than in the United Kingdom, a nation that is known for its progress on Dementia Friendly Communities (DFCs). However, while advanced initiatives exist at the citizen and Non-profit Organisation (NPO) levels, initiatives that comprehensively involve the community have not made much progress in areas such as local government agencies, public transit, and commercial facilities. Various restrictions and "tate-wari," an old Japanese way of working that dictates how work progresses through rigid, vertical structures, can be said to be obstacles to the advancement of DFCs. However, the City Office in Machida City, Tokyo is showing leadership and advancing the development of communities that place the authority to make decisions on dementia-related measures into the hands of those affected by dementia.

Machida City is located in the suburbs of Tokyo and has a population of 430,000 people. 27 per cent of its citizens are elderly persons aged 65 or older, which is an average figure for Japan. The greatest feature of Machida City

No.	Statements	Public services
1	I received an early diagnosis and I have a reasonable degree of control over the treatment I receive and my life.	
2	I have a wide range of options for essential and/or necessary support that suit my needs.	
3	I am not forced to move to a hospital or a nursing-care facility. I know I have a choice of where and how I spend my last years and will pass peacefully away, being treated with dignity and respect.	
4	I have a general practitioner who listens attentively to me and thinks together about my concerns.	
5	I can express my true feelings to my family, and they understand and support me.	
6	My caretaker's role is respected and supported. Caretakers in my area receive proper aid from their local community that enhance the role of caretakers.	
7	I have friends with whom I can be myself, and I can enjoy my time with them and talk about my concerns openly.	
8	I continue to engage in my hobbies and activities I've been involved in for years.	
9	I have been committed to the development of my community by being proactively engaged in my favorite work and community services.	
10	I have opportunities to spontaneously learn about dementia and the life of people living with dementia.	
11	I am well informed about financial aid for people living with dementia and I understand that I'm financially covered.	
12	I have opportunities to share my experience on living with dementia and to make policy recommendations regarding living with dementia to my community and/or local government.	
13	I am not discriminated against or treated differently even though I am living with dementia.	
14	I can go anywhere I wish and enjoy shopping and dining out without having to worry.	
15	I can casually ask my neighbors for help when needed.	
16	I can say without hesitation "We are also members of the community that plan and make itself dementia-friendly."	

"I" in this set of the statements represents "I" as a person living with dementia and/or "I" as a person who may start living with dementia. The system statement regarding dementia friendly communities have been developed, defined and clarified based on the experience of people living with dementia and people who may start living with dementia. The statements have also reflected the thought of people in a community about their ideal dementia-friendly communities after they think what if they start living with dementia."

Figure 1: Dementia Friendly Community Vision and Public Services in Machida city



Figure 2: A "Living Together with Dementia Meeting" in Machida City

is the fact that its community development is being led by those living with dementia, and once a week, they gather to hold "Living Together with Dementia Meeting" meetings that are focused on decision-making (See figure 1). The members of these meetings discuss many things, including their personal experiences and feelings, as well as troubles they've encountered, and they also share knowledge and attitudes that help those with dementia live better lives. These meetings act as a space that allows people with dementia who have experienced the same difficulties to gather together and speak openly about what's on their minds.

A second great feature of Machida City is the fact that it fosters connections between those living with dementia and the local community. Beyond discussions in meetings, information related to these discussions are disseminated to the local community, and those living with dementia are engaged in work to broaden opportunities to contribute to the local community. Furthermore, the members of the Living Together with Dementia Persons meetings give lectures on dementia and talk about their personal experiences in after-school care programs as well as junior high and high schools. I would like to call attention to the day service managed by 44-year-old Takayuki Maeda. At his day service, people with dementia are paid to wash cars at car dealerships. They are paid several hundred yen per vehicle, but for those living with dementia, this also gives them an opportunity to work and is connected to their own self-confidence. Showing people in a positive form despite the fact that they are currently living with

dementia leads to the elimination of biases within the local community.

A third great feature of Machida City's future vision for community-development is that it has been created by people with dementia. They have created 16 statements that use "I" as their subject, such as "I received an early diagnosis and I have a reasonable degree of control over the treatment I receive and my life." These statements express a vision for the type of community that people living with dementia want to live in and is the result of many conversations over a six-month period that included the participation of people with dementia together with the City Office, local NPOs, and private companies (See figure 2).

Since 2004, once a year in Omuta City, Fukuoka Prefecture, a large-scale training exercise is conducted, and in this exercise, crowds of citizens participate in finding a person with dementia who is wandering about. A citizen plays the role of an elderly person who left their house and has gone missing, and the citizens participating in the exercise make efforts to disseminate information through phone, fax, as well as email, and to inform the elderly person's family of their whereabouts.

For the past few years, those living with dementia have actively made themselves heard, and they have been deeply involved in the development of dementia friendly communities as well as in decision-making on related measures. You might say that DFCs in Japan have finally begun to gain real traction.

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. They are cost-saving in the long-run.

The evidence base for risk reduction continues to expand. The WHO recently launched Guidelines on risk reduction of cognitive decline and dementia, which show that reducing modifiable risk factors could

reduce an individual's risk of developing dementia.¹⁸ Simultaneously, political support for risk reduction is slowly building, with the WHO expanding their framework for non-communicable disease (NCD) prevention and control to include dementia under mental and neurological conditions. However, findings from the World Alzheimer Report 2019 show that 75 per cent of people are unaware that they can do something to prevent dementia suggests that more needs to be done to communicate risk reduction messages to the public if national policies are to be effective.¹⁰

Professor Gill Livingston, Professor of Psychiatry of Older People at University College London (UCL) shared her views on the dementia prevention or risk reduction landscape

In many high income countries, like the US, UK and France, despite the overall increase in numbers of people with dementia, the age-specific incidence rates have come down in recent years suggesting the possibility of reducing the risk of dementia by targeting social, educational, economic and medical factors.¹⁹ In 2017 we launched 'The Lancet commission on dementia prevention, intervention and care'²⁰ and reported that up to a third of all dementias were potentially preventable if nine risk factors were eliminated at specific points in the lifecourse. These risks were less education, hypertension, hearing impairment, smoking, obesity, depression, lack of exercise, diabetes and lower social contact.

Although the report covered other areas, it was prevention which attracted attention, so much so that it was in the top 25 of the 2018 global Altmetric scores which indicates how often articles and other outputs are discussed around the world. This publicity, earlier work and other initiatives, contributed to a greater public and professional acceptance of the idea of using changes in lifestyle risk to prevent dementia. This is illustrated by findings that up to 2017, nearly half the

public thought dementia was inevitable and nothing could be done to reduce the risk²¹ but in 2019 this had reduced to around a quarter.¹⁰

Importantly, the vast majority of dementia research has taken place in high income countries (HICs), meaning worldwide studies inevitably have little low and middle income countries (LMIC) data, particularly from Africa and Latin America.²² The numbers of people with dementia in LMICs are rising faster than in HICs because of increases in life expectancy and greater risk factors.²³ We therefore used data from the 10/66 surveys²⁴ to calculate the potentially modifiable risk of dementia considering the same nine risk factors, finding it was 40 per cent in China, 41 per cent in India and 56 per cent in Latin America.²⁵ This suggests there is a greater potential for reducing the rates of dementia risks are even higher in LMICs than in HICs, so the need for action is even greater.

There is little randomised controlled trial (RCT) evidence for interventions to prevent dementia, partly because some interventions are difficult to randomise

(for example, new evidence shows that midlife social contact and marriage appears protective against dementia but increasing these through randomisation is impractical)^{26,27} and because of the long follow-up period required. The World Health Organisation's guidelines for interventions to prevent dementia are mainly based on their general health benefits rather than RCTs showing prevention of or delay in dementia.¹⁸

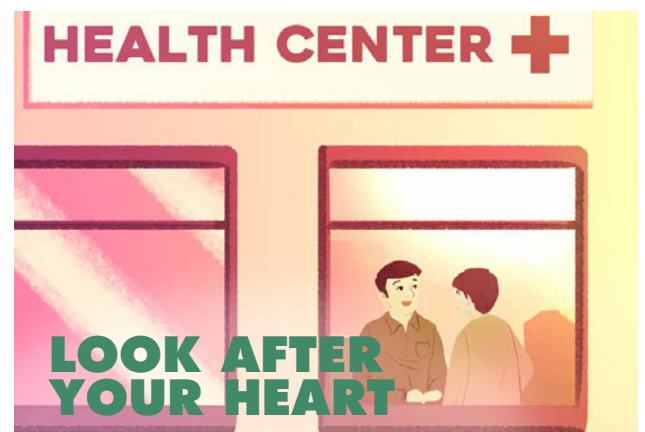
RCTs can theoretically be used for hypertension treatment, although the control group may do notably worse than the intervention group so the trial has to stop.²⁸ In SPRINT MIND, the intensive intervention group aimed for a systolic BP<120mmHG, compared to standard treatment of <140mmHG. Cognitive assessment two years after stopping the trial, found those in the intensive intervention group had a reduced risk of MCI and dementia.²⁹ A recent meta-analysis found there was no consistent difference between classes of anti-hypertensive drug for the effect on dementia;³⁰ however, risk lowers more when there was a larger systolic pressure differential between the intervention and control group.³¹

The FINGER trial of multimodal interventions to prevent cognitive impairment had statistically significant but small effect and the effects of worldwide FINGERS

are awaited. The 'healthy ageing through internet counselling in the elderly' (HATICE) study for vascular risk, compared an interactive internet platform plus remote support by a coach, with basic health information and found slightly lower risk of future dementia in the intervention group, with a larger effect in high-risk populations.^{32,33}

In summary, the dementia risk reduction landscape continues to find more evidence about the same and further potentially reversible risk factors that are related to the incidence of dementia. Observational studies suggest that changing these can reduce dementia but there is little RCT evidence, except for hypertension. Current reduction in risk has been in high income countries and those with more socioeconomic advantage. In the future, targeting high risk populations, with potential to make more difference, should be the priority.

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 graphics developed as part of the ADI-PAHO awareness raising campaign.

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

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 per cent 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.

Reduce your risk



Follow a healthy diet



Be physically active



Look after your heart



Challenge your brain



Enjoy social activity

SINGER study: an update from Dr Christopher Chen, Director of the Memory Ageing and Cognition Centre, National University Health System, Singapore

The multifactorial and heterogeneous nature of late-onset dementia suggests that multidomain lifestyle interventions could reduce worldwide burden. Positive results from the landmark Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER) support such an approach.

Hence, World-Wide FINGERS (WW-FINGERS) was launched in 2017 and currently includes over 20 countries in the first global network of multidomain lifestyle intervention trials for dementia risk reduction and prevention. WW-FINGERS aims to adapt, test and optimize the FINGER model to reduce risk across the spectrum of cognitive decline – from at-risk asymptomatic states to early-symptomatic stages, in different geographical, cultural and economic settings. WW-FINGERS aims to harmonize and adapt multidomain interventions across various countries and settings, facilitate data sharing and analysis across studies, and promote international joint-initiatives

Singapore differs in many respects from Finland; hence it was felt that adaptations might be needed to ensure acceptance of and adherence to interventions, as well as assessments that are appropriate in terms of language, ethnicity, culture, environment, and risk of dementia.

to identify globally implementable and effective preventive strategies. The aim is not to replicate FINGER, but rather to adapt and optimize so as to test whether the FINGER-based protocols are feasible and effective in various populations. 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.

Singapore differs in many respects from Finland; hence it was felt that adaptations might be needed to ensure acceptance of and adherence to interventions, as well as assessments that are appropriate in terms of language, ethnicity, culture, environment, and risk of dementia.

The SINGapore GERiatric intervention study to reduce physical frailty and cognitive decline (SINGER) is presently in its pilot phase, aiming to evaluate culturally appropriate adaptations of the FINGER interventions, and the feasibility of implementing this protocol in 70 seniors, aged >65 years, with mild-to-moderate frailty and/or cognitive impairment over a 6-month period. The main outcome of this pilot study is the feasibility of and adherence to the multidomain intervention as concerns have been raised particularly for the dietary and cognitive interventions which could require novel and culturally appropriate approaches. We aim to develop scalable digital platforms and build partnerships so as to conduct a larger definitive study in 1,200 elderly community dwelling Singaporeans who are at risk for cognitive impairment and dementia. This larger study comparing self-guided lifestyle management versus a structured multidomain lifestyle intervention will also incorporate neuroimaging and blood biomarkers so as to investigate mechanisms of action.

PREVENT study: an update from Professor Craig Ritchie and Graciela Muniz Terrera from the University of Edinburgh

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.³⁴

PREVENT Dementia Global (PDG) studies is a network of studies set up in low- and middle-income countries (LMIC)ⁱⁱ 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.³⁵

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 with 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.

Examples of PDG studies include, amongst others, initiatives in Uruguay and India. For example, the study in Uruguay, a South American country of about 3.4 million individuals with almost 15 per cent of its population aged 65 years and older, involves the deployment of a questionnaire about individuals' lifestyle preferences and capacity to adopt risk reducing lifestyle behaviours via a digital platform that is used by over 250,000 retired individuals in the country. It further involves testing

cognition remotely using the digital platform, which will facilitate the validation of the digital cognitive battery in the local population and the validation of remote testing as a mean to study the wider population. Additionally, the recently developed electronic medical history database will be used to link medical history data with results collected remotely via the digital platform to further questions about brain health and its risk factors in the population of older adults of this small country in South America.

PREVENT Dementia Global (PDG) studies is a network of studies set up in low- and middle-income countries (LMIC) that follow a design similar to PREVENT Dementia's.

In India, Prof. Vijayalakshmi Ravindranath from the Centre for Brain Research established a longitudinal study of individuals living in urban and rural areas of the country. This study is semi harmonized with the Prevent Dementia study in Scotland, and used the same battery used in PREVENT, Cognito³⁶, to test participants' cognitive functioning.

The harmonized design of these two studies represents a unique opportunity to test and compare the robustness of findings generated studying the Indian and Scottish populations to differences in life course and context. Importantly, this PDG collaboration creates opportunities for the generation of new hypotheses about the impact of context and lifestyle on mechanisms associated with poor brain health and pathological developments.

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 may only have access to limited resources. Moreover, government-backed initiatives like Brain Health Scotland, which will deliver rapid implementation of research into clinical practice and public health policy can be used as exemplars both for higher as well as low- and middle- income countries as they (as is the case with Brain Health Scotland) are predicated on equity of access to assessments and interventions.

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

WHO risk reduction guidelines

Following the development of the World Health Organization (WHO) Guidelines on risk reduction of cognitive decline and dementia³⁷ in 2019, WHO's focus has been on working with countries to develop and implement risk reduction interventions at the national level. One such effort is the recent national workshop organized by the State of Qatar in Doha on 23–24 February 2020. In 2018, the State of Qatar launched the Qatar National Dementia Plan,³⁸ marking dementia as a public health priority and representing one of the first dementia plans launched in WHO's Eastern Mediterranean Region (EMRO). The workshop held by the State of Qatar in February 2020 aimed to catalyze the implementation of the Qatar National Dementia Plan. It brought together a diverse group of national stakeholders, including health care professionals, members of academia, government representatives and carers of people with dementia, as well as international experts to discuss the implementation of the Qatar National Dementia Plan. Workshop discussions focused on three key topics: (i) risk reduction; (ii) research and innovation; and (iii) carer support.

During this two-day workshop, international experts and WHO representatives presented tools and evidence that could be used at a national level to help reduce the risk of dementia. More specifically, risk reduction sessions focused on integrating dementia risk reduction into national noncommunicable disease (NCD) programmes and implementing evidence-based risk reduction interventions. To address these topics, WHO provided support in facilitating small group discussions to identify strategies to (i) integrate dementia into existing risk reduction programmes for other NCDs and existing care pathways, (ii) build capacity to implement programme-level integration and better identify people at risk of dementia, and (iv) map evidence gaps and generate information required to effectively develop, implement and evaluate dementia risk reduction interventions.

RISK REDUCTION OF COGNITIVE DECLINE AND DEMENTIA

WHO GUIDELINES



Moving forward, WHO will continue to work with countries, international experts, civil society, academics, people with dementia and their carers, and other stakeholders to identify ongoing needs and tailor support at a country- and regional-level. Novel strategies for implementation include for example digital technology solutions.

In November 2019, the Norwegian government launched a strategy designed specifically to combat non-communicable diseases (NCDs) in low-income countries. The strategy is the first of its kind and is accompanied by dedicated funding of 200 million Norwegian Kroner (US\$21.9 million).³⁹

Nasjonalforeningen for folkehelsen (Norwegian Health Association) was one of the stakeholders consulted in the development of the strategy. Dementia was not explicitly mentioned in the document. It is common in Norway to have many national plans for different disease areas, and the government has committed to risk reduction and prevention as a crucial part of the public health strategy and the upcoming national dementia plan.

In May 2018, the Norwegian Minister for Children, the Elderly and Gender Equality, announced the Government's decision to launch a new national dementia strategy for Norway 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 Norwegian National Board of Health and Welfare until 2022. When the plan is finished it should be presented to the current Norwegian Government and then rolled out across the country.

Nasjonalforeningen for folkehelsen (Norwegian Health Association) met with the Minister for Ageing and Public Health in September 2019 to discuss the

new dementia plan and its overall goal. They looked to the WHO's Global Action Plan for inspiration for topics and launched some new initiatives to support people with dementia in the workplace, diversity, and dementia-friendly hospitals. After this meeting, the government decided to engage with and involve the user representatives to give inputs to the new dementia plan. In November 2019, the Minister met with their working group and standing committee for dementia and further meetings happened in January 2020.

In March 2020 the Minister of Health (who took over the policy areas of Ageing and Public Health) along with other representatives from the Ministry of Health and Care Services met people with dementia from different geographical areas facilitated by Nasjonalforeningen for folkehelsen (Norwegian Health Association). People with dementia and their carers gave their input to the policymakers about the importance of receiving a diagnosis, the importance of follow-up after the diagnostic work-up and being able to maintain an active work-life.

Nasjonalforeningen for folkehelsen (Norwegian Health Association) was invited to write and have submitted one of the chapters for the new dementia plan. The fourth Norwegian dementia plan will be launched in October 2020 together with the national budget.

Former Minister for Ageing and Public Health, Sylvi Listhaug at the office of Nasjonalforeningen for folkehelsen to meet with people with dementia and carers to give input to the new dementia plan



CASE
STUDY

Vietnam STAGE 3B

Several activities have been conducted with the support of the Australian and Vietnamese Governments through a joint NHMRC-NAFOSTED funded project towards developing a national dementia plan for Vietnam (APP1154644).

The General Department of Preventive Medicine (GDPM), Ministry of Health of Vietnam called a meeting with the Therapeutic Service Administration and two leading mental health and aged care providers to discuss the inclusion of dementia into the Ministry's working agenda. The GDPM subsequently submitted to the Minister of Health a proposal to develop and implement a national action plan for the period 2021–2025 that integrates dementia, mental health disorders and non-communicable diseases (NCDs). ADI and the WHO have also provided technical assistance and support.

The national action plan of dementia, mental health and NCDs is in development and will be endorsed by the Vietnamese Government by the end of 2020.

Inter-generational Self Help Club program supported by HelpAge in Vietnam

The Vietnam Association of the Elderly has nearly 100,000 branches with about 8.3 million members across the country.⁴¹ Supported by HelpAge Vietnam, more than 1700 of these branches have evolved into Inter-Generational Self-Help Clubs (ISHC) that provide programs for microcredit, livelihoods, health promotion, and elderly rights to their members.⁴² Given the lack of current social care and support specific for dementia in Vietnam, with the facilitation by ADI Asia Pacific, inclusion of dementia as a sub-content of the Inter-generation Self Help Clubs' program is currently in discussion with HelpAge Vietnam.



Discussion with key national dementia stakeholders

To allow for a more harmonized response across the health sector, given the shared risk factor profile and more effective use of limited resources, an integrated national action plan for dementia and NCDs is sensible. However, the NHMRC-NAFOSTED project team is cognisant of the potential for fragmentation and lack of dedicated resources being allocated to dementia, and will continue to work with the government to ensure dementia receives due attention.⁴⁰



Discussion with HelpAge Vietnam to include dementia into their Inter-generation Self Help Clubs' program

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 a formal diagnosis of dementia is both a fundamental right and crucial first step towards receiving treatment, care and support. 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.⁴³

ADI's report Dementia in sub Saharan Africa noted a complete absence of any equivalent word for 'dementia' in several countries.⁴³ Without the necessary language, diagnosis cannot be sought. With a diagnosis, dementia becomes visible, adding to understanding and eventually acceptance of the condition.

Achieving a diagnostic rate of 50 per cent of those affected in both LMIC and HIC is an ambitious target that will require a combination of significant investments 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 when 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.^{44,45} A recent study presented strong evidence that blood phosphorylated tau 181 may be a promising biomarker for Alzheimer's disease,⁴⁶ but we are still some way from a simple, practical and scalable test.

"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 64). Of the data currently available online from the Observatory, only three countries out of 21 pilot Member States have provided any data on diagnostic rates or other indicators.

An OECD report on care revealed that diagnosis actions and targets are present in just a little over half of countries where plans have been adopted.⁴⁷ However, countries must heighten the prioritization and tracking of diagnosis in dementia in their national plans and other policies.

It is only through diagnosis that governments can set out robust post diagnostic support, working with partners in health and care, civil society and in the private sector to enable people living with dementia to live as well as possible for as long as possible, and to facilitate remaining at home and in the community for as long as possible. Diagnosis, alongside a treatment, when the breakthroughs do come, also helps to tackle the still major issue of stigma surrounding dementia, including in healthcare practitioners (HCP) as evidenced in ADI's World Alzheimer Report 2019, which found that 62 per cent of HCPs still believe that dementia is a natural part of ageing.

Diagnosis, treatment, care and support during COVID-19

Older people, especially those living with dementia, are especially vulnerable during the COVID-19 pandemic. People living with dementia are largely in the age group most likely to suffer from severe symptoms of COVID-19; face difficult decisions around healthcare treatments and hospital admissions; and especially in lockdown or quarantine, may become more anxious, stressed, and withdrawn during the outbreak. However, coverage and attention around dementia has been largely excluded from the main cited non-communicable diseases (NCDs) or "underlying conditions" in initial data and research findings, despite the fact that the behavioural or emotional symptoms experienced by people living with dementia are directly impacted by the outbreak, with potentially serious implications.

Age is the biggest risk factor for both COVID-19 and dementia.

The COVID-19 pandemic has highlighted another global crisis: care. In many countries, problems surrounding a lack of funding, training and resources in care environments, and a growing demand for care, have been exacerbated by this global infectious disease outbreak.

COVID-19 has sadly highlighted the degree of ageism which still permeates many countries' social structures and institutions. One of the biggest challenges for governments has been responding to the spread of the virus in long term care settings such as care homes. In many places care homes have become hot spots for the spread of the virus, even where lockdowns have been enforced, and this is complicated by a number of factors like the difficulty of enforcing social distancing; access to personal protective equipment (PPE); the use of agency staff, for example when regular staff have tested positive; and the prevalence of other NCDs.

In several European countries in particular, the failure of governments to place adequate emphasis on proactively addressing the spread of the virus in care home facilities at the outset of the outbreak (by lockdown, securing adequate PPE, and testing residents coming from hospitals), has resulted in disproportionate

COVID-19-related mortality in long-term care facilities. There was a general focus on patients coming into intensive care and concerning reports in Italy of care homes being paid to move non-critical COVID-19 patients into their facilities.⁴⁸

Moreover, countries including the UK, Italy, France and Spain, did not initially release data on COVID-19-related mortality in care homes, despite the rates being proportionally higher than the general population. This is largely due to a lack of testing, making it difficult to determine cause of death; it is hard to differentiate in care homes between people who have pneumonia because they have pneumonia and those who have pneumonia as a result of COVID-19.

Researchers based at the London School of Economics (LSE) created the Long-Term Care responses to COVID-19 (LTCcovid) group, which has published data, revealing that more than half of all coronavirus deaths in these countries were among care home residents.⁴⁹

Conversely, many Asian countries, heeding lessons from the SARS (severe acute respiratory syndrome) pandemic, made more concerted efforts to ensure COVID-19 did not disproportionately affect care homes, promptly locking down care homes, providing PPE and introducing widespread testing.⁴⁸

In view of the widespread global shortages of medical resources, especially ventilators, it is vital that healthcare professionals have clear guidelines to facilitate extremely difficult decision making – often in pressurised triage situations – about access to treatment. Decisions should not be made based purely on age or the existence of a condition like dementia, which would be in violation of that individual's human rights. Issues relating to under-resourcing and unpreparedness of health systems, highlighted and exacerbated by the current crisis, have provided concrete lessons which we *must* heed.

The prevalence of non-communicable diseases (NCDs) including mental health conditions, stroke and cardio-vascular disease, is likely to increase as a result of COVID-19. We are yet to see the immediate impact on dementia, with fears that the pandemic will have interrupted the diagnosis pathway for many and we are only just starting to see data about death rates associated to people with dementia. The chronic underfunding of NCDs (currently around 3 per cent of all global health funding yet accountable for a majority of morbidity and mortality) is leading to infrastructural inadequacies that will lead to health systems collapsing – as has been the case in Italy, Spain and now the USA – in the face of large disease outbreaks. People living

with NCDs must be given commensurate funding and support services to manage their conditions.

The COVID-19 pandemic has highlighted a critical need for innovation in the provision of dementia care at all levels of health and social care systems globally – from primary care doctors and nurses, neurologists and other specialists, to both formal and informal carers – to join the field of ageing and geriatrics in response to growing need. It is imperative that governments recognise the need to integrate and coordinate health and long-term care and to fund both equally.

International human rights instruments specifically supporting the rights of older persons must be developed and adequately enforced at the national level. Existing instruments do not adequately support people against age discrimination, especially given that less than 1 per cent of Human Rights Treaty Bodies show recommendations for older persons.⁵⁰

A research report by ADI, GADAA and Alzheimer's Pakistan highlighted the additional challenges posed by humanitarian emergencies on people with dementia. It also showed the challenges that barriers such as stigma and poor access to social and health care systems pose even at times of peace, and these challenges are exacerbated when the existing health systems or social networks relied upon breakdown, disproportionately affecting those with poor access to these structures in the first place.⁵¹

The WHO's Global action plan, which was unanimously adopted by all 194 Member States, includes a commitment to planning for humanitarian emergencies which considered individual support for people with dementia and community psychosocial support. ADI calls on all governments to include dementia in their COVID-19 response plans.

Adelina Comas-Herrera, Assistant Professorial Research Fellow at the Care Policy and Evaluation Centre (CPEC) at the London School of Economics and Political Science (LSE), and founder of LTCcovid said:

"LTCcovid was established to collect resources and evidence to inform policy and practice measures to COVID-19 in long-term care systems. It helped open up a discussion with the media and governments around the initial shortcomings of the response to COVID-19 in many countries. It took months before we had any data on COVID-related-deaths in long-term care facilities, but we were hearing reports from the media of terrible situations and high numbers of deaths. In many countries care homes were not a high priority in the response to the pandemic, in fact, very few countries prioritised testing or access to PPE in such facilities until quite late. But there are some exceptions – particularly in Asia – where they had dealt with SARS and MERS and where some tough lessons had been

learned. It is crucial that we have strong data on the people who rely on long-term care, so we can include them in epidemiological models, and that we collect data on the impact of COVID in this population so that we can allocate the right resources to the right places.

So far, the only information we have about the impact on people living in care homes is the number of deaths, but of course there are other impacts of the lockdown measures, such as the psychological and physical impact of people with dementia being locked in their room and of disruptions of access to care for other health conditions. This is something we need to collect data on."

"It is crucial that we have strong data on the people who rely on long-term care, so we can include them in epidemiological models, and that we collect data on the impact of COVID in this population so that we can allocate the right resources to the right places." *Adelina Comas-Herrera*

Does COVID-19 risk derailing progress on dementia and NCDs? A view from NCD Alliance

The COVID-19 pandemic illustrates in many ways the advocacy demands of the noncommunicable disease (NCD) community over recent years. Our calls to action in the lead up to the UN High Level Meetings (HLM), on NCDs in 2018 and on Universal Health Coverage (UHC) in 2019, are well embedded in the Political Declarations signed by Heads of State and Government. But there are critical gaps between global commitments and real-world action to roll out policies and investment for NCD prevention and treatment, including for dementia and mental health. This lack of action may now be coming to haunt policymakers charged with responding to the pandemic.

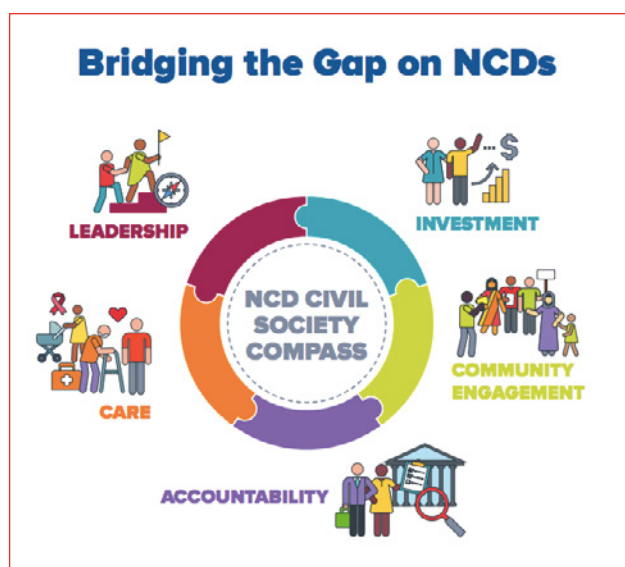


Figure 3: NCD Alliance Bridging the Gap on NCDs From global promises to local progress (2020)⁵²

Research has shown that people living with NCDs (PLWNCDs) are at an increased risk of severe complications and death due to COVID-19.⁵³ While all age groups are at risk of contracting COVID-19, older people face a significant risk of developing severe illness due to the physiological changes that come with ageing, which are compounded by NCDs. In addition, emerging evidence indicates that severe COVID-19 may also cause life-threatening or long-lasting impacts, such as cardiac injury, acute kidney disease, neurological disorders, blood clots, and damage to liver and intestinal function.^{54,55,56,57} In addition, there is the toll on mental

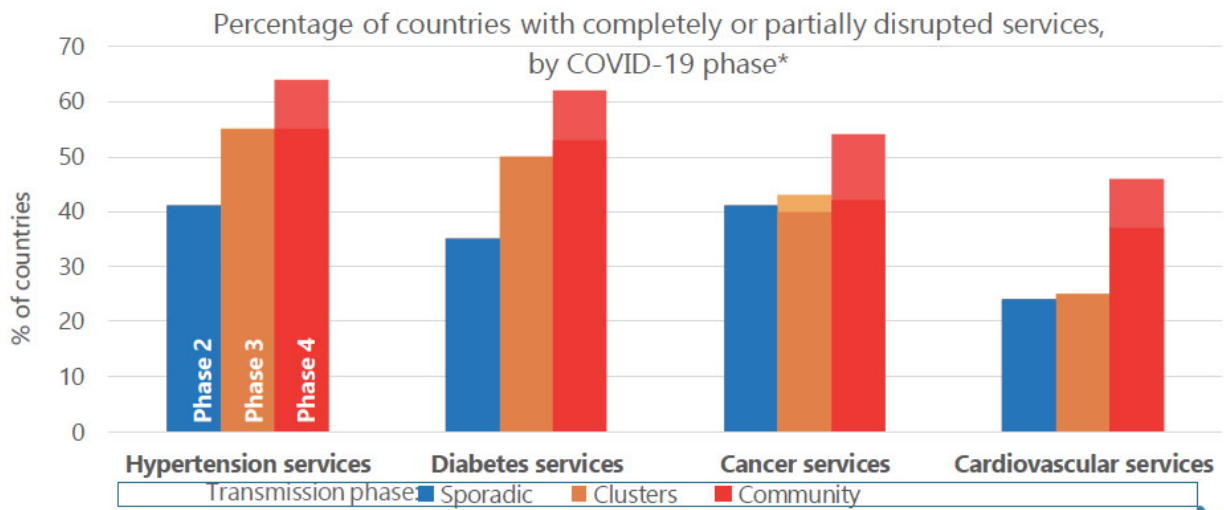
health and well-being due to the physical distancing orders in place in many countries around the world, which pose particular challenges to people living with dementia and their carers.

Chronic underinvestment in the prevention, diagnosis, treatment, and care of NCDs long preceded the pandemic and has resulted in a growing population of people living with NCDs as well as those who have not yet been diagnosed, potentially more susceptible to the more devastating effects of COVID-19. Together with the potential long-term impacts of COVID-19 and its treatments, people living with NCDs will further require frequent interactions with already over-stretched healthcare systems.

Recent analysis from the WHO shows that essential NCD services have been disrupted in over three-quarters of reporting countries due to COVID-19. Due to these disruptions in screening, diagnosis, treatment and care, there may be instances of people presenting in the post-emergency phase of the pandemic with symptoms of more advanced diseases, such as later stage cancers, uncontrolled hypertension, and chronic kidney disease. Rehabilitation services are the most severely affected, perhaps betraying a mistaken belief that these are not essential. Palliative care provision, which was already severely lacking in 60 per cent of countries, and cardiovascular emergency care are also disrupted. The study has not yet sought to include data on dementia diagnosis and care, which is a vital gap to be closed to understand the impact on the 50 million people living with dementia worldwide, their loved ones and carers.

The COVID-19 pandemic has shown that global health is interconnected and only as strong as our weakest health systems and has devastatingly reinforced that it is overdue for all governments to fulfil their political commitments to invest in universal health coverage (UHC). The Political Declaration of the 2019 UN HLM on UHC recognised that addressing NCDs and mental health and well-being must be integral part of UHC, ensuring that everyone can access the services they need without financial hardship. **Investment in UHC, including prevention of NCDs, would be the insurance policy the world needs to build resilience against global health threats.**

The more severe the transmission phase of the COVID-19 pandemic, the more NCDs services are disrupted



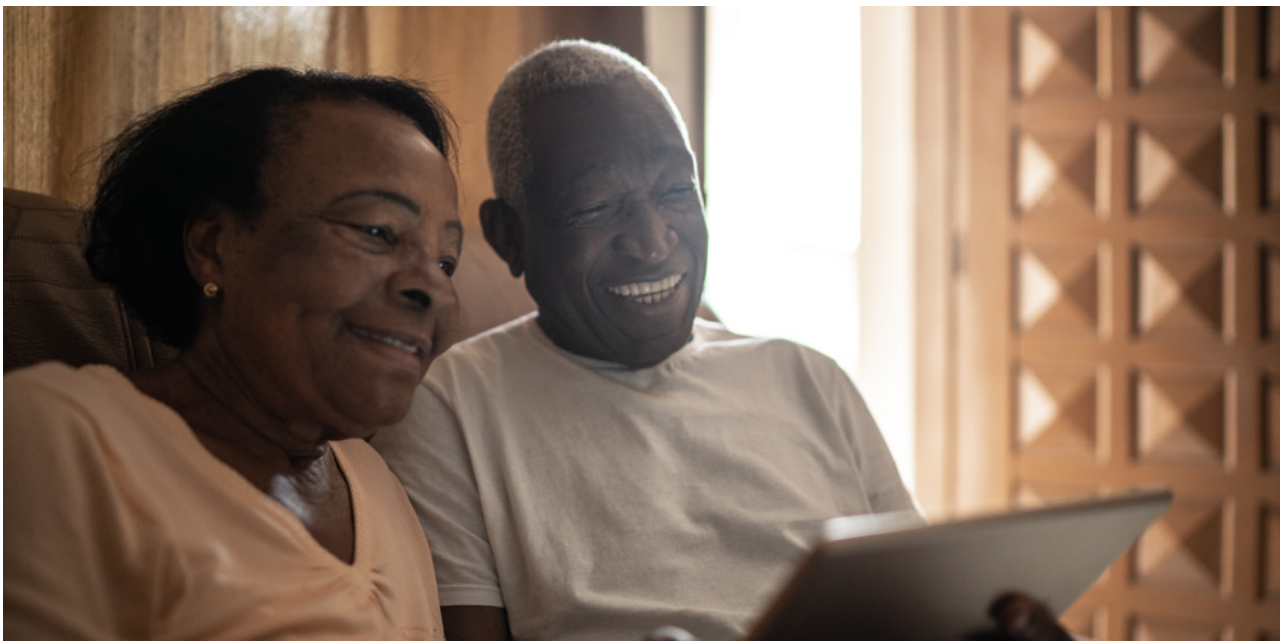
*Countries reporting unknown levels of disruption shown in lighter shade

Figure 4: WHO rapid assessment of service delivery for NCDs during the COVID-19 pandemic⁵⁸

Note on NCD and Mental Health COVID-19 dementia related data

Despite some excellent initial data through the rapid assessment from the NCD Department at the WHO dementia data is currently absent. ADI participates in the WHO Civil Society Working Group on NCDs which has a COVID-19 focus at present and has raised the question about inclusion of dementia data capture going forward. In addition, we understand that the WHO Mental Health Department will be

adding some additional COVID-19 questions to their atlas questionnaire. ADI's report with GADAA and Alzheimer's Pakistan⁵¹ also revealed the difficulty in capturing dementia data in crisis situations – and ADI is keen to find ways to correct this.



Examining post diagnostic support across the United Kingdom and Ireland

The following content was provided by Kielan Arblaster and Ella Robinson from the Alzheimer's Society, Dr. Bernadette Rock from the Alzheimer's Society of Ireland and Jim Pearson from Alzheimer Scotland.

Post-diagnostic support (PDS) offered after a dementia diagnosis may include Cognitive Stimulation Therapy (CST), cognitive rehabilitation and group reminiscence therapy but also less clinically led services such as exercise, gardening, baking and animal-assisted therapy. These are recommended for use by the National Institute for Health and Care Excellence.^{59,60}

One service providing an exemplary standard of PDS in England is Sheffield Memory Service, which offers a range of interventions to support the mental and physical health and wellbeing of people living with dementia and their families and carers.⁶¹ Following a diagnosis, a collaborative care plan is developed and reviewed within six months. Working with specialist teams at Sheffield Health and Social Care NHS Foundation Trust, support includes educational interventions as well as access to a rapid response home treatment team. It also offers CST, psychoeducation groups aimed at developing coping strategies, cognitive behavioural therapy and assistive technology interventions.

While there are services in England that provide an exemplary standard of care and support, there is national variation in the provision of PDS. This is due to several factors such as workforce, training, funding, and access to clinical services. According to the second National Memory Clinic Audit, just above two-thirds (68 per cent) of memory clinics offered access to CST. However, around 85 per cent offered access to specialist post-diagnostic counselling, and 98 per cent offered access to education and support for carers. Service structure and commissioning behaviours also impact access to PDS. For instance, dementia support workers – a key aspect of PDS enabling people to navigate the health and social care system – are mainly provided by the third sector, namely Alzheimer's Society, and commissioned by local Clinical Commissioning Groups and Local Authorities.ⁱⁱⁱ This is particularly pertinent given that 59 per cent of commissioners in England state their dementia advisers run education groups for people with dementia and their carers as well as providing dementia friends training.⁶²

Wales has a large range of PDS to people who are given a formal diagnosis of dementia. The support

ranges from information and advice hubs, like Ysbyty George Thomas in the Rhondda, to exercise and social engagement groups, such as DementiaGo in Gwynedd in North Wales. This support is naturally dependent on population needs and funding streams, but with the £9m a year funding allocated under the National Dementia Action Plan, the level of PDS in Wales is continually growing and expanding into new technology areas. An example of this is a new virtual reality therapy scheme in Gwent, set up based on evidence of success of similar projects in England.

Another type of PDS available in Wales is Book Prescription Wales – a scheme aiming to help people with mild to moderate emotional problems to make use of high-quality self-help books.⁶³ The successful scheme involves a GP or other healthcare professional prescribing a therapy book which are available from any branch library across Wales.

Ireland

In June 2017 the Irish National Dementia Office (NDO) ran a PDS grant scheme in order to increase staff capacity to deliver dementia post-diagnostic supports and to make them more equitably available. The scheme is part of a broader dementia post-diagnostic programme of work which supports the implementation of the National Dementia Strategy (NDS). Following a review of the literature, the grant scheme focused on three interventions – (1) cognitive stimulation therapy (CST), (2) cognitive rehabilitation (CR) therapy and (3) psychoeducational (PE) interventions.

The findings show that implementation was impacted by the:

- confluence of staff experience, skills, readiness and know-how
- choice of intervention – adopting an existing intervention or developing a new one
- embeddedness of staff within their organisation and within the wider health system
- management support
- local context e.g. level of demand among people with dementia
- need for ongoing supervision, mentoring and feedback for less experienced staff.

ⁱⁱⁱ Around three-quarters of dementia adviser services are commissioned by CCGs and LAs, and provided by Alzheimer's Society.⁶²

The vast majority of participants rated interventions very positively. They particularly welcomed the focus on social interaction and peer support within group interventions e.g. CST and CR, and overall participants found the information and advice to be practical and useful. For group CR it was also more cost effective.

The Alzheimer Society of Ireland (ASI) is of the view that these interventions are of value to people living with dementia and their families, and it is noteworthy that those providing the interventions also reported significant value added to recipients as well as overall care objectives including staff morale and satisfaction. There were challenges for carers and people with dementia who took part in the interventions. For example, carers sometimes struggled to access the venue for the intervention, but this refers to a lack of resources and funding.

ASI believes that additional resources should be made available to put psychosocial interventions on a firm and consistent footing within the dementia sector in Ireland.

ASI believes that additional resources should be made available to put psychosocial interventions on a firm and consistent footing within the dementia sector in Ireland. Acceptability of CST internationally is high and these programmes should be scaled up in Ireland. CR also has potential to offer valuable support for people with dementia and considerations should also be given to investing in this. Investment is necessary if these interventions are to be scaled up and the evidence from this evaluation is that there will be a significant return from any new investment in this area for people with dementia, their families and carers, formal care providers and wider society.

This PDS project links directly to Action area 4 of the WHO's Global action plan on the public health response to dementia, 'dementia diagnosis, treatment, care and support'. It supports development of a pathway of "efficient, coordinated care for people with dementia, and builds the knowledge and skills of staff to deliver evidence-based, culturally-appropriate and human rights-oriented health and social care."

Scotland

Since 2010 the Scottish Government has developed and adopted three consecutive national dementia strategies, each building on the previous strategy. The strategies are underpinned by a human rights-based approach which recognises people with dementia and carers as equal citizens and seeks to put them at the

heart dementia policy and practice. Alzheimer Scotland, along with many other key partners including people with dementia and carers, have played a leading role in developing the national strategies and monitoring their implementation. Over the past decade Scotland's three national dementia strategies have made a significant impact in driving change in many areas of dementia care and support. This includes transformational approaches to PDS, Coordinated Integrated Care, Advanced Care, General Health Care, Specialist Dementia Care and Allied Health Professional practice.

Whilst the dementia policy framework in Scotland is well developed and sustained progress has been made across key areas, significant gaps remain in the translation and practice at local level. The devolved budgets and decision making to Scotland's young integrated health and social care partnerships is welcome as it provides for greater local decision-making. However, it also presents challenges in ensuring that dementia is recognised as a local as well as a national priority and translating the national strategy commitments into local delivery. Scotland's national guarantee to offer high quality PDS to every person diagnosed with dementia is a good example. While it has been transformative to those who receive it approximately half of those entitled are not referred to this crucial support.

Alzheimer Scotland's major focus has been developing their local active voice networks so that local people with dementia, their families and carers are empowered to become a collective movement for change which can influence local Health and Social Care Partnerships to deliver these national commitments.

Scotland's national dementia strategy is under review and plans were in pace to commence a national consultation during the summer of 2020. However, that has understandably been delayed as Scotland like the rest of the world focuses on responding to the current global pandemic. The impact of the pandemic has highlighted the inequalities people with dementia and carers face, which has meant that they have been disproportionately affected by this terrible pandemic. We must ensure that these inequalities are addressed as we move forward and begin to visit Scotland's fourth dementia strategy.

Alzheimer Scotland's major focus has been developing their local active voice networks so that local people with dementia, their families and carers are empowered to become a collective movement for change which can influence local Health and Social Care Partnerships to deliver these national commitments.

Chair of ADI, Glenn Rees on Dementia Care Pathways and Systems Design

Development of services pathways, setting out the services needed by people with dementia, are viewed positively as a way of encouraging consideration of efficient and effective service delivery and coordination. Often dementia services pathways are structured around health promotion and prevention, awareness and recognition, assessment and PDS, care management, ongoing review and end of life.

Pathways hold out the hope of consumers and all those in the field being better informed.

From a consumer perspective the reasons for supporting a pathway for dementia include the prospect of an early diagnosis, the availability of appropriate information, equity of care based on evidence and remaining independent and at home for as long as possible. Pathways hold out the hope of consumers and all those in the field being better informed.

Dementia pathways can be useful in exploring how dementia care may overlap and intersect with other pathways. Many people with dementia will have complex needs for both health and social care and often for access to mental health services.

Despite these perceived benefits there are risks. The multiple objectives suggest that pathways may suggest clarity when there is none.⁶⁴ Some pathways may be driven by the need to assist primary care staff in supporting people with dementia.⁶⁵ Others by a perceived need for a guide to effective care planning.⁶⁶ Yet others for achieving an integrated pathway for dementia and best practice.⁶⁷

Moreover, implementation is unlikely to be straightforward. Health systems, individual clinicians and service providers will have their own views about care practice. For example, in

how diagnosis is communicated, the approach taken to person centred care and care standards.

Pathways may suggest a linear solution when care will in practice need to respond to individuals and the reality that individuals will enter the care system at very different points.

From a consumer viewpoint there may be benefits in focussing on key issues in the delivery of health care rather than mapping services. For example, achieving a streamlined continuum of home care that supports access to a range of services in the home including allied health services as their assessed needs change. Implementing a philosophy of care that includes re-ablement as part of planning, maximising functional independence and deterioration prevention. And critically to make the care system driven by the needs of the person with dementia and their informal carer not funding streams.



In summary, dementia care pathways are an important tool in analysing the key elements of – the dementia care journey but are a beginning not a solution. In developing policy, it could be said that the logic of dementia care pathways developed from different perspectives – whether medical or economic – is useful in displaying the logic of the key issues that are important to good dementia care. The reality of designing a health care system that balances the medical, economic and social imperatives is hugely more complex and involving as it must address societal values in terms of autonomy, efficiency and effectiveness and equity – and of course compassion.

Working with all stakeholders to promote person-centered Care

Provided by Sam Fazio from the Alzheimer's Association.

In 2018, the Alzheimer's Association (US) published the *Dementia Care Practice Recommendations* as a supplement to *The Gerontologist*.⁶⁸ The Practice Recommendations were developed to better define quality, person-centered care across all residential and community-based settings and throughout the disease course. The Recommendations outline evidence-based quality care practices in 10 areas (see below). However, the publication and dissemination of the Practice Recommendations was just the beginning of our work.

The Recommendations lay the foundation for the Association's evidence-based, systems-wide approach to working with providers, member organizations, accrediting bodies, and policymakers toward the implementation, adoption, and evaluation of these Recommendations. For instance, providers and companies can now have their training curricula reviewed against the Practice Recommendations and receive essentiALZ™ certification. In addition, accrediting bodies can ensure that accreditation and certification are rooted in evidence-based content.

Policymakers are also invested in person-centered care. The United States federal government is driving person-centered policies through the National Plan to Address Alzheimer's Disease, the country's strategic plan to tackle the Alzheimer's crisis. In conjunction with the Plan's goals, public and private stakeholders have pursued policies relevant to the Recommendations. For example, Congress passed the BOLD Infrastructure for Alzheimer's Act, which creates an Alzheimer's public health infrastructure across the country. In 2017, the Centers for Medicare & Medicaid Services (CMS) implemented billing code G0505 (now CPT® code 99483), which reimburses clinicians for providing care planning for persons with cognitive impairment. In order to promote these services, Congress is currently considering the Improving HOPE for Alzheimer's Act.

State governments are also deeply involved in the care of people with dementia. They regulate standards for high quality long-term care in both institutional and community-based settings. Currently, 49 states have published state Alzheimer's plans and most of them include recommendations focused on improving



dementia training standards in direct care settings, leading states to enact laws requiring staff to provide care based on the Dementia Care Practice Recommendations. Current state legislative efforts aim to:

1. Require a minimum of six to eight hours of evidence-based dementia training for all those who serve individuals with dementia
2. Ensure continuing education to reinforce best practices in the care of those with dementia
3. Implement a culturally-competent curriculum that incorporates principles of person-centered care
4. Allow portability of completed dementia care training across employment settings
5. Ensure trainers meet minimum requirements to qualify as instructors of a dementia curriculum
6. Designate a state agency to monitor dementia training programs, evaluate their effectiveness, and ensure compliance with state dementia training requirements

This combination of public and private stakeholders promoting and implementing person-centered care is critical to improving the quality of care and of life for persons living with Alzheimer's and related dementias, caregivers, families, and professionals.

Kate Swaffer, Chair, CEO & co founder of Dementia Alliance International (DAI), a registered non-profit organization whose membership is exclusively for people with a medically confirmed diagnosis of any type of dementia from all around the world:

"DAI continues to host many weekly online peer-to-peer support groups, cafés, brain health meetings, webinars and other events and meetings for members. Our brain health meeting and cafés are also open to our families and friends, and our webinars to members, families, and the wider dementia community of health care professionals, academics and service providers. They have proven to be even more important during the global COVID-19 pandemic, and we have increased how many groups and participants we host so that we could provide much needed additional support for people already experiencing isolation and loneliness. The encouraging thing since the pandemic is that many advocacy organisations are now also providing online support groups, for both care partners and people with dementia, as everyone has been forced to self-isolate, and we are hopeful that these will continue.

Intensified through this pandemic, we have seen that people with dementia, and older people more generally, are facing far greater discrimination and experiencing much worse isolation than they were before. They have become at far greater risk of both the indirect, and direct health and well-being impacts of COVID-19. This is in part, due to existing inequity in access to quality health care, the challenges posed by social distancing measures,



Kate giving a presentation on human rights and the WHO action plan in Sydney

where people rely on personal care and support, as well as the complications that may occur for those with underlying co-morbidities. Many have been restricted to their homes and are likely to remain restricted for weeks and even months after the rest of the community emerges from social and physical isolation. The World Health Organization (WHO) guidelines have recognised from the outset of the pandemic that there are additional considerations for people with disability including people with dementia, and older people – beyond those applying to most others.

In 2020, the rest of the world suddenly experienced what people with dementia and their families experience on a daily basis after diagnosis, such as isolation, distancing (from many family and friends), fear, anxiety and stigma. DAI hopes that after this pandemic, dementia will not be forgotten, and that we will not be left behind. Dementia must be at the forefront of our governments' minds, in policy, strategies and in campaigns towards realising the seven action areas of the WHO's Global action plan are achieved. We are all in this together, and people with dementia and their families must not be left behind".



WHO mhGAP

WHO's Mental Health Gap Action Programme (mhGAP) is an initiative to scale up services for mental, neurological and substance use (MNS) disorders, with a particular focus on low- and middle-income countries. These conditions include depression, psychoses, self-harm/suicide, epilepsy, dementia, disorders due to substance use, and mental and behavioural disorders in children and adolescents. It should be noted that the mhGAP evidence-base is due for scientific review in 2021 and will be updated accordingly.

As part of the mhGAP suite, the mhGAP-Intervention Guide was developed to help implement interventions for each of these priority conditions. The Guide focuses on training non-specialist healthcare providers and provides specific information related to dementia assessment and management, 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 dementia and its effects, and focuses on promoting respect, dignity and the human rights of those with MNS conditions. The app version of the Intervention Guide provides access to comprehensive information through tablets or mobile phones. The mhGAP Humanitarian Intervention Guide (mhGAP-HIG) is an adaptation of the mhGAP Intervention Guide and includes first-line management recommendations for MNS conditions for non-specialist healthcare providers in humanitarian emergencies.

To complement these tools, the mhGAP Operations Manual supports district health managers and others responsible for integrating mental and physical health services. The manual offers practical guidance and necessary tools for planning, preparing, implementing, monitoring and evaluating mhGAP. The mhGAP Community Toolkit (field testing version) is the most recent addition and provides guidance for programme managers on how to identify local mental health needs and tailor community services to address these. Launched at WHO's Mental Health Forum in 2019, it offers practical information and necessary tools for community providers to promote mental health, prevent mental health conditions and expand access to mental health services.



Creation of new Brain Health Unit at WHO

Globally, neurological disorders affecting the brain are the leading cause of disability and the second leading cause of death, accounting for 9 million deaths per year. The largest contributors to the global neurology burden in 2016 were stroke, migraine, dementia, meningitis and epilepsy.

The 2019 Mental Health Forum included a consultation session on WHO's integrated approach to brain health. The session included a panel discussion with contributions from people with lived experience, policy makers, healthcare providers, civil society, academia and other United Nations agencies. It also provided the opportunity for participants to comment and make suggestions on WHO's integrated approach to brain health.

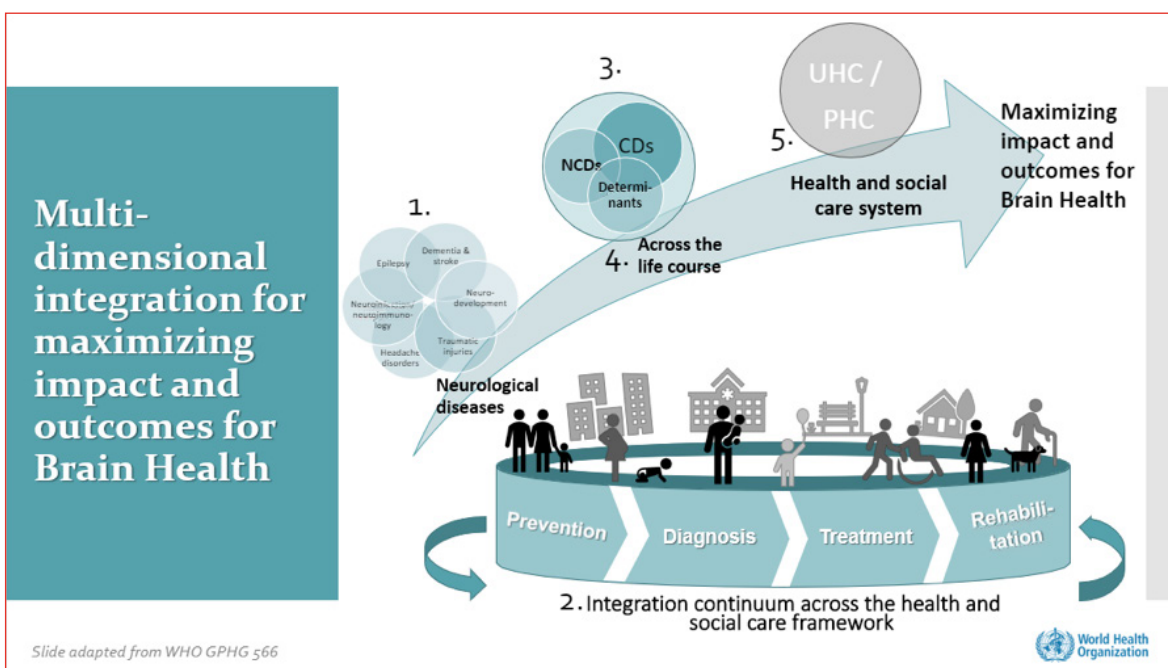
In early 2020, a distinct Brain Health Unit was created under the purview of WHO's Mental Health and Substance Use Department to implement this approach, which was also reflected in the addition "Synergies in addressing the burden of epilepsy and other neurologic diseases" presented as part of agenda item 11.6 on epilepsy during the 73rd World Health Assembly in May 2020.

The vision of WHO's newly established Brain Health Unit is to promote optimal brain development, cognitive health and wellbeing for all across the life-course, and across all brain health conditions (including dementia). To achieve this vision, the Brain Health Unit has four major strategic objectives:

- To strengthen policies, service delivery, health information systems, technology, research and innovation for brain health;
- To provide technical assistance and guidance on how to formulate an integrated approach to brain health using promotion, prevention, treatment, care and rehabilitation;
- To foster increased investment and inter-agency collaboration and across sectors;
- To work globally with partners at country-level for more impact.

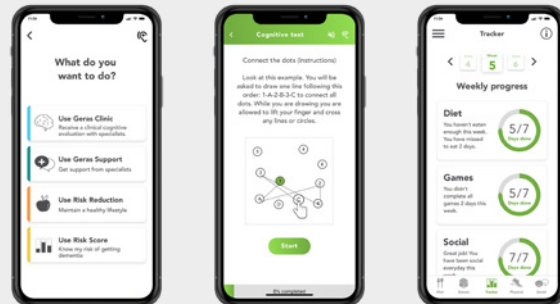
Key to the realisation of this vision is an integrated approach at multiple levels:

- across the multiple neurological diseases or brain conditions;
- across the care continuum ranging from prevention, diagnosis and treatment to rehabilitation;
- across other disease programmes such as NCDs and communicable diseases as well as with social determinants of health;
- across the life-course.
- Brain health needs to be integrated within health and social care systems for Universal Health Coverage and Primary Health Care.
- Lastly but importantly, an integrated approach to brain health necessitates the meaningful and consistent engagement of people living with brain health conditions.



Geras Solutions – detecting early-stage cognitive decline and providing risk reduction and support tools

Innovation and technology, especially around artificial intelligence and big data, will undoubtedly play an increasingly important role in the pre- and post-diagnostic stages of dementia. The ability to monitor and track cognitive and functional changes can support the work of health care professionals. It is essential, however, that people with dementia and carers are engaged in every aspect of the development, design and monitoring of such technology. We asked Rickard Forsman, one operator in this field, Geras Solutions, to give us an update on their work.



Diagnosing dementia is often the result of a long and painful process. Geras Solutions helps individuals with Alzheimer's and other cognitive diseases to live a better life, by empowering healthcare to help affected individuals get the care they deserve. The platform is the result of intense research and can now provide better decision support tools focused on diagnostics, treatments and support for patients.

The Geras Solutions Cognitive Test is a newly developed digital screening tool for cognitive impairment. It is integrated within the CE-marked Geras Solutions platform. Development of the AI screening tool is the result of collaboration with neuroscientists at the memory clinic at Karolinska University Hospital, and Karolinska Institutet in Stockholm, Sweden. The cognitive screening tool is a further development, using a combination of widely acknowledged cognitive assessment methods and includes additional proprietary tests developed at the memory clinic at Karolinska University Hospital.

Users can have their cognitive abilities screened using self-administered tests and forms that objectively measure cognition via thousands of digital data points. The data collected is then interpreted by computational scoring tools and presented to professionals to obtain a

comprehensive understanding of the patient's cognitive abilities. By automating the processing and organizing of the collected data it is possible to provide clinically reliable decision support.

Results from the latest study at Karolinska University Hospital Stockholm concluded that Geras Solutions' self-administered test has higher sensitivity and specificity than current golden standards. But more importantly, it allows for better patient access and resource utilization in healthcare.

The COVID-19 pandemic has shown the importance of digitalized tools, where healthcare's ability to manage hospital visits has been impeded.

Geras Solutions also offers a Risk Reduction tool can help individuals to delay cognitive decline through lifestyle changes. The approach is based on the recommendations and results from the FINGER-study. Additional modules provide follow-up support via video chat functions to family members, carers and individuals who may have a dementia diagnosis or require further guidance.

All this is done supporting the vision of providing increased access to better care, while also empowering healthcare to deliver the care that affected individuals deserve.

Chapter 5

Support for dementia carers



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

The World Alzheimer Report 2019¹⁰ Attitudes to dementia (a study of 70,000 people globally) revealed that while dementia carers hold positive sentiments about their caring role, a majority of them admit that caring impacts on their health, including their mental health. It is crucial that carers of people living with dementia are able to access adequate support services due to the potential effects on their wellbeing of their caring role, as well as the change in relationship with the person they are caring for.

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.

Professor Henry Brodaty, Professor of Ageing and Mental Health, Director, Dementia Centre for Research, Collaboration and Co-Director, Centre for healthy Brain Ageing, University of New South Wales on carers as invisible second patients:

For most community-dwelling people living with dementia, care is provided informally by unpaid carers. Carers are usually spouses, other family members or friends and more often women. Family carers provide about half of the care-associated costs – slightly less in high-income countries and more in low- and middle-income countries (LMIC) where rates of nursing home and community care are much lower.

Family carers are prone to higher levels of stress, depression and anxiety than their peers in the general population and lower morale and satisfaction with life. However, many family carers endorse positive reasons for caring such as a sense of love, a feeling of reciprocity for many years together, spiritual fulfilment and feelings of mastery

and accomplishment. Such carers experience less burden and better health, relationships and social support. Carers who feel it is a responsibility, an emotional obligation or that they are obliged, are more likely to suffer psychological distress, burden and anxiety and to admit the person living with dementia into care.

Other consequences of dementia caregiving are poorer physical health, compromised immune function, high carer burden as well as financial and social disadvantages. The strain of caring can manifest as depression and anxiety; rates of both are high. Carers use more medications, have higher levels of stress hormones and generate lower levels of antibody responses than non-carers. Carers are less likely to engage in preventative health

behaviours such as exercise, and are more likely to smoke, drink alcohol and eat unhealthily and have poor sleep patterns.

About one-third of dementia carers report feeling socially isolated as they tend to sacrifice their leisure pursuits and hobbies, restrict time with friends and family and give up or reduce employment.^{69,70} Social isolation is a risk factor for carer burden and depression which in turn may exacerbate social withdrawal. Interventions may assist by increasing the number of support persons for carers, their satisfaction with their support network, and the assistance they receive with caregiving.

Carers, through their unpaid support, make an enormous contribution economically to national economies. Simultaneously, they generate significant indirect costs to the economy, as many carers reduce or completely cease their employment and many utilise government pension schemes.

Carers are more vulnerable to adverse effects if they are spouses, live with the person with dementia, are female, have previous tendencies to be anxious or depressed, have poorer coping skills, have fewer supports and are caring for persons who manifest behaviours distressing to the carer.

Education and training can arm carers with knowledge, skills, and coping strategies that are helpful such as WHO's iSupport programme. Provision of practical and emotional support and respite care can relieve stress and burden. Mobilising family and friends to help are even more effective than arranging formal or paid support. Benefits have been demonstrated with specific psychological therapies for depression and anxiety. Home visits by occupational therapists to model different ways of engaging and helping persons with dementia are effective. National Alzheimer Associations for carers and persons with dementia offer support to individuals and through groups which can be virtual as well as in-person. Dementia Alliance International (DAI) is a virtual support network for and by persons with dementia.

The adage that dementia does not affect just one person, there is always a second patient, is accurate. Families, friends and health professionals should be mindful of the effects of being a carer and know there are strategies for helping carers cope. During the years of the trajectory of dementia there are good and bad times. Extra support may be needed at critical points such as when the diagnosis is made, distressing behaviours develop, basic self-care requires assistance, admission to residential care is arranged and death occurs. Assisting carers to manage better can improve the quality of lives of both the care giver and the care recipient.⁷¹



Chair of ADI, Glenn Rees on the importance of putting carer support centre stage

It was family carers of people with dementia in the early 1980s who advocated for information, education and training and other support and succeeded in bringing dementia to the attention of many governments.

The turn of the century saw a slow move to make Alzheimer's organisations inclusive of people with dementia for example in Scotland and Australia. My impression is that since that time the policy focus on the needs of carers has diminished.

Carers should be centre stage because the supply of informal carers is set to decline in many countries and because they continue to provide most of the support and care. If there is no informal carer, or the carer is unable to continue their role, it is likely that it will be that much more difficult for the person with dementia to stay at home for as long as they might wish and that this in turn increases pressure for residential care.

The Global target refers to support and training for carers and, in proposed action, to a much wider set of strategies including the carers physical, mental health and relational needs. This wider focus needs to be considered in framing dementia care plans.

First, **access to information** not just about dementia and available services but the quality of those services. Post diagnosis the priority is information, planning and support.

Second, **reducing the fragmentation of home care services** such as support with the activities of daily living (bathing, dressing, functional mobility and feeding) for the person with dementia and the instrumental activities of living (such as shopping, housework and transport). As the disease progresses there may be a need for case management to assist with needed access to a range of care and health services for those with complex needs.

Third, to support **psycho-social interventions**.⁷² There is a need for a multi-faceted approach. For example, the Resources for Enhancing Alzheimer's Caregivers Health (REACH)⁷³ targets depression, burden, self-care, social support and problem behaviours in the person with dementia. Intervention strategies include

education, stress and mood management techniques, communication skills, and problem solving delivered in 12 sessions over 12 months.

Another example, is the Care of People with Dementia in their Environments (COPE) program.⁷⁴ This is a structured occupational therapy and nursing intervention for people with dementia and their caregivers living at home. COPE aims to support and empower people with dementia and their carers to independently manage everyday difficulties.

Fourth, to use **carer assessment tools** that are sensitive not only to physical needs of carers but their relational needs. There are complex interdependencies inherent in care giving, the dynamics of which change as dementia progresses and increased support is needed including support in decision-making. This requires a full understanding is needed of past and future relationships. One approach to achieving a negotiated outcome with the informal carer is the Carers Outcome Agreement Tool (COAT).⁷⁵

Fifth, to compensate for lost income and the costs of care in a way that gives the carer **flexibility** in performing their role. Some countries achieve this through carer pensions and/or allowances where full time care and support is provided. Others provide individualised planning and funding to the individual with dementia that assists the individual and their family to tailor the assistance sought to their needs.

Sixth, provide access to **respite care**. This must be flexible to meet emergency needs (if the informal carer is ill), in respect of location (home and centre based) and planned respite (that the informal carer can rely upon at intervals). This is essential to ensuring the informal carer can continue care but also well designed to give the person with dementia the possibility of activity and social engagement to look forward to.

The mix of strategies will vary by country, but it is certain that more vision is needed in support of carers.

Spotlights on Carers – How Together in Dementia Everyday (tide) a UK-wide Charity is being responsive to the needs carers of people with dementia and ensuring that their voices are heard during Covid-19

Together in Dementia Everyday (tide) is a UK-wide charity focusing exclusively on ensuring that carers of people with dementia use their voices and that as a society, we reflect and respond to their unique needs.



in their caring hours; carer burnout; increased social isolation/loneliness as well as real concerns about the future.

Whilst the current Covid-19 crisis has come as a shock to so many, it has created a particularly frightening reality for the UK's 700,000 unpaid carers of people living with dementia, whose contribution to the care economy is estimated to be at least £13.9bn and make up 40 per cent of the dementia workforce.

Increase in their caring hours – The majority of carers are now providing more care than before as a result of the need for self-isolation or shielding, withdrawal of local services and reduced support from social care providers. Many carers are reporting concerns about home care workers visiting without adequate Personal Protective Equipment (PPE) and the risk of spreading infection. This has resulted in some carers choosing to reduce the support they receive from paid services, placing yet more strain on them. One carer, of many carers, who spoke of the issue of PPE stated:

Following a UK-wide survey with our tide carer members at the beginning of the pandemic, we are committed to ensuring that they remain connected, well informed and continue to use their caring experience to influence policy, research and practice. This is particularly important as the coronavirus pandemic is having a profound impact on them currently, but is also casting its long shadow that will extend far into the future.

“As recently reported the distribution of PPE especially within social care has been a ‘shambles’...”

Tide has established a [Covid-19 Hub](#) on our website, providing information and activities to enable carers to remain connected and well informed including a specific set of [resources for carers and people from Black and Minority Ethnic \(BAME\) communities](#). Furthermore, tide is working collaboratively with the University of Liverpool which is leading the first [UK COVID-19 research](#) study to explore the effects of social service closures on the lives of older people, people with dementia and unpaid carers. We have also pivoted our [Law for Dementia Carers project](#), funded by the Legal Education Foundation to take account of the new [UK Covid-19 2020 Act](#), which was hurriedly enacted in March to address the pressures in local authorities. Our work will focus on health and social care elements of the Coronavirus Act 2020, and specifically the impact of the potential introduction of Care Act Easements on carers of people with dementia. The information gathered through this project will inform the UK Government's planned 6-month review of the legislation.

Many carers are also reporting faster deterioration of the dementia symptoms of the people they cared for with the result being an increased complexity and intensity of care that now have to provide.

From our work with carers of people with dementia during the lockdown period of Covid-19 virus in the UK, we are hearing of the frightening daily reality that many carers are experiencing, including a significant increase

Carer burnout – It is acknowledged that 70 per cent of carers of people with dementia report that caring has a negative impact on their physical and mental wellbeing. (This is an increase on the global figure of 50 per cent highlighted in ADI's World Alzheimer Report 2019). This is increasing as many carers worry about their ability to cope with their current demanding situation combined with the uncertainty that they are facing by not knowing when social support services will re-open again, and when these do, in what shape and form. They are concerned that they may lose their right to paid carer support and would face significant barriers when re-applying for a care package once the lockdown is over. Many carers are extremely concerned about being able to continue caring safely and effectively, whilst maintaining their health and wellbeing at this time. They have also reported that across the UK nations the Covid-19 guidance is not

uniform and sometimes the key messages delivered from the governments have been confusing and conflicting for carers.

Some carers had, until recently, been in work which provided some 'space' for them to recuperate. However, for many, this is no longer an option as they had been furloughed and were now at home.

Adding to the incidence of carer burnout are also concerns around financial issues and sudden changes to their daily caring routines. One carer commented:

"I have given up a well-paid job to care for my husband Keith 2yrs ago. He is 56yrs old and has suffered early onset dementia for the past three years. As a result of Covid -19, his dementia deteriorated at pace. I left him in a wheelchair in the car park of a care home and haven't seen him for 4 weeks. It was all so sudden! Almost immediately all our benefits stopped –and our family income has been reduced from £1000 a month to £400. I have only £113 to live on per week." I feel that I have just been dropped into the middle of an ocean! As carers of people with early-onset dementia – we are forgotten and the impact is seismic."

Social Isolation and loneliness –Very few carers have access to continued social support networks. Some organisations have adapted and are providing remote support in the form of zoom internet meetings, regular phone calls, coffee mornings, and activities to try and keep carers connected. However, only a small proportion of carers may be able to access this kind of virtual support and we are extremely concerned at the further impact coronavirus will have on the incidence of social isolation and

loneliness. A carer who responded to our online survey just simply stated:

"It's a very lonely life".

Grief Loss and Bereavement – A small number of carers shared that the person they care for had recently died, either as a result of the coronavirus outbreak or from a pre-existing condition. For these carers, the crisis had affected their ability to provide end of life care or the subsequent practical arrangements such as funerals. With the continued crisis in the UK care home sector, we are anticipating that these situations will increase and continue to have longer-term mental health implications as people are unable to process grief in the usual way. A former carer who had recently lost his wife said that the isolation felt particularly hard:

"I am finding the self-isolation depressing as I have to deal with my bereavement and isolation. I fear for my mental health at times".

Voice of carers – Given the important contribution that carers of people with dementia make to the care system, without which it would simply implode, this crisis now needs to be a turning point in how as a society we recognise, respect and work with carers of people with dementia as equals. **It has never been more important that governments as well as employers and policymakers, take action to recognise that carers of people with dementia are individuals in their own right, and not simply an adjunct to the person they are caring for.** tide will continue to work with carers of people with dementia so that they can collectively use their caring experience, assert and claim their rights now and in the future.



WHO iSupport program

Background

In 2017, the World Health Organization (WHO) launched *iSupport*⁷⁶, an online knowledge and skills training programme for 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.

Country implementation

iSupport is currently being adapted in 13 countries, including Australia, Brazil, China, the Czech Republic, Greece, Japan, Malta, the Netherlands, Portugal, Qatar, Switzerland, Wales and Nigeria. For example, in February 2020, Qatar held multi-stakeholder focus groups during a national workshop in Doha, which WHO attended. This will support the implementation of iSupport both as an online programme and through a hardcopy manual, and the development of a mobile application for iSupport in Qatar. Similarly, Switzerland successfully secured funding to adapt and translate iSupport into Italian, with adaptation to begin later this year. Finally, a first research study of the programme was recently completed in India.

Lessons learned and ongoing activities

Lessons learned from country implementation include the importance of conducting multi-stakeholder user testing and focus groups in order to appropriately tailor the programme to local needs, the need to align iSupport with emerging technological developments and trends, and the usefulness of building on other countries' experiences. In order to facilitate the exchange of mutual learning between countries, WHO held three iSupport webinars in 2019 in view of creating a Community of Practice (CoP) focused on (i) the adaptation and implementation of iSupport and (ii) iSupport research. The CoP provides an opportunity for countries implementing iSupport, and those interested in doing so, to exchange good practices, and identify common challenges and solutions. It also provides a platform to foster broader collaboration in the area of support for dementia carers.



The way forward

Moving forward, WHO will continue to foster and develop the iSupport CoP through ongoing webinars and opportunities for information exchange, mutual learning and research. WHO is currently undertaking a review of iSupport to identify how the programme can be optimized for user-friendliness, uptake in low- and middle-income countries, and to leverage easy-read infographics and new technologies within the context of COVID-19.

iSupport is currently being adapted in 13 countries, Australia, Brazil, China, the Czech Republic, Greece, Japan, Malta, the Netherlands, Portugal, Qatar, Switzerland, Wales and Nigeria.

Grupo Ermita carer diploma course

Since its foundation in 1996, ADI's member in Guatemala, Grupo Ermita, has had the support of the Galileo University from Guatemala City. The main component of this support is the diploma course 'Care of the elderly adult with emphasis in Alzheimer's disease.' With Grupo Ermita providing inputs for its content, Galileo University, with the support of the Ministry of Public Health, took on the course as its own.

The course has now run 29 times and trained 1,800 carers. Students have come from a variety of backgrounds: family members; professional nurses; auxiliary nurses; medical doctors; dentists; psychologists; physiotherapists; social workers; auditors, among others. This diploma course with Galileo University is of great added value, as it allows to professionally train people to study care of the elderly and especially for those with dementia.

The University assumes the full costs of the diploma course and donates 100 per cent of the revenues of the course (via enrolment fees) to the association. In this way, the course is the main revenue for Grupo Ermita, thus assuring its sustainability.

Until last year the Diploma was taught only in person, but has since been run three times online, with a platform which can host up to 15,000 students. The online modality has helped to reach the entire national territory, with students in all the regions of Guatemala.



Participants during a session of the Galileo University diploma course

It is also a very valuable resource for reaching the indigenous areas of the nation, and it is available for all of Latin America.

How innovations and community-based network create an impact in the Asia Pacific region

Alzheimer's Disease International (ADI)'s Asia Pacific Regional Office (APRO) was established in 2013 at the initiative of a few members in the region. Currently there are 20 ADI members in the Asia Pacific region. The main objective was to strengthen all members in the region through the basic pillars on advocacy, capacity building, partnership and leadership and to help members to be self-reliant in the long run. The Asia Pacific region is home to 60 per cent of the world's population, some 4.3 billion people and includes the world's most populous countries: China, India and Indonesia. There are an estimated 23 million people living with dementia in the region and forecasting the biggest increase in numbers based on the ageing population demographic.

Innovations and a community-based network have played a significant role in creating impact in the region – members have supported each other, information and

technical skills have been shared on several dementia care training modules/ approaches, knowledge has been transferred and resources have been explored and exchanged.

In South-East Asia sub-region, Indonesia, a population of 270 million people with an estimated 1.2 million people with dementia has been demonstrating their strength in awareness raising, education and intergeneration initiatives through the recent Youth Engagement Programme – a solid partnership between Alzheimer's Indonesia (ALZI) and Atma Jaya University. The focus has been in advocacy, partnership at all levels, strengthening and empowering people with dementia, family caregivers, youth and the communities, thus the organization became the go-to-source for any dementia related matters (nationally) and it has grown from six chapters to 22 chapters with more than 6000

followers and hundreds of partners (national, regional and global) in less than five years.

In response to COVID-19, ALZI has initiated several programmes including an online webinar sessions for people living with dementia and caregivers reaching up to 225 participants per session (and more than 17K Facebook and YouTube viewers). Programmes included interactive sing-a-long sessions, involving talented musicians; an online dementia care tips and tricks tutorial video and online care navigation counseling involving a multi-disciplinary team to provide solutions and create meaningful engagements for people with dementia and family caregivers. In addition to webinar sessions, information related to COVID-19, in the form of infographics and articles have also been produced, reaching through the entire region via a partnership with HelpAge International Asia Pacific and other partners including corporate sectors, local and international NGOs. In addition, several other international and regional organisations approached ALZI to collaborate through the dissemination of information and content to support people with dementia and family caregivers.

Fundraising and distribution of more than 15,000 masks for people with dementia have also been conducted through the chapters' community based network from Sumatera, Java, Sulawesi to the remote areas in the Eastern part of Indonesia involving other organisations, companies, government and institutions.



Photo credit: Arsineh Houspian

Dementia Australia, the national organization that provides advocacy, support services, education and information to an estimated 459,000 people living with dementia (among their population of 25 million people), representing the sub-region of Oceania in the Asia Pacific Region, continues to demonstrate a leading role in innovation and technology. An example – the free "A Better Visit" app for tablets features a range of two-player games designed to enhance communication and facilitate positive social interactions between



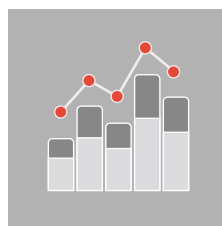
Photo credit: Dipa Mulya

people with dementia and their visitors. The app was launched in November 2018 and with 5,000 downloads since then, the feedback on the impact has been overwhelmingly positive, including users referring to the app as "innovative and thoughtful" and providing the chance for "a few laughs". Another example of technological innovation is a project that created customized technology solutions to help people living with dementia reach personal goals and to better enjoy their lives. As part of the project, participants were asked what difficulties they were experiencing with their dementia, loneliness and problems remembering to perform everyday tasks were common responses. The technology was then customized and used to address these concerns including introducing iPads, Smart lights, Google Home and GPS solutions. COVID-19 has certainly created a surreal and uncertain time. To support people living with dementia, families and carers, aged care workers on the front line and staff working in Homecare, Dementia Australia has developed "Tip Sheets" to assist with some of the inevitable challenges during isolation.⁷⁷ They have also developed short 2 to 3-minute videos for social media providing tips on how best to deal with some of the challenges staff may encounter. To date, these videos have had 39,000 views. Australia's Minister for Aged Care and Senior Australians, Senator the Hon. Richard Colbeck has been meeting twice weekly with Aged Care Peaks including Dementia Australia to ensure the concerns of clients and providers are addressed.

Australia and Indonesia are clear examples of how innovations and community-based network have empowered people with dementia and family caregivers to receive the quality of life and care they deserve. APRO supports these initiatives, shares examples of good practice, amplifies their messages and adds them to advocacy efforts in the region.

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. To date, the World Alzheimer Report 2015 is the most popular and regularly cited source of much of the global information on dementia.

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.

This year we know that 52 countries have now submitted data to the GDO, for 49 countries their GDO country profiles are available online⁷⁸ – equating to only 25 per cent of the total countries in WHO. The target is 50 per cent. With approximately 40 countries are in the process of collecting and submitting data, we are making slow progress. 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 they become available. It is imperative that Alzheimer associations from across the world are involved and support and their governments in maintaining and reviewing data input into the GDO on behalf of their country.

In 2016, Raj Long published a paper for the UK's Department of Health and Social Care titled 'Finding a Path for the Cure for Dementia'⁷⁹ Many of the points raised in the report – around the need for improving data registries – are still very pertinent to this day, which speaks to the fact that nothing much has changed in this area. It would be fair to say that data registries have continued to grow since 2016, but data sharing

has not grown proportionally along with these general developments. Open source data sharing is needed to ensure data is shared de facto and spontaneously. There must be legal mechanisms for researchers and pharmaceutical companies sharing data to a registry to protect them from indemnity.

As highlighted by Paola Barbarino in the last edition of From plan to impact:

"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."

Most poignantly, there is currently no prophylactic or therapeutic treatment for any stage of Alzheimer's disease or other dementias. Since the 2016 report was written, progress continues to be made towards further understanding the areas beyond the focus on amyloid and extending to tau, but the disease is still far from being fully understood. Although research continues, the lack of a cure or even an intervention to halt progression for Alzheimer's disease is still nowhere in sight after decades of research. Although some pharmaceutical companies continued with research and development (R&D), none have actually been successful in bringing forward a meaningful disease modifying agent at any stage of Alzheimer's disease. The failure of recent drug development by a number of companies is a testament of the continuum of the moratorium in the quest for a therapeutic cure for Alzheimer's disease. There is still much to be learnt on the aetiology and the causative mechanism for Alzheimer's disease.

Another major factor is the need for political mobilisation behind dementia. The current COVID-19 pandemic has shown how world leaders can come together to find common – and often hard – solutions when the pressure to do so is great enough. As a matter of equity, the dementia movement must come together to ensure equal access to a treatment when it becomes available. Indeed, the majority of people living with dementia live in low- and middle-income countries.²³ Such political momentum was seen in 2013 when the G8 championed the Dementia Challenge.⁸⁰ This resulted in several movements including setting up of the World Dementia Council, establishment of an International Regulators Platform from 10 leading international agencies and bringing researchers together. Much of this was possible as the political will at that point was catalytic to creating

the momentum. As political leaderships and their manifestos change, the momentum of the drive behind the mandate also waned.

Data registries are important for a number of reasons and including the critical need to better understand the complex aetiology of dementia. Ultimately, the lack of a breakthrough treatment for dementia continues to create a catch-22, where governments are more likely to see the value in a commitment to dementia if there is a breakthrough, but more funding and attention are needed to drive the research. The only way this will be overcome is with genuine long-term political commitment grounded in a belief that this is a moral necessity.

Aliaa Ahmed Ibnidris Elsiddig and Emiliano Albanese from the University of Geneva share some observations on the GDO:

“Countries with limited data on dementia would benefit from large scale research projects that generate up-to-date evidence on dementia prevalence, incidence, diagnostic, care and treatment needs as well as dementia plans and policies. Wide-spread community sensitization and awareness campaigns should complement these initiatives to inspire dementia-friendly communities and participatory engagement in dementia research. Such initiatives, especially when backed up by local stakeholders, NGOs and governments, could be a solid starting point for a robust platform for further research. Once developed and strengthened, such systems would facilitate the regular updating of the GDO indicators based on local and regional occurrences and needs. Moreover, research projects of this scale constitute excellent training opportunities for early-career researchers due to the width and depth of research, which would include a large proportion of GDO indicators.

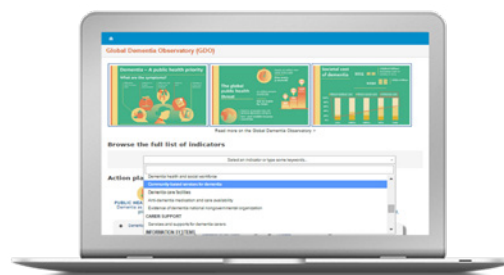
Having been trained on and exposed to these data collection and reporting methods, participating researchers are uniquely positioned to ensure the continuity of local dementia information systems.

In order for this to happen, however, buy-in and ownership of local authorities is critically important for successful implementation and long-term impacts. Furthermore, such projects might be constrained by myriad factors driven by financial, political, cultural and logistical aspects. Completed and on-going research projects succeeded in overcoming many of these limitations through local, regional and international agreements and collaboration. Being able to conduct projects of this scale and vision can improve research output as well as work as a platform generate the GDO indicators at the country level.”

WHO's Global Dementia Observatory

By the start of 2020, 52 countries submitted data to the Global Dementia Observatory (GDO), covering 61 per cent of the world's population, with approximately 60 per cent being high-income and 40 per cent low- and middle-income countries. The GDO country profiles that provide a snapshot of countries' progress towards reaching global targets and other actions recommended in the global dementia action plan are available online.⁷⁸ GDO data collection is ongoing in over 40 countries, which will bring the total population coverage to 80 per cent. The GDO acts as the monitoring mechanism for the [Global dementia action plan on the public health response to dementia 2017–2025](#)¹ and available GDO data informed the [first progress report for WHA73](#).⁸¹

In line with the global dementia action plan, the Heads of Government and States of G20 countries committed to implementing a “*comprehensive set of policies to address dementia, including promoting risk reduction and sustainable provision of long-term care as well as inclusive societies aiming to improve quality of lives of people with dementia and caregivers*” last year. Based on interim GDO analyses, global accelerated action will be required over the next five years to achieve the Global action plan's targets by 2025. However, despite the G20 commitment, global commitment is at risk due to reduced country leadership and funding reprioritization as a result of the COVID-19 pandemic.



To maintain dementia as priority on the global political agenda, WHO will release a Global Status Report on the Public Health Response to Dementia in early 2021. The report will provide a detailed analysis of the Global action plan's implementation status. It will also propose mechanisms and catalysts to accelerate action in areas where strategic gaps have been identified based on GDO data and other available evidence. Strategic gaps exist, for example, in the areas of dementia risk reduction, awareness and friendliness, care and support, as well as research and innovation.



STRiDE

As part of the STRiDE (Strengthening Responses to Dementia in Developing Countries) project, each country team is researching and writing an in-depth situational analysis that describes the unique political, economic, and social structures in their country. This will help lay the foundation for future policy recommendations by identifying the gaps, realities and opportunities for change in the dementia care sector. (See Chapter 7 for more on STRiDE).

Working in collaboration with WHO colleagues and country focal points, the STRiDE team incorporated the GDO data questions into the research for the situational analyses. The result has been an influx of rich data on GDO indicators around awareness, risk reduction, diagnosis and treatment, carer support, information systems and research in each of the seven STRiDE countries.

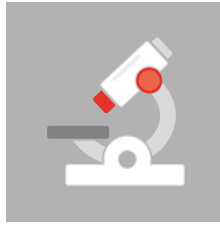
These data form important baselines from which to measure change, but they also indicate gaps in support provision and highlight areas where key interventions, underpinned by a strong dementia policy framework, could make a dramatic difference to the lives of people affected by dementia.



STRiDE NGO partners at a workshop in London

Chapter 7

Dementia research and innovation



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

The World Alzheimer Report 2018 revealed the stark statistic that the global ratio of publications on neurodegenerative disorders versus cancer is 1:12. A recently published progress report by WHO presented at the 73rd World Health Assembly revealed that in 2017, less than 1 per cent of PubMed research output focused on dementia, which was significantly lower than other NCDs such as cancer and cardiovascular disease, which accounted for 10.7 per cent and 7 per cent of output, respectively.⁸¹ Greater investments in all areas of dementia research must be met by a genuine political commitment.

There is still no disease-modifying treatment for dementia, although in the past year two Phase 3 clinical trials have shown potentially promising results. It must

be stressed, however, that greater investments across the broad spectrum of dementia research areas are needed. Non-pharmacological areas such as basic science, care, risk reduction and public health, are woefully underfunded. A paper published in the *Lancet* in 2019 revealed that between 2011 and 2016 six of the G7 countries (all excluding Japan) increased their investments in dementia research by 136.9 per cent.⁸² However, this is 4.5 times lower than the equivalent 2016 investment in cancer research. Moreover, the main proportion of this money was dedicated to identifying a cure or disease-modifying treatment by 2025. The paper called for greater investments in health and social care; a call which is echoed in ADI's publications and statements again and again.

Dementia research investment in the US: a case study

Provided by Maria Carrillo, PhD, Chief Science Officer, Medical & Scientific Relations, Alzheimer's Association.

The link between research and global public health has never been more clear. Scientists worldwide are working tirelessly to develop treatments and vaccines for the novel coronavirus COVID-19 that has had such a profound effect on individuals, families and nations.

With the same relentless commitment, investigators around the globe work to develop improved methods to detect, treat and prevent Alzheimer's disease and other dementias. While the research of many is on hold at this unprecedented time, some research continues to speed ahead.

Just this spring, researchers from the Anti-Amyloid Treatment in Asymptomatic Alzheimer's Disease (A4) study published data linking high levels of beta-amyloid in the brains of cognitively normal individuals to an increased risk of future cognitive decline. Other

researchers reported that an abnormal form of the tau protein was found in the brains of individuals with familial Alzheimer's more than 20 years before they were expected to develop symptoms. These are critical advances.

An influx of U.S. federal and global philanthropic investments has fueled progress and enabled researchers to explore and advance bold, brave ideas. We are investigating all facets of neuroscience, including once-overlooked potential culprits of Alzheimer's and dementia. Biomarkers, pharmacological treatments and modifiable lifestyle factors are among the topics that have seen tremendous scientific progress in the United States and abroad.

Basic science research is foundational to expanding our knowledge of biomarkers and identifying possible targets for new therapies. One model for how government, industry and nonprofit organizations can collaborate to accelerate this research is the

Accelerating Medicines Partnership – Alzheimer's Disease (AMP-AD), convened under the US National Institutes of Health (NIH). Together, AMP-AD partners expect to provide approximately \$185 million in biomarker, target discovery and preclinical validation research funding over five years, and data generated from AMP-AD will be accessible to the global research community.

Another model that brings the strength of public-private partnerships to the forefront is the Innovative Medicines Initiative (IMI), a partnership of the European Union and European pharmaceutical companies. Among the IMI-funded projects to increase tools for basic science research and drug discovery are the European Bank for Induced Pluripotent Stem Cells (EBiSC) and Investigating Mechanisms and Models Predictive of Accessibility of Therapeutics Into the Brain (IM2PACT). EBiSC has greatly expanded the availability of induced pluripotent stem cells, which can be used to test the toxicity and efficacy of new therapeutics long before they enter clinical trials in humans. IM2PACT is increasing our understanding of the blood-brain barrier (BBB) so new therapeutics can be developed to cross the BBB and disrupt processes that may contribute to Alzheimer's and dementia. Adding to these findings, researchers funded by the NIH, Alzheimer's Association (US) and a private foundation have found that abnormal BBB breakdown near areas including learning centers like the hippocampus may be an early biomarker of cognitive decline.

There has been a surge in the development of fluid and imaging biomarkers, including rapid progress toward a sensitive, specific, and accurate blood test for Alzheimer's that has excited the field.

There has been a surge in the development of fluid and imaging biomarkers, including rapid progress toward a sensitive, specific, and accurate blood test for Alzheimer's that has excited the field. More tools that enable faster clinical trials give us hope for treatments on the horizon.

While we have seen promising treatments advance to the next phases of clinical trials and potential approval, I would be remiss to not acknowledge the ending of several later-phase trials employing beta-amyloid cleaving enzyme (BACE) inhibitors that brought disappointing results to study volunteers, their families and

researchers. We both recognize this disappointment and know that findings from these studies will bring valuable lessons to the field on how best to conduct clinical trials, and where to focus our energies moving forward. We are working with a group of industry and academic leaders to continue to evaluate BACE as a potential target in the future.

In addition to cautious optimism about treatments, there is palpable excitement about mounting evidence that modifiable risk factors may help ward off cognitive decline. The Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER) made history when results suggested that a multi-pronged approach combining health and lifestyle factors could improve or maintain cognitive function in at-risk older individuals. Several countries have followed suit, with research projects involving Australia, Singapore, China, Spain, Sweden, France, Germany and the United States comprising World Wide FINGERS (WW-FINGERS). In the United States, the Alzheimer's Association is committing \$35 million to the US Study to Protect Brain Health Through Lifestyle Intervention to Reduce Risk (US POINTER). The University of California, Berkeley, has been awarded a grant (R01AG062689) expected to total more than \$47 million over five years from the National Institute on Aging of the NIH to incorporate advanced brain imaging into US POINTER. The award will support the US POINTER Neuroimaging Ancillary Study, which will use amyloid and tau positron emission tomography and magnetic resonance imaging scans to assess the effects of multicomponent lifestyle interventions on the brain, including overall and regional brain shape, size and blood flow, and indicators of heart health risk and small vessel disease. This imaging study is the first large-scale US investigation of how lifestyle interventions — including exercise, diet, cognitive stimulation and health coaching — affect biomarkers of Alzheimer's and dementia in the brain.

Biomedical dementia research is experiencing unprecedented advances, and the field of psychosocial and behavioral research is also advancing. With an NIH award expected to total more than \$1.3 million over five years, the Alzheimer's Association is establishing an international research network called Leveraging an Interdisciplinary Consortium to Improve Care and Outcomes for Persons Living with Alzheimer's and Dementia (LINC-AD) to improve care and psychosocial outcomes for individuals with dementia.

By securing these much-needed dollars, the US government ensures that Alzheimer's and dementia research grows at home. But Alzheimer's and dementia affect all countries of the world, and we must come together in partnership, collaboration, and global sharing to bring research successes to every nation.

Dr. José Luis Molinuevo, Scientific Director of the Alzheimer Prevention Program at BarcelonaBeta Brain Research Center (BBRC) and member of ADI's Medical and Scientific Panel (MSAP) Executive Committee shares his view on recent breakthroughs on the treatment of Alzheimer's disease:

"After years of disappointing news regarding trial results in Alzheimer's disease, recently we have been facing some positive ones. On one hand, Biogen announced that they are filing to the US Food and Drug Administration (FDA) the results of their phase 3 Aducanumab trials, which have shown a cognitive benefit in those patients treated at the highest dose. Independent of the FDA resolution, this is good news that benefits the Alzheimer's field and brings hope to AD drug development. On the other, Green Valley announced that China's National Medical Products Administration has approved Oligomannate (GV-971) as a new drug for the treatment of mild to moderate Alzheimer's disease and improving cognitive function.

The timelines and implications for the field regarding the potential approval of Aducanumab or that of Oligomannate coming into the market are very different. If Aducanumab is approved, it implies that removing amyloid, even when the brain is full of amyloid plaques and tau tangles, has a clinical benefit on top of some biomarker associated ones. Additionally, Aducanumab could be in the US market next year and would be targeting an earlier population, patients with prodromal or mild Alzheimer's dementia that will need, from a regulatory perspective, biomarker confirmation of Alzheimer's pathology. There are two immediate inferences to this fact; one, that not everybody with prodromal or mild Alzheimer's dementia will be a candidate for the drug, since between 20- 30% of them may not have underlying AD pathology and the second, that we have to get ready for biomarker testing of our patients if we are willing to offer them compounds like Aducanumab. To start with, current memory clinics and dementia departments will need to invest and adapt their operating procedures in order to incorporate either core Alzheimer's cerebrospinal fluid biomarkers testing or amyloid PET for offering

a biomarker-based diagnosis. In addition, they will have to increase their capacity for providing i.v. medication, since Aducanumab will be administered through continuous intravenous infusion. Finally, it is possible that regulatory bodies ask for sequential MRI follows ups to ensure safety through monitoring the presence of ARIAs (amyloid related imaging abnormalities). The remaining question is how paying bodies, mostly private in the US but government funded ones in Europe, will react to Aducanumab approval and how willing will they be to pay for the first disease modifying drug entering our field. In my opinion, although prescriptions may be limited to those fulfilling the regulatory criteria and also able to tolerate the dose showing benefit, this will be an important opportunity for introducing new therapeutic approaches that can be both a game changer and a potential solution for preventing Alzheimer's disease if we trial them earlier in the continuum.

On the other hand, Green Valley Oligomannate (GV-971) approval in China for the treatment of mild to moderate AD is aiming to replicate their positive results in a global trial. If positive, this compound will be used in mild to moderate dementia of the Alzheimer type and will not require biomarker confirmation of Alzheimer's pathology. Therefore, we may have an additional compound to complement the symptomatic benefit offered by current approved drugs in a few years to come. Its introduction to the market will be technically easier, since no biomarkers and no infusion will be needed, but in contrast will be competing with already existing well-known generic drugs.

Overall, I think these are good news and I remain optimistic with the hope that we can all keep on working together to defeat Alzheimer's disease."

"Overall, I think these are good news and I remain optimistic with the hope that we can all keep on working together to defeat Alzheimer's disease."

Dr. José Luis Molinuevo

Biogen and Eisai announce plans to file for market approval of Alzheimer's drug

In October 2019, Biogen and Eisai announced they plan to file for market approval for the drug aducanumab, an investigational drug for early Alzheimer's disease, following new analysis showing reduced clinical decline in people with early Alzheimer's disease.

The Phase 3 clinical studies ENGAGE and EMERGE were discontinued in March 2019 following futility analysis by an independent monitoring committee that indicated the trials were unlikely to succeed.⁸³

Following the discontinuation of EMERGE and ENGAGE, additional data from these studies became available. After reviewing this larger dataset from the Phase 3 EMERGE Study in close consultation with the US Food and Drug Administration (FDA), Biogen found that aducanumab had met its primary endpoint and showed a statistically significant reduction in slowing clinical decline versus placebo. However, the Phase 3 ENGAGE study did not meet its primary endpoint. The results in EMERGE related to cognition and function including memory, orientation, and language, as well as improving daily activities like conducting personal finances, performing household chores, and independently traveling out of the home. It is believed that the discrepancy between the earlier futility analysis of the drug and the new analysis of the larger dataset is largely due to patients' greater exposure to higher doses of aducanumab.

If approved, aducanumab would become the first therapy to reduce the clinical decline of Alzheimer's disease and would also be the first therapy to demonstrate that removing amyloid beta resulted in better clinical outcomes.

Biogen and Eisai have initiated a re-dosing study that aims to offer access to aducanumab to all eligible patients who were actively enrolled in the aducanumab studies in March 2019.

Samantha Budd Haeberlein, Vice President, Late-Stage Clinical Development at Biogen, said: *"We believe that these positive results for aducanumab represent a turning point for patients, caregivers, physicians, and scientists in the fight against Alzheimer's disease. We look forward to working with the FDA and regulators around the world to find a path to make the drug available to patients. Most importantly, we envisage a future where physicians may finally have an option to offer patients to help reduce clinical decline in Alzheimer's disease."*

Kate Swaffer, Chair, CEO and Co-Founder of Dementia Alliance International (DAI), said: *"It is with both excitement, but also some apprehension that people diagnosed with dementia receive this news. For too long the focus was only on a cure, and we have also had many failed trials. To know we may be close to a disease modifying drug, as we have for so many other chronic conditions such as diabetes, increases hope for us all."*

We are assured that Biogen will work towards filing for market approval for aducanumab as soon as possible, working closely with regulatory authorities, institutional review boards and principal investigators. They plan to submit their Biologics License Application to the FDA by when possible and will continue dialogue with regulatory authorities in international markets to make the drug available across the world.



Oligomannate (GV-971) Approved in China for Cognitive Improvement in Alzheimer's Disease

We asked two of the researchers that have been working on Oligomannate to summarise the current position for us, Jinhe Li, CEO of US Green Valley Pharmaceuticals and Jeffrey Cummings, Translational Science Lead Advisor for Shanghai Green Valley Pharmaceuticals:

Oligomannate (GV-971) is the first drug approved anywhere in the world for the treatment of Alzheimer's disease (AD) since 2003. The Chinese National Medical Products Administration (NMPA) approved the agent on November 2nd and it became available in Chinese pharmacies on December 29, 2019.

Oligomannate is a mixture of oligosaccharides derived from seaweed. Preclinical mechanistic studies demonstrated that Oligomannate suppressed Alzheimer-related changes in the gut microbiota; reduced the associated bacterial metabolites, decreased peripheral inflammation and, in turn, reduced the brain inflammation observed in the Alzheimer model mice. The intervention reversed the cognitive impairment in the mice.

A Phase 1 clinical trial demonstrated that Oligomannate is safe and well-tolerated. In a 24-week Phase 2 clinical trial with participants in mild to moderate phases of Alzheimer's disease (AD), Oligomannate showed trend effects on the AD Assessment Scale-cognitive subscale (ADAS-Cog) and significant impact on the Clinician Interview-Based Impression of Change with caregiver input (CIBIC+) in participants receiving doses of 450 mg twice daily.

The 36-week Phase 3 trial included 818 participants with mild-to-moderate AD administered 450 mg of Oligomannate twice daily or placebo. The trial was conducted at 34 sites in China. Participants were not on donepezil or any other cognitive-enhancing treatments. Oligomannate was safe and well tolerated; 82 per cent of participants assigned to active treatment completed the trial (compared to 84 per cent to those assigned to placebo). Oligomannate demonstrated efficacy in improving cognition with a significant drug-placebo difference on the ADAS-Cog and trial termination and sustained improvement from week 4 to week 36 of the trial. The drug-placebo difference increased over the course of the trial. There was a trend toward improvement on the CIBIC+ with the most severely impaired patients showing the greatest global improvement. There was no measurable improvement of daily function in the whole group; patients with the most severe cognitive improvement had significant functional benefit.

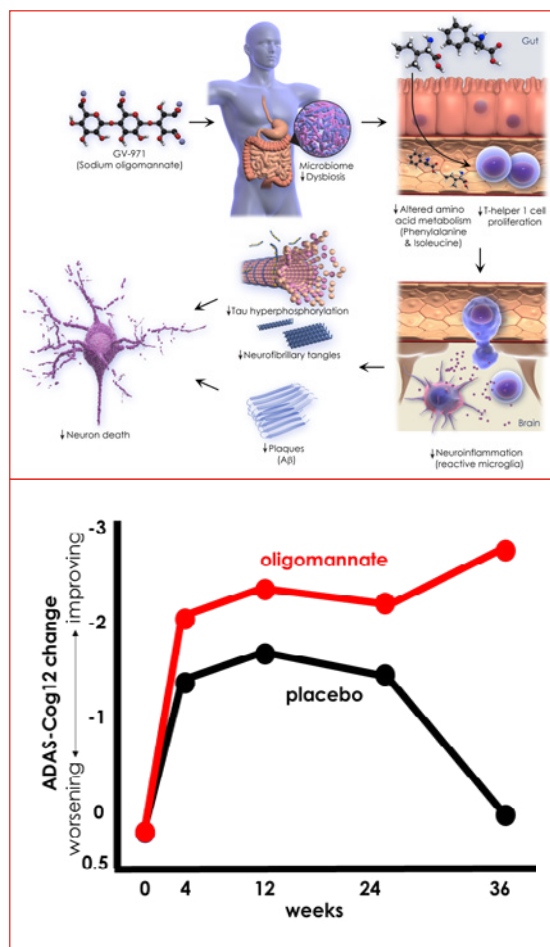


Figure 5. Putative mechanism of Oligomannate to reduce brain inflammation through its effects on the microbiome (©J Cummings; Illustrator M de La Flor) (top) Effects of Oligomannate on the ADAS-cog over the course of the 36-month trial (bottom).

Following its recent approval in China, Green Valley plans to submit marketing authorization applications in selected countries in 2020. In addition, Green Valley has consulted US Food and Drug Administration (FDA) and the European Medicines Agency (EMA) regulatory authorities regarding a planned a multi-national global phase 3 clinical trial (GREEN MEMORY) to support global regulatory filing of Oligomannate. The GREEN MEMORY trial will be initiated later this year at 200 sites across North America, Europe and the Asia Pacific. The 18-month trial will recruit 2100 participants with mild-to-moderate AD. Biomarkers will be collected to determine the mechanism of action in AD participants. Green Valley Pharmaceuticals welcomes global collaboration and partnership to accelerate cure/ treatments for AD.

STRiDE

In all seven STRiDE countries, field work focussing on stigma is well underway. Each country has run focus groups to help understand existing knowledge, attitudes and behaviours towards people with dementia and carers and their experiences of stigma and discrimination. Each country team is also in the process of finalising their situational analysis that describes the current dementia care, treatment, and support in their country – identifying gaps, but also opportunities for promoting policy change.

STRiDE has had to 'pause' all field work due to COVID-19, but country teams continue with data analysis and ongoing collaboration with national advisory groups, as well as research that can be done without face to face contact.

NGO partners are leading on the development of Knowledge Exchange, Impact and Engagement plans and attended a week-long workshop in London in January to share learning and discuss a mini-project on pathways to policy. The group held sessions on how to effectively plan, measure and demonstrate impact, how to engage with key stakeholders and communicate emerging evidence, and how to explore what persuades policy makers to initiate policy change. The group also discussed the key steps involved in moving from research into policy recommendations; with a particular focus on how the evidence emerging from STRiDE will help underpin the policy process – helping to zero-in on policy priorities that are feasible, cost-effective, and aligned with stakeholder and government priorities. Below are some views from colleagues who attended:

"Research is empowering, it brings hope. The meeting was important, not only as a great opportunity to share experiences and learn from other countries, but also in reminding us to keep our eyes on the impact we hope to achieve through this research project." *Dr Tara Puspitarini Sani, STRiDE-Indonesia NGO Lead*

"The meeting allowed me not only to know better the situation of other STRiDE countries and to see what unites us, the companionship of the NGOs allowed me to learn and realize what I can bring to my organisation. The situational analysis and the SWOT developed by the researchers in Mexico will be the basis of the work to developed with the different associations to be a single voice of dementia instead of many little voices seeking to have a greater impact at the federal level." *Rosa Farres, STRiDE-Mexico NGO Lead*

"Coming together with NGO leads in London last January was deeply inspirational to me and, I believe, to the whole team. The mutual sharing and caring put us all in the right mindset to take up the challenges one faces when supporting people living with dementia and their caregivers to live well. The discussions and reflections made clear the need for coordinated actions across stakeholders, and the importance of each one within this complex interplay of compromises. There is a lot to be embraced, and the week we spent together made me feel treasured and motivated to carry out the knowledge exchange, impact and engagement approaches and activities, in sync with the Brazilian team." *Elaine Mateus, STRiDE-Brazil NGO Lead*

STRiDE (Strengthening Responses to Dementia in Developing Countries) 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. The project aspires to go beyond research; to strengthen capacity in each country to conduct research and then to turn that research – using evidence,

advocacy, and stakeholder engagement – into actual policy change that will have a positive impact on the lives of people affected by dementia. 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.

The delisting of “anti-Alzheimer’s” drugs in France

Since June 2018, the French Government has totally delisted certain so-called “anti-Alzheimer’s” drugs. France Alzheimer and related diseases and the millions of people affected by dementia have shared the same sense of incomprehension and abandonment in response to this decision. Indeed, left with no alternative solution, and in response to the French Government’s intransigence, the Association decided, on September 2018, to conduct a national survey to raise awareness of the issue.

Its results identified three direct and worrying consequences:

1. The sudden cessation of the treatment is causing a brutal increase in cognitive impairments, affecting people’s quality of life. This deterioration was reported by 52 per cent of respondents.
2. Families already under pressure now have to pay considerably more for these treatments out of their own pockets: 2 out of 3 respondents were taking at least one of the four drugs when the announcement on delisting was made. 70 per cent of them have

no plans to stop their treatment. The main reason given, by 62.5 per cent of the respondents, was the effectiveness of their treatment. 20 per cent have stopped their treatment and 10 per cent expect to stop soon, mainly because of the excessive cost, especially given that VAT on these drugs has increased by 8 percentage points.

3. The therapeutic relationship between doctor and patient has broken down. Only 55 per cent of those who have decided to stop taking their treatment will continue to see a specialist, 38 per cent have already stopped doing so, and 7 per cent are considering it. This point represents a real threat for the diagnostic process, an essential prerequisite to a coordinated healthcare pathway.

Since the publication of these results France Alzheimer is strongly advocating for the French Ministry of Health to reinforce non-medicinal support for people with dementia. This is especially important as the national neurodegenerative diseases Strategy came to an end in December 2019.

Horizon Europe: a missed opportunity

When ADI saw the Mazzuccato report in 2018⁸⁴ – in which dementia was suggested as a major scientific priority going forward for Horizon Europe – we rejoiced, as we felt this could be the injection of enthusiasm and belief in dementia research we needed. Europe is lagging behind on research in comparison to the large investment made by the National Institute on Ageing in the US and all over the world it has been increasingly hard to attract young research talent in our field.

We observed with increasing disappointment the subsequent drafts which showed how Alzheimer’s disease had been dropped from the major priority spot and other diseases, not less deserving of course but perhaps less challenging, had taken its place.⁸⁵

When the final call showed that cancer had “won” and there was no mention of Alzheimer’s and dementia, we felt discouraged. We think all diseases are important and cancer is surely very important, but our World Alzheimer Report 2018⁸⁶ highlighted that for every 12 studies on cancer there is only 1 on neurocognitive disorders (not just Alzheimer’s or dementia). We have a massive chasm to fill and it will not be filled

by ignoring the problem. ADI has been successful in advocating the importance of dementia in much more challenging arenas, we successfully advocated for the WHO Global plan in 2017 and recently energetically and successfully advocated for dementia to appear in the G20 2019 declaration and subsequent Health Ministers declarations.^{87,3} Dementia is one of the biggest challenges of the 21st century; we need leadership, encouragement and funding, we need Europe to take a leading role. There are 50 million people living with dementia globally a figure forecasted to more than treble very soon. The disease also impacts hundreds of millions more through care. It is already a US\$1trillion per year condition and the one that people fear the most. Our World Alzheimer Report 2019 highlighted that 62 per cent of healthcare practitioners still erroneously think it is the product of normal ageing. We face an enormous challenge and one which Horizon Europe has so far failed to take on. We will need the entire Alzheimer’s and dementia movement to keep the pressure on if we want one of the wealthier coalitions on the planet to take on the role of leader in this field of research.

Bart de Strooper, Director of the UK Dementia Research Institute shares his views on why now is the time to step up our investments in dementia research:

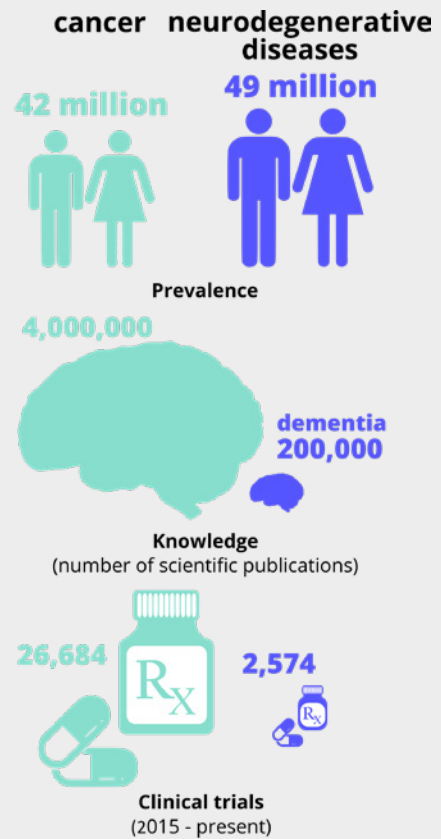
We continue to live longer lives, but this good news has a flipside: neurodegenerative disorders such as Alzheimer's are on the rise. After more than a decade of failed clinical trials, interest of the pharmaceutical industry is wavering. Yet, within the research community and in patient organizations optimism is growing. A dazzling amount of new insights are changing the way we view neurodegeneration and the people confronted with it.

New technologies have brought us a whole range of entirely novel drug candidates and therapeutic approaches to treat brain diseases, for example antisense therapy for Spinal Muscular Atrophy and Huntington's, therapeutic antibodies for Alzheimer's disease, or the array of new applications of gene therapy for Parkinson's disease. Together with the progress in imaging and early biomarkers, huge strides in early risk assessment, prevention and early diagnosis are within reach if we invest properly.

Did you know that, despite a similar disease prevalence, there have been 10-fold less clinical trials for neurodegenerative diseases than for cancer over the past five years? Also the number of scientific publications, a crude measure for the scientific knowledge generated, remains 20-fold lower for dementia than for cancer. As a result, brain diseases are currently among the most understudied clinical conditions. New strategies and approaches are required urgently to overcome barriers to curing neurodegenerative disorders.

In China, brain research is one of the six priority areas forming the Plan for the National Economy and Social Development, and the Chinese Institute for Brain Research launched in 2018 is designed to host

over 1,200 scientists and technicians in 100,000 m² research space. In the US, research support through the BRAIN Initiative reached over \$1.3 billion in 2019, while the yearly budget of the National Institute of Neurological Disorders and Stroke now surpasses \$2,000 million. It is obvious that the EU will simply lose its competitive edge if it ignores that final frontier of knowledge.



Sources: Global Burden of Disease Study, Pubmed, clinicaltrials.gov

“As a scientist, I remain optimistic. I truly believe that the advances made on a daily basis throughout research labs across the globe will change the lives of millions worldwide. In the near future, people will be younger and healthier when diagnosed with conditions such as Alzheimer's and Parkinson's, and we will have better options to care for them and help them manage their disease. We are on the verge of important breakthroughs. Now is the moment to invest more in research to radically transform the way we diagnose, care and treat dementia.” **Bart de Strooper**

ADI's CEO Paola Barbarino shares her views on the Lausanne Dialogues

The Lausanne Dialogues were created 6 years ago by the Swiss Government, OECD, the CEOi initiative and ADI. The purpose was to enable high level thinking and dialogue around a possible pharmacological breakthrough and the state of global readiness and preparedness in Alzheimer's and dementia between multilateral, bilateral and national governments, payers and regulators with the whole of the pharmaceutical industry, a small selection of university, NGOs and people with dementia in attendance. It sounds large but it is actually an intimate gathering by invitation only, with never more than 150 people attending.

In the last few years, in the absence of biomedical news, the emphasis had shifted to biomarkers but this year thanks to the Biogen announcement that a therapeutic breakthrough may be forthcoming with aducanumab, there was real buzz in the air and it was very interesting to see payer agencies at

last starting to ponder what could be a repayment model if we finally get medication that works. Much as it was interesting, it was, however equally disheartening to see how little they are prepared to deal with a breakthrough. Dementia and Alzheimer's are a huge and growing issue, we estimate well in excess of 50 million people have dementia globally and if anything is made available we can be pretty sure that millions will want it. But this is the value added of a gathering where we can candidly debate and ask these questions and hope that all participants will work with renewed energy on resolving these issues once they return home.

From ADI's perspective it is interesting to observe whether whatever may be available will be available for everyone in the world or if there will be inequalities in the way people can access treatment. This is our chance to remind participants that we must not leave anyone behind.



Paola presenting on a panel at the Lausanne Dialogues VI with Dr Marwan Sabbagh, Director of Banner Health Institute and Dr Tarun Dua, Department of Mental Health and Substance Abuse, WHO

Conclusion and recommendations

COVID-19 has highlighted the scale of the challenges faced by the global dementia community. It has also exacerbated the individual challenges of the millions of people living with dementia. It is evident that the pandemic has greatly impacted on post diagnostic support services globally and there is a real concern that it will impact on diagnostic pathways and disrupt research and clinical trials. The crisis has woken the world up to issues surrounding social care that ADI and others have been highlighting for years, and carers now more than ever need psychosocial support to allow them to continue caring under increased stress, impacting on their mental health, which research highlights as a concern at the best of times. The high numbers of deaths in care homes, in many European countries in particular, and often non-transparent reporting of this has, highlighted the need for disaggregated data on dementia and COVID-19. However, there is hope that the prophylactic and diagnostic developments highlighted in chapter 7 could change the prognosis for the 50 million people living with dementia.

Only three plans were launched since the last edition of this report was released in 2018. Based on our calculations, more than 26 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 – a herculean task. However, it is heartening to see so much progress towards national dementia policy and other services to support people with dementia, their carers and families. These developments have been maintained in the face of adversity, with countries like China, Germany, Iceland and India making progress through ingenuity and a genuine commitment to addressing the needs of people living with dementia, a group which has been greatly affected and most at risk during the COVID-19 pandemic. Maintaining political momentum is essential, but extremely difficult in the context of a multiplicity of worthy and competing causes within the global health landscape. However, the COVID-19 pandemic has shown the costs of inaction. The crisis has highlighted the already strong case for building robust health and social care systems which are adequately prepared to support the millions of people living with dementia, many of whom have other NCDs like diabetes and cardiovascular disease. We must ensure that dementia remains a priority during and after these unprecedented times. This will require some lateral thinking and innovation, like the NGOs in New Zealand combining efforts to propose a national plan to the government in anticipation of the general election campaign.

However, good intentions must also be married with strategic direction, and this is why the WHO's Global action plan is such a useful resource. Our research reveals that funding and prioritisation issues are key barriers to developing and implementing plans, and monitoring and evaluation of plans is a key consideration. It is encouraging to note that several plans are in the process of being evaluated, including the current plans of Scotland and Chinese Taipei. Several other countries are in the process of developing new plans, building on the insights offered by previous iterations – Czech Republic, Japan and the Netherlands to name a few. There is hope Kenya will be

the first country in sub-Saharan Africa to develop a national dementia plan. We must commend these developments, but not become complacent.

There is a lot of work to be done to unlock the potential of the landmark WHO Global action plan on dementia. Three years into the implementation of the plan, there are significant 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 breakthrough we also need much more research in all areas.

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.

Post-diagnostic support services are being provided by guarantee by a small number of countries, and day care services have adapted to meet the needs of populations restricted to their homes by physical distancing measures during the pandemic. More and more groups of people living with dementia and carers are being established, giving a powerful advocacy voice to all aspects of dementia from plan development to advising on health care development. Dementia friendly communities and initiatives keep evolving. The upcoming WHO toolkit on dementia friendly initiatives will provide a useful guidance to an action area of the Global plan which relies so heavily on the collaboration between partners, including national dementia associations.

From a research perspective, there are some robust research projects exploring the relationship between brain health, modifiable risk factors and dementia, such as the FINGER, SINGER and PREVENT studies, which importantly are globalising. Tools such as the WHO's risk reduction guidelines should provide evidence and concrete policy actions for policy-makers in this fast-growing area of resource and policy. The WHO's Global Dementia Observatory (GDO) will be an invaluable 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.

ADI calls on all governments to heed the lessons of the novel coronavirus outbreak and continues to call strongly for each of them to dedicate a minimum of 1 per cent of the societal cost of dementia to research. It is only through research that we will ultimately make the breakthroughs in risk reduction, treatment, care and cure that we all strive for. We must address the challenges and opportunities presented by the global COVID-19 pandemic with optimism and vigour.

References

- 1 World Health Organization (WHO). Global action plan on the public health response to dementia 2017–2025 (2017): https://www.who.int/mental_health/neurology/dementia/action_plan_2017_2025/en/
- 2 World Health Organization. Global Dementia Observatory (2019): <https://apps.who.int/iris/bitstream/handle/10665/272642/9789241514132-eng.pdf?ua=1>
- 3 Okayama Declaration of the G20 Health Ministers (2019): <https://www.alz.co.uk/sites/default/files/pdfs/G20%20Okayama%20Declaration%202019.pdf>
- 4 Public Health Agency of Canada. A Dementia Strategy for Canada (2019): https://www.canada.ca/content/dam/phac-aspc/images/services/publications/diseases-conditions/dementia-strategy/National%20Dementia%20Strategy_ENG.pdf
- 5 Alzheimer's Disease International (2020): <https://www.alz.co.uk/news/covid-19-sharing-experience-and-advice-from-adis-member-association-in-china>
- 6 Alzheimer's Disease International (2020): <https://www.alz.co.uk/content/adi-webinars-on-dementia-and-covid-19>
- 7 Alzheimer's Disease Chinese. Key messages on China's Mental Health and Psychological Support for Older Adults during the Outbreak of COVID-19 (2020): <https://www.alz.co.uk/sites/default/files/pdfs/MHPSS-Key%20messages-EN-min.pdf>
- 8 Alzheimer's Disease International and Prince, P. M., Comas-Herrera, M. A., Knapp, P. M., Guerchet, D. M., & Karagiannidou, M. M. World Alzheimer Report 2016: Improving Health Care for People Living with Dementia (2016): <https://www.alz.co.uk/research/WorldAlzheimerReport2016.pdf>
- 9 Alzheimer Italia. Coronavirus Emergency 10 useful tips to face the home-quarantine period with our relatives with dementia (2020): <https://www.alz.co.uk/sites/default/files/pdfs/Alzheimer-Italia-10-tips-for-quarantine.pdf>
- 10 Alzheimer's Disease International. World Alzheimer Report 2019: Attitudes to dementia (2019): <https://www.alz.co.uk/research/WorldAlzheimerReport2019.pdf>
- 11 World Alzheimer's Month campaign site: <https://www.worldalzmonth.org/>
- 12 ADI-PAHO campaign site: www.paho.org/lets-talk-dementia
- 13 Dementia Alliance International (2020): <https://www.dementiaallianceinternational.org/human-rights/convention-of-state-parties-on-the-crp-d/>
- 14 Dementia Alliance International. Hello my name is blog: <https://www.dementiaallianceinternational.org/hello-my-name-is-cheryl-day/>
- 15 Dr Linda Barclay and Glenn Rees and Alzheimer's Disease International (2019) World Alzheimer Report 2019: Attitudes to dementia. London: Alzheimer's Disease International. Page 94.
- 16 Cowan, T. (2019). College students' and community members' attitudes toward dementia: The impact of dementia friends sessions (2019) *Gerontology & Geriatrics Education*
- 17 O'Connor, M., and McFadden, S. Development of Psychometric Validation of the Dementia Attitudes Scale (2010) *International Journal of Alzheimer's Disease*.
- 18 World Health Organization. Risk reduction of cognitive decline and dementia: WHO guidelines (2019): https://www.who.int/mental_health/neurology/dementia/guidelines_risk_reduction/en/
- 19 Wu YT, Beiser AS, Breteler MMB, et al. The changing prevalence and incidence of dementia over time – current evidence. (2017) *Nat Rev Neurol* 13(6): 327–39.
- 20 Livingston G, Sommerlad A, Orgeta V, et al. Dementia prevention, intervention, and care. (2017) *The Lancet* 390(10113): 2673–734.
- 21 Cations M, Radisic G, Crotty M, Laver KE. What does the general public understand about prevention and treatment of dementia? A systematic review of population-based surveys (2018) *PLoS One*: 13(4).
- 22 Anstey KJ, Ee N, Eramudugolla R, Jagger C, Peters R. A Systematic Review of Meta-Analyses that Evaluate Risk Factors for Dementia to Evaluate the Quantity, Quality, and Global Representativeness of Evidence (2018) *Journal of Alzheimer's disease* 70(s1): S165–S86.
- 23 Prince M, Wimo A, Guerchet M, Ali G, Wu YT, M P. World Alzheimer Report 2015 – The Global Impact of Dementia: An analysis of prevalence, incidence, cost and trends. (2015): <https://www.alz.co.uk/research/WorldAlzheimerReport2015.pdf>
- 24 Prince M, Ferri CP, Acosta D, et al. The protocols for the 10/66 dementia research group population-based research programme (2007) *BMC public health* 7(1): 165.
- 25 Mukadam NS, N. Huntley, J. Livingston, G. Population attributable fractions for risk factors for dementia in low-income and middle-income countries: an analysis using cross-sectional survey data (2019) *Lancet Glob Health* 7: e596–603.
- 26 Sommerlad A, Ruegger J, Singh-Manoux A, Lewis G, Livingston G. Marriage and risk of dementia: systematic review and meta-analysis of observational studies (2018) *J Neurol Neurosurg Psychiatry*; 89(3): 231–8.
- 27 Sommerlad A, Sabia S, Singh-Manoux A, Lewis G, Livingston G. Association of social contact with dementia and cognition: 28-year follow-up of the Whitehall II cohort study (2019) *PLoS Med* 16(8): e1002862.
- 28 Williamson JD, Supiano MA, Applegate WB, et al. Intensive vs Standard Blood Pressure Control and Cardiovascular Disease Outcomes in Adults Aged >=75 Years: A Randomized Clinical Trial (2016) *JAMA* 315(24): 2673–82.
- 29 Group SMIftSR, Williamson JD, Pajewski NM, et al. Effect of Intensive vs Standard Blood Pressure Control on Probable Dementia: A Randomized Clinical Trial (2019) *JAMA*.
- 30 Peters R, Yasar S, Anderson CS, et al. An investigation of antihypertensive class, dementia, and cognitive decline: A meta-analysis. (2019) *Neurology*.
- 31 Peters R, Warwick J, Anstey KJ, Anderson CS. Blood pressure and dementia: What the SPRINT-MIND trial adds and what we still need to know. (2019) *Neurology* 92(21): 1017–8.
- 32 Richard E, Jongstra S, Soininen H, et al. Healthy Ageing Through Internet Counselling in the Elderly: the HATICE randomised controlled trial for the prevention of cardiovascular disease and cognitive impairment. (2016) *BMJ Open* 6(6): e010806.
- 33 Richard EMvC, EP. Hoevenaer-Blom, MP. Coley, N. Barbera, M. vander Groep, A. et al. Healthy ageing through internet counselling in the elderly (HATICE): a multinational, randomised controlled trial (2019) *Lancet Digital Health* 1(8): e424–e34.
- 34 Ritchie, C. W and Ritchie, K. "The PREVENT Study: A Prospective Cohort Study to Identify Mid-Life Biomarkers of Late-Onset Alzheimer's Disease. (2012) *BMJ Open* 2(6).
- 35 Ngandu et al. A 2 Year Multidomain Intervention of Diet, Exercise, Cognitive Training, and Vascular Risk Monitoring versus Control to Prevent Cognitive Decline in at-Risk Elderly People (FINGER): A Randomised Controlled Trial (2015).
- 36 Karen R, Guilhem R, Craig RW, Alain B, Vanessa P, et al. (2014) COGNITO: Computerized Assessment of Information Processing. *J Psychol Psychother* 4: 136.
- 37 See the following link for additional information: https://www.who.int/mental_health/neurology/dementia/guidelines_risk_reduction/en/
- 38 See the following link for reference and additional information: <https://www.moph.gov.qa/english/strategies/Supporting-Strategies-and-Frameworks/QatarNationalDementiaPlan/Pages/default.aspx>
- 39 NCD Alliance, Better Health, Better Lives – Norway's development strategy on NCDs (2019): <https://ncdalliance.org/resources/better-health-better-lives-norways-development-strategy-on-ncds>
- 40 Nguyen, T.A., et al., Towards the development of Vietnam's national dementia plan—the first step of action (2019) *Australas J Ageing*.
- 41 World Bank, Taking stock: An update on Vietnam's recent economic developments – Special focus: Promoting healthy and productive aging in Vietnam (2016): <http://documents.worldbank.org/curated/en/201841468616790980/pdf/107004-WP-PUBLIC.pdf>
- 42 Williamson, C., Policy Mapping on Ageing in Asia and the Pacific – Analytical Report (2015) HelpAge International: <https://www.refworld.org/pdfid/55c9e6664.pdf>

- 43 Alzheimer's Disease International, Dementia in sub-Saharan Africa: Challenges and opportunities (2017): <https://www.alz.co.uk/research/dementia-sub-saharan-africa.pdf>
- 44 Jodi L. Liu et al. Assessing the Preparedness of the U.S. Health Care System Infrastructure for an Alzheimer's Treatment (2017): https://www.rand.org/pubs/research_reports/RR2272.html
- 45 Jakub P. Hlavka et al. Assessing the Preparedness of the Health Care System Infrastructure in Six European Countries for an Alzheimer's Treatment (2018): https://www.rand.org/pubs/research_reports/RR2503.html
- 46 Alzheimer's Disease International (2020): <https://www.alz.co.uk/news/new-blood-test-research-for-diagnosis-of-alzheimer-s-disease-shows-promising-results>
- 47 OECD, Care Needed: Improving the Lives of People with Dementia, (2018): *OECD Health Policy Studies*.
- 48 Reynolds, E, CNN: The world sacrificed its elderly in the race to protect hospitals. The result was a catastrophe in care homes (2020): <https://edition.cnn.com/2020/05/26/world/elderly-care-homes-coronavirus-intl/index.html>
- 49 Comas-Herrera, M. A., et al. Mortality associated with COVID-19 outbreaks in care homes: early international evidence (2020): <https://ltccovid.org/wp-content/uploads/2020/05/Mortality-associated-with-COVID-21-May.pdf>
- 50 Center of Old Age and Aging Studies, Pontificia Universidad Católica de Chile, International Conference on Human Rights of older persons & non-discrimination (2017): <https://www.ohchr.org/Documents/Issues/OlderPersons/ConferenceSantiagoReport.pdf>
- 51 Alzheimer's Disease International, Global Alzheimer's & Dementia Action Alliance and Alzheimer's Pakistan, Forgotten in a Crisis Addressing Dementia in Humanitarian Response (2019): <https://www.alz.co.uk/forgotten-in-crisis-addressing-dementia-humanitarian-response>
- 52 NCD Alliance Bridging the Gap on NCDs From global promises to local progress (2020): https://ncdalliance.org/sites/default/files/resource_files/Bridging%20the%20Gap_Brief_FINAL.pdf
- 53 Prevent Epidemics, COVID-19 pandemic severity assessment framework by age (2020): <https://preventepidemics.org/covid19/science/insights/covid-19-pandemic-severity-assessment-framework-by-age/>
- 54 Bernstein, Johnson, Kaplan, McGinley, Independent: Coronavirus damages kidneys and hearts as well as lungs, US doctors find (2020): <https://www.independent.co.uk/news/world/americas/coronavirus-symptoms-lung-kidney-heart-covid-19-us-doctors-a9466701.html>
- 55 Naicker, S. et al, The Novel Coronavirus 2019 epidemic and kidneys (2020) *Kidney International* 97, 824–828.
- 56 Perel P, Grobbee DE. The Heart in the Time of the 'Coronavirus' (2020) *Global Heart* 15(1):24.
- 57 Jing-Wei Li et al, The impact of 2019 novel coronavirus on heart injury: A systemic review and Meta-analysis (2020) *Progress in Cardiovascular Diseases* doi: 10.1016/j.pcad.2020.04.008
- 58 WHO rapid assessment of service delivery for NCDs during the COVID-19 pandemic: <https://www.who.int/publications/m/item/rapid-assessment-of-service-delivery-for-ncds-during-the-covid-19-pandemic>
- 59 Hodge, S et al., Second English National Memory Clinic Audit Report conducted by the Royal College of Psychiatrists funded by the Department of Health (2015): <https://docplayer.net/21488635-Second-english-national-memory-clinics-audit-report.html>
- 60 National Institute for Health and Care Excellence, Dementia: assessment, management and support for people living with dementia and their carers (2018): <https://pathways.nice.org.uk/pathways/dementia#path-view%3A/pathways/dementia/dementia-management.xml&content-view-node%3Anodes-interventions-to-promote-cognition-independence-and-wellbeing>
- 61 National Collaborating Centre for Mental Health, The Dementia Care Pathway: Appendices and helpful resources (2018): https://www.rcpsych.ac.uk/docs/default-source/improving-care/nccmh/dementia/nccmh-dementia-care-pathway-appendices-and-helpful-resources.pdf?sfvrsn=af44de5d_10
- 62 Ipsos MORI (2016), 'Dementia Advisers Survey: Survey of provision of dementia adviser services', Online, accessed 06/02/2020: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/513191/Dementia_Advisers_Full_Report.pdf
- 63 Welsh Government, Book Prescription Wales (2019): <http://www.wales.nhs.uk/ourservices/initiatives/bookprescriptionwales>
- 64 Samsi, K and Manthorpe, J, Care pathways for dementia: current perspectives (2014) *Current Interventions in Aging* 9: 2055–2063.
- 65 Dementia Roadmap: <https://dementiaroadmap.info/>
- 66 KPMG, Dementia services pathways – an essential guide to effective service planning (2014): <http://www.wimmerapcp.org.au/wp-gidbox/uploads/2014/04/KPMG-2011-Dementia-Services-Pathways.pdf>
- 67 Naidoo, M and Bullock, R, An Integrated care Pathway for Dementia: Best Practice for Dementia care (2001) *Kingshill Research Centre*.
- 68 Fazio, S et al, Alzheimer's Association Dementia Care Practice Recommendations (2018) *The Gerontologist*, Volume 58, Issue suppl.1.
- 69 Alzheimer's Association Alzheimer's disease facts and figures (2014) *Alzheimer's & Dementia*, 10 (2): e47–e92.
- 70 Brodaty, H. and Hadzi-Pavlovic, D., Psychosocial effects on carers of living with persons with dementia (2019) *Australian and New Zealand Journal of Psychiatry*, 24: 351–361.
- 71 Recommend reading for fuller discussion and references: Seeher K, Brodaty H, Family carers of people with dementia, in *Dementia*, 5th Ed. Eds Ames D, O'Brien JT, Burns A 2017, pp142–160.
- 72 Brodaty, H and Donkin, M, Family caregivers of people with dementia, *Dialogues Clin Neurosci* 2009;11(2):217–28.
- 73 Schulz, R. et al., Resources for Enhancing Alzheimer's Caregiver Health (REACH): Overview, Site-Specific Outcomes, and Future Directions (2003) *Gerontologist* 43(4): 514–520.
- 74 Care of Persons with Dementia in their Environments (COPE): <https://fsrtc.ahslabs.uic.edu/cope/>
- 75 Hanson, E, Magnusson, L and Nolan, J, Swedish experiences of a negotiated approach to carer assessment: the Carers Outcome Agreement Tool (2008) *Journal of Research in Nursing* 13 (5) 391–407.
- 76 World Health Organization, WHO iSupport: a programme for Carers of People Living with Dementia (2019): https://www.who.int/mental_health/neurology/dementia/isupport/en/
- 77 Dementia Australia, Dementia Help Sheets to navigate coronavirus (COVID-19): <https://www.dementiadaily.org.au/tips-for-people-living-with-dementia-their-families-and-carers-in-relation-to-coronavirus-covid-19/>
- 78 World Health Organization, Global Dementia Observatory (GDO) country profiles (2020): https://www.who.int/mental_health/neurology/dementia/GDO_country_profiles/en/
- 79 Long, R, Finding a Path for the Cure for Dementia: An independent report into an integrated approach to dementia research (2015): https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/451874/DH_DementiaReport_acc.pdf
- 80 Prime Minister's challenge on dementia 2020 (2015): <https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020/prime-ministers-challenge-on-dementia-2020>
- 81 Seventy-third World Health Assembly A73/32 Provisional agenda item 23, Progress reports: Global action plan on the public health response to dementia 2017–2025 (decision WHA70(17)(2017)): https://apps.who.int/gb/ebwha/pdf_files/WHA73/A73_32-en.pdf
- 82 Pickett, J and Brayne, C. The scale and profile of global dementia research funding (2019) *The Lancet* 394(10212): P1888–1889.
- 83 Alzheimer's Disease International (2019): <https://www.alz.co.uk/news/biogen-and-eisai-remain-committed-after-discontinuation-of-engage-and-emerge-programmes>
- 84 Mazzucato, M, Mission-Oriented Research & Innovation in the European Union: A problem-solving approach to fuel innovation-led growth (2018) *European Commission*: https://ec.europa.eu/info/sites/info/files/mazzucato_report_2018.pdf
- 85 Presidency Non-Paper in view of preparation of the COMPET Council on 19 February 2019: https://www.politico.eu/wp-content/uploads/2019/02/SPOLITICO-19021821470.pdf?utm_source=POLITICO.EU&utm_campaign=e050e22208-189556261
- 86 Alzheimer's Disease International, Patterson, C., World Alzheimer Report 2018 The state of the art of dementia research: New frontiers (2018): <https://www.alz.co.uk/research/world-report-2018>
- 87 Alzheimer's Disease International (2019): <https://www.alz.co.uk/news/dementia-and-healthy-ageing-given-prominent-focus-at-g20>

Appendix A

Table of states represented by region, ADI status, plan stage and status

Country	Region	ADI member / development	Plan stage	Plan status
Afghanistan	Asia Pacific			
Albania	Europe	YES	STAGE 2B	Initial meetings with government but no further progress
Algeria	Africa			
Andorra	Europe			
Angola	Africa			
Antigua and Barbuda	Caribbean			
Argentina	Americas	YES	STAGE 2C	Proposed national strategy 2016, regional plan in Tucumán province
Armenia	Europe	YES	STAGE 2B	Initial meetings with government but no further progress
Aruba	Caribbean	YES	STAGE 2	The Government has initiated some activities such as a dedicated Council on Ageing
Australia	Asia Pacific	YES	STAGE 4A	National Framework on Dementia 2015–2019 , but inadequate funding; GDO pilot
Austria	Europe	YES	STAGE 4A	Plan 2015 , but inadequate funding
Azerbaijan	Asia Pacific			
Bahamas	Caribbean			
Bahrain	Middle East			
Bangladesh	Asia Pacific		STAGE 1	No plan , though ageing and NCDs are Government priorities; GDO pilot
Barbados	Caribbean	YES	STAGE 3B	In development
Belarus	Europe			
Belgium	Europe	YES	STAGE 2D	No plan, but regional dementia plans in Flanders and Wallonia
Belize	Americas			
Benin	Africa			
Bermuda	Caribbean	YES	STAGE 1	Association trying to connect with government
Bhutan	Asia Pacific			
Bolivia	Americas	YES	STAGE 1	Association trying to connect with government
Bonaire	Caribbean	YES	STAGE 4	National Plan has been development , implementation to follow
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 2B	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	Plan in development
Bulgaria	Europe	YES	STAGE 2	Currently no plan, but dementia is expected to be included in new Health Strategy in 2021
Burkina Faso	Africa			
Burundi	Africa	YES		
Cambodia	Asia Pacific			
Cameroon	Africa	YES	STAGE 1	Association trying to connect with government
Canada	Americas	YES	STAGE 4A	National Dementia Strategy launched in 2019, with some funding committed
Cape Verde	Africa			
Cayman Islands	Caribbean	YES	STAGE 2B	Initial meetings with government but no further progress
Central African Republic	Africa			

Country	Region	ADI member / development	Plan stage	Plan status
Chad	Africa			
Chile	Americas	YES	STAGE 5	Plan 2017 , but plan needs a push, to go beyond diagnosis, and geographically beyond limited geographical coverage; GDO pilot
China	Asia Pacific	YES	STAGE 3B	Plan in development , dementia currently grouped under national health plan
TADA Chinese Taipei	Asia Pacific	YES	STAGE 5B	Dementia Plan 2018–2025 , plan being evaluated
Colombia	Americas	YES	STAGE 2A	Dementia incorporated into mental health policy
Comoros	Africa			
Congo	Africa			
Cook Islands	Asia Pacific			
Costa Rica	Americas	YES	STAGE 5A	Plan 2014–2024 , with several related laws and policies in place; GDO pilot
Côte d'Ivoire	Africa			
Croatia	Europe	YES	STAGE 3A & 3B	Strategy in development . Commission to be developed
Cuba	Caribbean	YES	STAGE 5A	Strategy 2016 , updated in 2017 to meet action areas of Global plan
Curacao	Caribbean	YES	STAGE 3B	Plan in development , good progress
Cyprus	Europe	YES	STAGE 3B	Draft of plan almost complete, but stalled due to competing priorities
Czech Republic	Europe	YES	STAGE 3C	Plan 2016–2019 expired . Slow progress on the new plan
Democratic Peoples Republic of Korea	Asia Pacific			
Democratic Republic of the Congo	Africa			
Denmark	Europe	YES	STAGE 4A	Plan 2009 , but only partially funded
Djibouti	Africa			
Dominica	Caribbean	YES		
Dominican Republic	Caribbean	YES	STAGE 3B	In development , GDO pilot
Ecuador	Americas	YES	STAGE 2B	No plan . Association in discussion with Ministry of Health, but competing priorities
Egypt	Africa	YES	STAGE 2B	
El Salvador	Americas	YES	STAGE 1	No plan
Equatorial Guinea	Africa			
Eritrea	Africa			
Estonia	Europe	YES	STAGE 3A	No plan , but Dementia Competence Centre established in 2018, with funding until 2021
Ethiopia	Africa			
Fiji	Asia Pacific			GDO pilot
Finland	Europe	YES	STAGE 4D	Plan 2012–2020 , but funding insufficient and will be replaced by a general ageing programme when it ends
France	Europe	YES	STAGE 2A	No plan , but evaluation of the Neurodegenerative diseases Plan 2014–2019 is upcoming; GDO pilot
Gabon	Africa			
Gambia	Africa			
Georgia	Europe	YES	STAGE 3C	Plan in development , but slow progress
Germany	Europe	YES	STAGE 3B	Plan in development , expected shortly
Ghana	Africa	YES		
Gibraltar	Europe	YES	STAGE 4	Strategy 2020
Greece	Europe	YES	STAGE 5	Plan 2018
Grenada	Caribbean		STAGE 2B	No plan , 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			

Country	Region	ADI member / development	Plan stage	Plan status
Guyana	Africa			
Haiti	Caribbean			
Honduras	Americas	YES	STAGE 1	No plan
Hong Kong SAR	Asia Pacific	YES	STAGE 3C	No plan , but in development
Hungary	Europe	YES	STAGE 3C	No plan , but in development; GDO pilot
Iceland	Europe		STAGE 5	National dementia strategy and action plan launched 2020
India	Asia Pacific	YES	STAGE 2B & 3A	Plan in development , progress stalled. Many other programmes relating to dementia
Indonesia	Asia Pacific	YES	STAGE 5B	Plan 2016 , but further funding needed
Iran	Middle East	YES	STAGE 3A	Plan in development , but progress stalled
Iraq	Middle East			
Ireland	Europe	YES	STAGE 5	Strategy 2011–2016 , continued beyond implementation phase but funding inadequate
Israel	Europe	YES	STAGE 4A	Plan 2013 , but funding challenges
Italy	Europe	YES	STAGE 4B	Plan 2014 , but funding challenges; GDO pilot
Jamaica	Caribbean	YES	STAGE 2B	Some contact with Ministry of Health; STRIDE team initiated and participates in a Jamaica Global Dementia Observatory Oversight Committee
Japan	Asia Pacific	YES	STAGE 5A	Plan 2015 , new plan in development; GDO pilot
Jordan	Middle East	YES	STAGE 3A	Regular meetings with Ministry of Health and funding committed to certain action areas; GDO pilot
Kazakhstan	Asia Pacific			
Kenya	Africa	YES	STAGES 2A & 3A	In development , Ministry of Health drafting plan, with Mental Health Taskforce established; dementia incorporated into grouped health plan
Kiribati	Asia Pacific			
Korea, Republic of	Asia Pacific	YES	STAGE 5	Plan 2015 , government preparing next plan
Kuwait	Middle East		STAGE 3	In development
Kyrgyzstan	Asia Pacific			
Lao People's Democratic Republic	Asia Pacific			
Latvia	Europe		STAGE 2A	In development , Mental Health Care Developments plan 2019–2020
Lebanon	Middle East	YES	STAGE 2B	No plan , but association in discussion with Ministry of Health; economic crisis
Lesotho	Africa	YES	STAGE 2B	No plan , but association in discussion with Ministry of Health
Liberia	Africa			
Libya	Africa			
Lithuania	Europe		STAGE 2B	No plan , but Initial meetings with government and a Dementia Working Group established
Luxembourg	Europe			Plan 2013
Macau SAR	Asia Pacific	YES	STAGE 5A	Policy 2016 , but has not been fully communicated, including on funding
Macedonia	Europe	YES		
Madagascar	Africa	YES	STAGE 2A & 2B	No specific plan , but dementia mentioned in the Mental Health strategic Plan and in the National Strategic Plan for Elderly People's Health (Plan stratégique National de Santé des Personnes Agées); Association in discussion with the Ministry of Health
Malawi	Africa			
Malaysia	Asia Pacific	YES	STAGE 3A & 3C	No plan , but progress towards plan; political changes
Maldives	Africa			GDO pilot
Mali	Africa			
Malta	Europe	YES	STAGE 5B	Strategy 2015–2023 , but no guarantee of funding in future
Marshall Islands	Asia Pacific			
Mauritania	Africa			

Country	Region	ADI member / development	Plan stage	Plan status
Mauritius	Africa	YES	STAGE 2C	No plan , but association in discussion with Ministry of Health; GDO pilot
Mexico	Americas	YES	STAGE 4A	Plan 2014 , including funding for some activities, but not adequate for the whole plan
Micronesia, FS	Asia Pacific			
Monaco	Europe	YES		
Mongolia	Asia Pacific		STAGE 2A	Dementia incorporated into National Strategy Programme for Healthy Ageing and Health of Older Persons 2014–2020
Montenegro	Europe	YES	STAGE 3C	Plan in development , but competing priorities
Morocco	Africa		STAGE 1	No plan
Mozambique	Africa			
Myanmar	Asia Pacific	YES	STAGE 2B	No plan , but association in discussion with Ministry of Health; GDO pilot
Namibia	Africa	YES	STAGE 2B	No plan , but association in discussion with Ministry of Health
Nauru	Asia Pacific			
Nepal	Asia Pacific	YES	STAGE 3A	No plan , but discussions with government and the government provides some financial support to people with dementia
Netherlands	Europe	YES	STAGE 5B	Plan 2013–2020 , with substantial funding. New plan being developed; GDO pilot
New Zealand	Asia Pacific	YES	STAGE 2C	No dementia-specific plan , but 2016 Healthy Aging Strategy has 2 specific action items on dementia and Dementia Action Plan presented to government
Nicaragua	Americas	YES	STAGE 2A	No plan , but plans to integrate dementia in National Mental Health Plan
Niger	Africa			
Nigeria	Africa	YES		No plan , but ageing plan in development reported in 2018
Niue	Asia Pacific			
Norway	Europe	YES	STAGE 4A/4B	Plan 2015–2020 , Ministry of Health committed to continuation of plan for 2020–2025, but no targeted funding
Oman	Middle East	YES	STAGE 2A & 2B	No plan , but dementia incorporated into National NCD Action Plan 2018
Pakistan	Asia Pacific	YES	STAGE 3C	Plan in development , including plan for Punjab province, but progress stalled
Palau	Asia Pacific			
Panama	Americas	YES		No plan
Papua New Guinea	Asia Pacific			
Paraguay	Americas			
Peru	Americas	YES	STAGE 2B	No plan , 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 3A	No plan , but National Healthy and Productive Aging Plan with National integrated Dementia Plan embedded in it, funded by WHO
Poland	Europe	YES	STAGE 2C	No plan , but dementia incorporated into treatment and care system dedicated to elderly people, and after consulting with Alzheimer associations the government is considering expanding funding under National Health Programme
Portugal	Europe		STAGE 3B	Regional Dementia Plans being developed
Puerto Rico	Caribbean	YES	STAGE 4B	Plan since 2015–2025 , but not implemented or funded
Qatar	Middle East	YES	STAGE 4A	Qatar National Dementia Plan 2018–2022 but no dedicated budget; GDO pilot
Rep. of Moldova	Europe			
Romania	Europe	YES	STAGE 2D	No plan , but dementia incorporated into Project Mental Health
Russian Federation	Europe	YES	STAGE 2A	National plan , but it has not been published
Rwanda	Africa			
Saint Kitts and Nevis	Caribbean	YES	STAGE 2B	No plan , but association in discussion with Ministry of Health
Saint Lucia	Caribbean			

Country	Region	ADI member / development	Plan stage	Plan status
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	Strategy 2017–2020 , currently under review
Senegal	Africa		STAGE 2A	No plan , but neurodegenerative diseases incorporated into national plan of action of the Ministry of health and social action
Serbia	Europe			
Seychelles	Africa		STAGE 2B	No plan , but association in discussion with Ministry of Health
Sierra Leone	Africa			
Singapore	Asia Pacific	YES	STAGE 5A	Plan , updated 2018
Sint Maarten	Caribbean	YES		
Slovak Republic	Europe	YES	STAGE 3C	Plan in development
Slovenia	Europe	YES	STAGE 4D	Strategy 2016–2020 and preparing for next plan; Long Term Care Act in development
Solomon Islands	Asia Pacific			
Somalia	Africa			
South Africa	Africa	YES	STAGE 2A & 2B	No plan , but dementia incorporated into incorporated in parts of the Mental Health, Ageing and NCD plans
South Sudan	Africa			
Spain	Europe	YES	STAGE 4B	National Alzheimer's Plan 2019–2023
Sri Lanka	Asia Pacific	YES	STAGE 2B	No plan , but possibility of integrating dementia into Mental Health Action Plan; political difficulties
Sudan	Africa			
Suriname	Americas	YES	STAGE 2B	No plan , but association conducting stakeholder meetings to initiate plan development
Swaziland	Africa			GDO pilot
Sweden	Europe	YES	STAGE 3B	Dementia Strategy 2018–2022 ; GDO pilot
Switzerland	Europe	YES	STAGE 4A	National Dementia Platform launched , but lack of funding; GDO pilot
Syrian Arab Republic	Middle East	YES	STAGE 1	
Tajikistan	Asia Pacific			
Tanzania, United Republic of	Africa	YES	STAGE 2A	No plan , but association in discussion with Ministry of Health and beginning to conduct stakeholder workshops
Thailand	Asia Pacific	YES	STAGE 2D	No plan , but new plan for Ageing Society and funding for dementia under Office of Non-formal Education, Ministry of Education
Timor-Leste	Asia Pacific			
Togo	Africa		STAGE 2A	No plan , but association in contact with Ministry of Health and dementia incorporated into grouped health plan; GDO pilot
Tonga	Asia Pacific	YES	STAGE 2C	No plan , 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	STAGE 2B	No plan , but potential to include dementia in National Mental Health policy; Dementia not included in national NCD plan
Tunisia	Africa	YES	STAGE 2A	Plan in development and integrated in mental health strategy but no funding and plans on hold; GDO pilot
Turkey	Europe	YES	STAGE 3B	National Dementia Strategy in development , expected soon
Turkmenistan	Asia Pacific			
Tuvalu	Asia Pacific			
Uganda	Africa	YES	STAGE 2B	No plan , but association in discussion with Ministry of Health and other stakeholders

Country	Region	ADI member / development	Plan stage	Plan status
Ukraine	Europe			
United Arab Emirates	Middle East	YES	STAGE 2B	No plan, but association in discussion with Ministry of Health
United Kingdom	Europe	YES	STAGE 5	Plan, see Appendix B for breakdown
United States of America	Americas	YES	STAGE 5B	Plan 2011, updated in 2019, substantial funding
Uruguay	Americas	YES	STAGE 2A & 3C	No plan but discussions with Ministry of Health; national mental health plan 2020–2027 includes dementia
Uzbekistan	Asia Pacific			
Vanuatu	Asia Pacific			
Venezuela	Americas	YES	STAGE 1	Plan previously in development, but political challenges
Vietnam	Asia Pacific		STAGE 3B	Government developing national plan on dementia, mental health and NCDs
Yemen	Middle East		STAGE 2C	No plan, but meetings with Ministry of Social Affairs and Labour to develop national Alzheimer association; humanitarian emergency
Zambia	Africa	YES	STAGE 2B	No plan, but Ministry of Health expressed commitment to developing a plan
Zimbabwe	Africa	YES	STAGE 2B	No plan, but association in discussion with Ministry of Health

Appendix B

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

Country	Region	ADI member / development	Plan stage	Plan status
Bonaire	Caribbean	YES	STAGE 4	National Plan has been developed, implementation to follow
Curacao	Caribbean	YES	STAGE 3B	Plan in development, good progress
Macau	Asia Pacific	YES	STAGE 5A	Policy 2016, but has not been fully communicated, including on funding
Northern Ireland	Europe	YES	STAGE 4D	Regional Strategy 2011, but plan under threat
Puerto Rico	Caribbean	YES	STAGE 4B	Plan since 2015–2025, but not implemented or funded
Scotland	Europe	YES	STAGE 5	Strategy 2017–2020, currently under review
TADA Chinese Taipei	Asia Pacific	YES	STAGE 5B	Dementia Plan 2018–2025, being evaluated
Wales	Europe	NO	STAGE 5A	Plan 2018–2022, being evaluated

About ADI

Alzheimer's Disease International (ADI) is the international federation of Alzheimer associations throughout the world. Each of our 102 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.



Alzheimer's Disease International

The global voice on dementia

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. ADI is partnered with Dementia Alliance International (DAI), a collaboration of individuals diagnosed with dementia providing a unified voice of strength, advocacy and support in the fight for individual autonomy for people with dementia.

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

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

Alzheimer's Disease International
57A Great Suffolk Street
London SE1 0BB
UK
Tel: +44 20 79810880
www.alz.co.uk



**Alzheimer's Disease
International**