

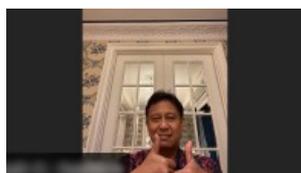
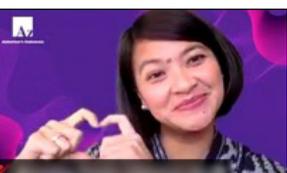


**Alzheimer's Disease
International**

The global voice on dementia

From Plan to Impact IV

*Progress towards targets of the
WHO Global action plan on dementia*



Authors

Paola Barbarino, Chris Lynch, Karen Watchman, Laura Dabas, Lewis Arthurton, Alzheimer's Disease International (ADI)

Contributors

Alireza Atri, MD, Chair of ADI Medical and Scientific Panel

Anna Borthwick, Executive Lead, Brain Health Scotland

Marco Blom, Scientific Director, Alzheimer Nederland

Dr Margaret Brown, University of the West of Scotland, Scotland

Professor Henry Brodaty, Scientia Professor of Ageing and Mental Health and Co-Director, Centre for Healthy Brain Ageing, University of New South Wales, Sydney, Australia

Neil Fullerton, Project and Communications Lead, Brain Health Scotland

Catherine Hall, Chief Executive, Alzheimer's New Zealand

Mira Josic de Hernandez, President of the Board of Trustees of the Fundación Alzheimer de Venezuela

Miia Kivipelto, Professor in Clinical Geriatrics at Karolinska Institute, Center for Alzheimer Research, and Director for Research & Development of Medical Unit Aging at Karolinska University Hospital in Stockholm, Sweden

Chelsea Kline, Associate Director, Center of Excellence, Alzheimer's Association, USA

Dr Karolina Kryszynska, Adjunct Research Fellow, School of Public Health and Preventative Medicine, Monash University, Australia

Dr Paul Kiwanuka-Mukiibi, Executive Director, Uganda Alzheimer Association

Shunichiro Kurita, MPM, Manager, Health and Global Policy Institute (HGPI)

Professor Gill Livingston, Professor of Psychiatry of Older People, UCL, London

Michael Dirk Roelof Maitimoe, Executive Director, Alzheimer's Indonesia

Francesca Mangialasche, MD, PhD, Center for Alzheimer Research, Karolinska Institute, Stockholm, Sweden

Maree McCabe, Chief Executive Officer, Dementia Australia

Alzheimer Scotland National Dementia Carers Alliance Network Research Group (NDCAN), Scotland

Katie Palmer, PhD, Center for Alzheimer Research, Karolinska Institute, Stockholm, Sweden

Ieva Petkute, Lead of Dementia Lithuania, Creative Director of Arts for Health Organisation "Socialiniai meno projektai", Senior Fellow of the Global Brain Health Institute (Trinity College Dublin / University of California San Francisco)

Glenn Rees, Honorary Vice President and Former Chair of ADI

Lenny Shallcross, Executive Director, World Dementia Council

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

Professor Craig Ritchie, Professor of the Psychiatry of Ageing, University of Edinburgh, Director of Brain Health Scotland

Dr Louise Ritchie, Reader, Alzheimer Scotland Centre for Policy and Practice, University of the West of Scotland, Scotland

Wendy Weidner, Research and Policy Project Lead, ADI

Tara Puspitarini Sani, Research Coordinator, Alzheimer's Indonesia

Alexandra Shchetkina, CEO, Foundation Alzrus, Russia

Kate Swaffer, CEO and Co-founder, Dementia Alliance International (DAI)

Professor Debbie Tolson, University of the West of Scotland and Scottish Dementia Research Consortium, Scotland

Yuda Turana, MD, Senior Researcher, STRIDE-Indonesia

ADI member associations

Brain Health Unit, World Health Organization

Acknowledgements

ADI would like to thank all national Alzheimer and dementia associations, and Dementia Alliance International for providing information included in this report.

ADI would like to thank the following corporate partners and donors for their support:

Anonymous Trust

Biogen

Eisai

Janssen

Novo Nordisk

Otsuka America Pharmaceutical, Inc.

Mary Oakley Foundation

F Hoffman-La Roche

The Van Otterloo Family

Published by Alzheimer's Disease International (ADI), London.
May 2021. Copyright © Alzheimer's Disease International.

Suggested citation: Alzheimer's Disease International (2021)
From plan to impact IV: Progress towards targets of the WHO Global action plan on dementia. London: Alzheimer's Disease International.



**Alzheimer's Disease
International**

The global voice on dementia

Contents

Foreword.....	4
Executive summary.....	6
Introduction.....	8
Methodology.....	13
CHAPTER 1	
Dementia as a public health priority.....	15
CHAPTER 2	
Dementia awareness and friendliness.....	26
CHAPTER 3	
Dementia risk reduction.....	34
CHAPTER 4	
Diagnosis, treatment, care and support.....	39
CHAPTER 5	
Support for dementia carers.....	51
CHAPTER 6	
Information systems for dementia.....	55
CHAPTER 7	
Dementia research and innovation.....	57
Summary.....	64
References.....	65
Appendix A – ADI member nations that are WHO Member States, with dementia plans represented by income group, plan stage, and status.....	66
Appendix B – ADI members (that are not WHO Member States) with dementia plans, represented by plan stage and status.....	72
Appendix C – Non-ADI members that are WHO Member States with no dementia plan.....	73

Foreword



Where are we at?

This is my 4th foreword to the *From plan to impact* report. We are now at the mid-way point of the WHO Global action plan on dementia, which should ultimately result in 146 Member States (countries) with National Dementia Plans by 2025. Currently, there are 40 national dementia plans globally, of which only 32 are in

WHO Member States. If we look at the WHO targets, the mountain to climb is now 114 plans by 2025 to reach the 146 country target. It is a mountain indeed!

There were positive moments in 2020, despite the pandemic gripping the world. Our members, Alzheimer and dementia associations in 5 continents, worked collaboratively and innovatively as never before. China, Dominican Republic, Germany and Iceland launched brand new plans and strategies. In one case, Italy, a long existing, but unfunded, plan finally got some funding.

The spirit of this report is to make sure that year after year we keep abreast of what is happening at a national level and translate that into calls to action. However, despite us being very alert and calling on governments and multilateral bodies to act at every opportunity, progress is still too slow.

The Global Dementia Observatory

It does not help that the main mechanism that this report was set up to monitor is still not running at optimal level. The Global Dementia Observatory (GDO) was set up by the WHO in 2017 to receive, update and make public, data from governments all over the world about their progress with the Global plan at national level. Yet, for the second year running there has been no published update of the data in the GDO. In the absence of new data, this report now provides the most updated published source of information on progress.

However, this report was not meant to, and nor does it, replace our need for the GDO. Our members need to see the data their governments provide to the WHO. This enables them to constructively engage with their ministries and challenge their data if they believe it does not reflect the reality on the ground. There are a number of good reasons why the WHO has had difficulties updating the GDO and we understand them. However, we do really need the data as soon as possible.

Ignoring Dementia

One of our biggest challenges continues to be that many governments do not have a way to classify dementia, it can sit awkwardly under a number of labels: mental health, brain health, non-communicable diseases, healthy ageing, sustainable development goals, universal health coverage and so on. This is not helping us at all as you can see from this quote from one of the contributors to the report:

"Furthermore, we have some specific challenges that have complicated the process towards a national dementia plan in Uganda. Apart from in textbooks, dementia or Alzheimer's disease remain undefined. There is no single word or phrase in any local languages to specify or describe the condition. In addition, from a policy perspective, there is no clarity over classification or categorisation of dementia as a disease. Currently, it falls under mental health although by default rather than planning. This presents the challenge that it is more difficult to develop a national plan and implement policy and practice for something that has neither a name nor policy 'home.'"

Paul Kiwanuka- Mukiibi, Uganda

Very recently, I had a meeting with the Minister of Health of a very populous nation who, halfway through the meeting, sent an aide to inform me that the Minister actually did not know what "dementia" was. As we all too readily know, dementia is overlooked in many countries as the stigma surrounding it is still very powerful, but it shows the scale of the challenge when a Minister of Health has no knowledge of what is currently the 7th leading cause of death globally and ranked in the top 3 in a growing number of countries.

COVID-19 and dementia

Also powerful is widespread ageism; witness the recent COVID-19 pandemic where many lives of older people were lost all over the world due to governments ignoring the clear and present danger the virus posed to them in a number of different and chilling ways. An example is the decision to deprioritise for treatment those having COVID-19 with dementia as an underlying condition.

Last year, I emphasised our concerns that COVID-19 would make governments go even slower in the implementation of their national plans, and that worry is still strong. Actually, COVID-19 is making the dementia crisis even bigger globally.

- Over 25% of deaths from COVID-19 were people living with dementia, who have been therefore disproportionately affected by the pandemic.
- Many people living with dementia have experienced cognitive deterioration from lack of social engagement due to isolation, shielding, distancing and lack of social services.
- Many carers and people living with dementia have seen the onset of depression and anxiety as a consequence of social distancing and lack of respite and care support.
- More recently, we have started to look at the impact of long COVID on the brain and there is a genuine concern we may be facing more onset of dementia as a consequence of COVID-19.

There are over 50 million people living with dementia in the world and at least 200 million people are likely to be impacted as family and friends. This crisis looks set to increase those numbers even more.

There are some interesting developments on the horizon, for example the WHO's new neurology and epilepsy global action plan may help us push the dementia action plan further but we are also concerned it may cause confusion, as in the Ugandan example above.

Diagnosis and post-diagnostic support

Other important developments this year include the increased need for timely diagnosis as the possibility of therapeutic breakthroughs is starting to materialise. However, diagnosis levels are still too low and post-diagnostic support even rarer. We will tackle this issue in greater depth in the World Alzheimer Report later this year. In the words of one of our members:

"It is a global imperative that we improve our dementia diagnosis rates. Consumers tell us that accessing support services early improves their understanding of dementia, their relationships and planning for the future and with the time it takes to diagnose dementia on average, it is critical that this is improved. We must significantly reduce the time it takes to diagnose dementia and increase the number of people accessing support without delay."

Maree McCabe, Chief Executive Officer, Dementia Australia

The movement grows stronger every day

The courage, resilience and determination of all those belonging to the dementia movement have been impossible to suppress, even in the face of all the obstacles thrown in our path by COVID-19. As we all work together to break the stigma surrounding the disease, we have created a strong momentum and a strong voice but we need to continue to press for change at every level to ensure a better life for people living with dementia and their families. We count on you to continue to work with us all.

Paola Barbarino
Chief Executive Officer
London, May 2021



Executive summary

Dementia is a global phenomenon, yet most people with a diagnosis live in low- and middle-income countries where access to services, support and care are limited. The World Health Organization (WHO) Global action plan on the public health response to dementia 2017–2025¹ aims to improve the lives of people with dementia and their carers,² while decreasing the impact of dementia on communities and countries. Alzheimer's Disease International (ADI) calls on the international community, in advance of the G7 and G20 planned for 2021, to recognise the growing inequality between different regions of the world in dementia prevention, diagnosis, treatment, care and support.

ADI produces the annual report, *From plan to impact*, to provide a critical update on the progress towards the WHO Global action plan. An important new point is that concerns highlighted in 2020 about potential disruption to dementia diagnosis due to COVID-19 have become a reality. Evidence of disruption in diagnosis is emerging due to a critical combination of appointments cancelled by healthcare professionals, some of whom have been relocated to other posts during the COVID-19 pandemic, or cancelled by families as a result of fear of infection from visiting hospital or medical centres.

The first three *From plan to impact* reports^{3 4 5} provided an overview of national responses to dementia around the world. By monitoring the results year on year, ADI have a clear vision of how fast (or slowly) nations are responding to the commitments of the Global action plan for dementia. Findings in this fourth report continue to demonstrate that targets are not being met quickly enough.



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

¹ The Global action plan on the public health response to dementia 2017–2025 can be accessed at: https://www.who.int/mental_health/neurology/dementia/action_plan_2017_2025/en/

² 'Carer' has been used throughout this report to refer to (unpaid) family members or friends, in contrast to employed 'care staff'.

³ From plan to impact: Progress towards targets of the Global action plan on dementia, 2018 <https://www.alzint.org/u/from-plan-to-impact-2018.pdf>

⁴ From plan to impact II: The urgent need for action, 2019 <https://www.alzint.org/u/from-plan-to-impact-2019.pdf>

⁵ From plan to impact III: Maintaining dementia as a priority in unprecedented times, 2020 <https://www.alzint.org/resource/from-plan-to-impact-iii/>

Key messages

- Globally 40 countries or territories have national dementia plans, 32 of which are WHO Member States.
- 2 of the 32 Member States, Finland and Russia, have integrated dementia plans under other policy areas; both address the targets and indicators that relate to the seven action areas of the WHO Global action plan and have ringfenced budgets.
- 28 new plans are needed annually to reach the WHO target of 146 plans (75% of Member States) by 2025. This is based on data collected from Alzheimer and dementia associations in April 2021 and assumes no additional plans are launched this calendar year.
- 21 countries are currently developing a national dementia plan or have integrated dementia within a wider health plan which is also in development.
- 141 WHO Member States do not yet have a plan in existence.
- 4 new national dementia plans were launched between May 2020 and May 2021: China, Dominican Republic, Germany, and Iceland.
- 3 existing plans have been positively evaluated and updated between May 2020 and May 2021 with new strategic plans in place: Norwegian Dementia Plan, 2025; Korean National Plan 4.0, and Netherlands National Dementia Strategy 2021–2030.
- 6 of the G7 nations have a national dementia plan.
- The WHO regions of Eastern Mediterranean and South East Asia have 1 national plan in each region, in Qatar and Indonesia respectively, while Africa has no plan yet in existence.
- Disruption caused by COVID-19 on health and social care exposed limitations in low- and middle-income countries due to fragile economies and weak infrastructure.
- Over 85% of ADI members and developing member associations reported knowledge of, or participation in, a dementia awareness campaign or dementia friendly activity, many as a direct result of participating in World Alzheimer's Month.

Recommendations

- ADI maintains that national dementia action plans are the best and most appropriate tool to bring about change. It is also recognised that some governments have developed integrated dementia plans under other policy areas, such as healthy ageing, mental health, neurology, or non-communicable diseases (NCD). In such circumstances, strategies or plans should always include the targets, indicators and, critically, ringfenced budgets that relate to the seven action areas of the WHO.
- ADI recognises valuable dementia-related care, activities and support provided by Alzheimer and dementia associations in countries where no national plan exists. This should be recognised by governments in order to inform future discussion and development in the knowledge that civil society, including community groups, non-governmental organisations, faith-based groups and membership associations, are often the driving force that facilitate change and instigate plan development at national level.
- ADI recommends that governments providing information to the WHO Global Dementia Observatory liaise with Alzheimer and dementia associations to ensure robustness and transparency of data.
- Urgent action is needed to investigate the potential increased risk of dementia caused by COVID-19 and to understand and mitigate the impact of COVID-19 on dementia diagnosis. Each government must take into account dementia and non-communicable disease risk factors in their COVID-19 response plans.
- While recognising country-specific contexts, ADI calls on governments to include principles of design for people with dementia in national plans, based on the recommendations from the *World Alzheimer Report 2020*.
- ADI urges governments developing and updating national dementia plans to include risk reduction messages, and to recognise the potential impact of such activities on individuals and society.
- ADI calls on all nations to support informal care, recognising that women make up a disproportionate amount of informal carers, a role that often reflects cultural norms.

Introduction

Over 50 million people globally have a form of dementia, with nearly 60% living in low- and middle-income countries.⁶ ADI predicts that this number will increase to 82 million in 2030 and 152 million in 2050, with a current annual cost of US\$ 1trillion, doubling by 2030.

This is the fourth *From plan to impact* report. It is being published at the half-way point in the 2017–2025 lifespan of the WHO Global action plan on the public health response to dementia and, as ever, it provides a critical update on progress. The action plan aims to improve the lives of people with dementia, their families and the people who care for them, while decreasing the impact of dementia on communities and countries. It contains targets in the seven action areas that individual governments have committed to meet by 2025. The WHO measures progress in relation to its own 194 Member States and requires periodical reporting on each of the action areas. This report aims to monitor the data provided by governments against the lived experience of ADI members, people living with dementia and their families.

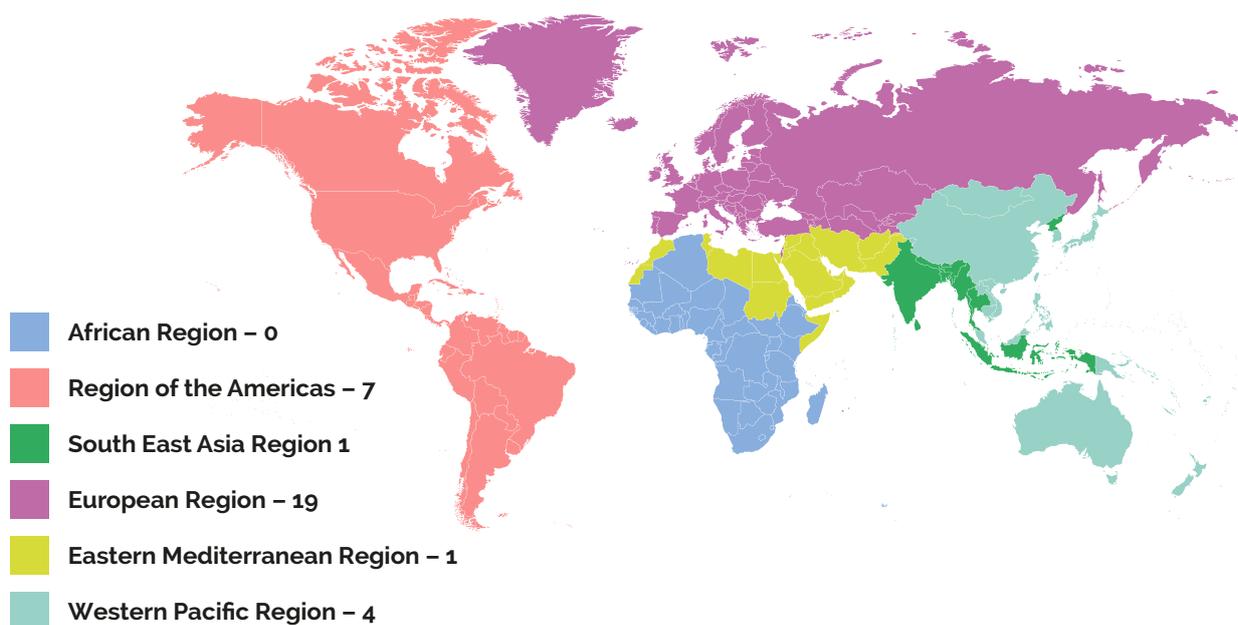
Within all *From plan to impact* reports, distinction has been made between 'countries' and 'territories' that have Alzheimer and dementia associations, and WHO Member States. It is important to note that not all countries and territories, where there are national plans for dementia, (and are members of ADI), are WHO Member States. When looking at national dementia plans by WHO region, the current breakdown of plans

presented, either standalone or integrated, is based on information received from member associations and associations on the ADI Membership Development Programme in April 2021. While ADI welcome, and are contributing to, the new WHO neurology action plan, it is vital that focus remains on the development of national dementia plans as required by the Global action plan on dementia.

Progress made towards the development or implementation of national plans has inevitably been affected by the COVID-19 pandemic which has been a public health priority for the duration of this reporting period, May 2020 – April 2021. Older people with dementia are particularly vulnerable to COVID-19 infection with physical confinement and increased isolation placing additional strain on wellbeing. Emerging evidence of cognitive impairment in all age groups as a result of COVID-19 may mean even larger numbers of people developing dementia in the future.

ADI calls on the international community, in advance of the G7 and the G20, at the time of writing scheduled to take place in the United Kingdom and Italy respectively in 2021, to urgently recognise the growing inequality globally in dementia prevention, diagnosis, treatment, care and support. Global leadership is required to promote the importance of developing and implementing national plans and to mitigate the impact of COVID-19 on people with dementia.

National Dementia Plans by World Health Organization Region



⁶ World Health Organisation, (2020) *Dementia*, Available at: <https://www.who.int/en/news-room/fact-sheets/detail/dementia>

Update from WHO on Dementia Global Status Report

In these unprecedented times, it is more important than ever to review progress and develop plans to strengthen health and social care systems for people living with dementia.

The WHO will release, during World Alzheimer's Month in September 2021, the Global Status Report on the Public Health Response to Dementia. The report will highlight new global dementia burden estimates and disease associated costs. The Global Status Report will also discuss the progress to date on achieving the global targets, based on data collected through the Global Dementia Observatory (GDO). This is an online data and knowledge exchange platform that allows the systematic monitoring of country level data and activities through 35 indicators pertaining to seven themes that are fully aligned with the seven action areas of the global action plan on the public health response to dementia 2017–2025. Throughout, the report will identify areas where more focused efforts are required in order to meet the 2025 targets, as well as showcase case studies highlighting best practices and opportunities to accelerate action.

Despite the global burden that neurological conditions impose, access to both services and support for such conditions is insufficient, especially in low- and middle-income countries. There also continues to be a lack of knowledge around neurological disorders, which in many countries is associated with high stigmatisation and discrimination. To address the growing burden of neurological disorders, a meeting of the 146th Executive Board in February 2020 requested the WHO to expand the scope of its technical report on epilepsy by adding a new section on *Synergies in addressing the burden of epilepsy and other neurologic diseases*.⁷ This section was presented as part of agenda item 11.6 on epilepsy during the 73rd World Health Assembly (WHA) in May 2020. Resolution WHA 73.10⁸ requests the Director-General to develop an Intersectoral global action plan on epilepsy and other neurological disorders 2021–2031 in consultation with Member States to ensure a comprehensive, coordinated response across multiple sectors.

To support the development of the new action plan, WHO organised formal virtual consultations on the discussion paper⁹ for the Intersectoral global action plan on epilepsy and other neurological disorders with Member States, United Nations agencies, and non-State actors including academic institutions, civil society and private sector. The draft Intersectoral global action plan on epilepsy and other neurological disorders will be submitted to the 150th session of WHO's Executive Board in January 2022, for consideration by Member States at the 75th World Health Assembly in May 2022.

WHO will release, during World Alzheimer's Month in September 2021, the Global Status Report on the Public Health Response to Dementia. The report will highlight new global dementia burden estimates and disease associated costs. The Global Status Report will also discuss the progress to date on achieving the global targets, based on data collected through the Global Dementia Observatory.

Through its life-course approach, the Intersectoral global action plan on epilepsy and other neurological disorders will help reinforce dementia as a global public health priority, within the broader context of neurological disorders. Similar to the Global action plan on the public health response to dementia 2017–2025, the Intersectoral global action plan on epilepsy and other neurological disorders will seek to prioritise neurological disorders within national policy agendas, harmonise a comprehensive response across health and social care systems and stakeholders, and ensure sustainable funding to support programmes for people living with neurological disorders, their families and carers. A strong focus will also be set on gender, equity and human rights, including to reduce stigma and discrimination, and empowering people with neurological disorders, their families and carers.

Brain Health Unit, WHO

⁷ The consolidated report can be accessed at https://cdn.who.int/media/docs/default-source/mental-health/a73-5-en.pdf?sfvrsn=4f601918_2

⁸ Resolution WHA 73.10 can be accessed at https://apps.who.int/gb/ebwha/pdf_files/WHA73/A73_ACONF2-en.pdf

⁹ The discussion paper can be accessed at <https://www.who.int/news-room/articles-detail/consultation-on-discussion-paper-on-global-action-plan-on-epilepsy-and-other-neurological-disorders>

What is a national dementia plan?

A national dementia plan is formally adopted by a government which commits to taking steps to encourage progress in key areas including dementia diagnosis, care, treatment, risk reduction, and research. The WHO recognises that creating and operationalising a dementia plan may involve a new standalone plan, strengthening an existing plan, or integrating dementia into existing dementia-related health plans. The WHO has developed a framework for every government to support the development of plans.¹⁰

While ADI maintains that national dementia action plans are the best and most appropriate tool to bring about change, it is also recognised that some governments have developed integrated dementia plans under other areas, such as healthy ageing, mental health, neurology, or non-communicable diseases. To be considered in this report, such strategies or plans should always include the targets, indicators, and ringfenced budgets that relate to the seven action areas of the WHO Global action plan on dementia. Each member nation can be guided by global targets when setting its own national targets, while taking into account their own circumstances. ADI recognises differences in available budgets and acknowledges competing priorities, including conflict and natural disasters, but reinforces the urgent need to develop robust dementia plans.

“The WHO framework really works, it helped us develop the plan.”
Ieva Petkute,
Dementia Lithuania

Towards a dementia plan: a WHO guide



ADI calls on governments to:

- acknowledge that there are cost saving benefits in implementing national plans, for example, in enabling people with dementia to live at home and in their community for as long as possible and desired.
- mitigate against unnecessary hospital admission.
- enable people with dementia and their carers to continue to be active and contributing members of society.

¹⁰ World Health Organization (2018) Towards a dementia plan: a WHO guide. Geneva: World Health Organization. Available at https://www.who.int/mental_health/neurology/dementia/policy_guidance/en/

7 action areas

1 Dementia as a public health priority



2 Dementia awareness and friendliness



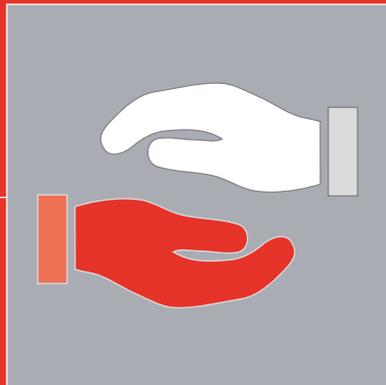
3 Dementia risk reduction



4 Diagnosis, treatment, care and support



5 Support for dementia carers



6 Information systems for dementia



7 Dementia research and innovation



Methodology

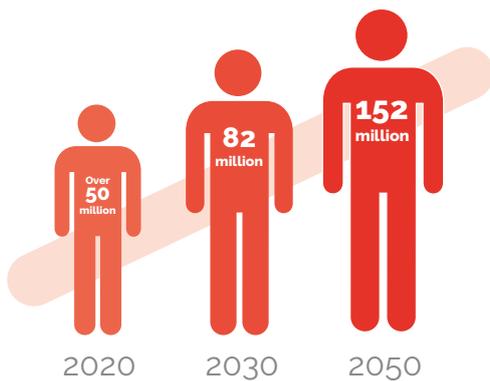


Around the world, there will be 1 new case of dementia every 3 seconds

To measure activity against the WHO Global action plan, ADI conducted desk-based research, and distributed a survey in April 2021 to 105 member associations, 13 developing associations on the Membership Development Programme,¹¹ and 4 other nations preparing to join the Development Programme, with an 89% response rate. Each member association is a national Alzheimer or dementia association in that country. A developing association refers to nations that are going through ADI's two-year Membership Development Programme and are aiming to demonstrate that they meet the required membership criteria.

The survey asked about the status of a national dementia plan, or dementia integrated into another policy area (global action area 1) based on 5 stages. It asked for examples of policy, research, and practice in relation to the remaining six action areas, and if COVID-19 had impacted on the diagnosis of dementia and provision of support.

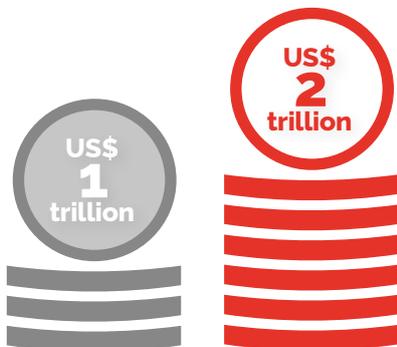
The ADI five stages of plan development, shown over the page, have been updated for 2021 to include progress towards plans that include dementia in an integrated plan under other areas or health issues.



Estimated growth in number of people with dementia 2020–2050

Report structure

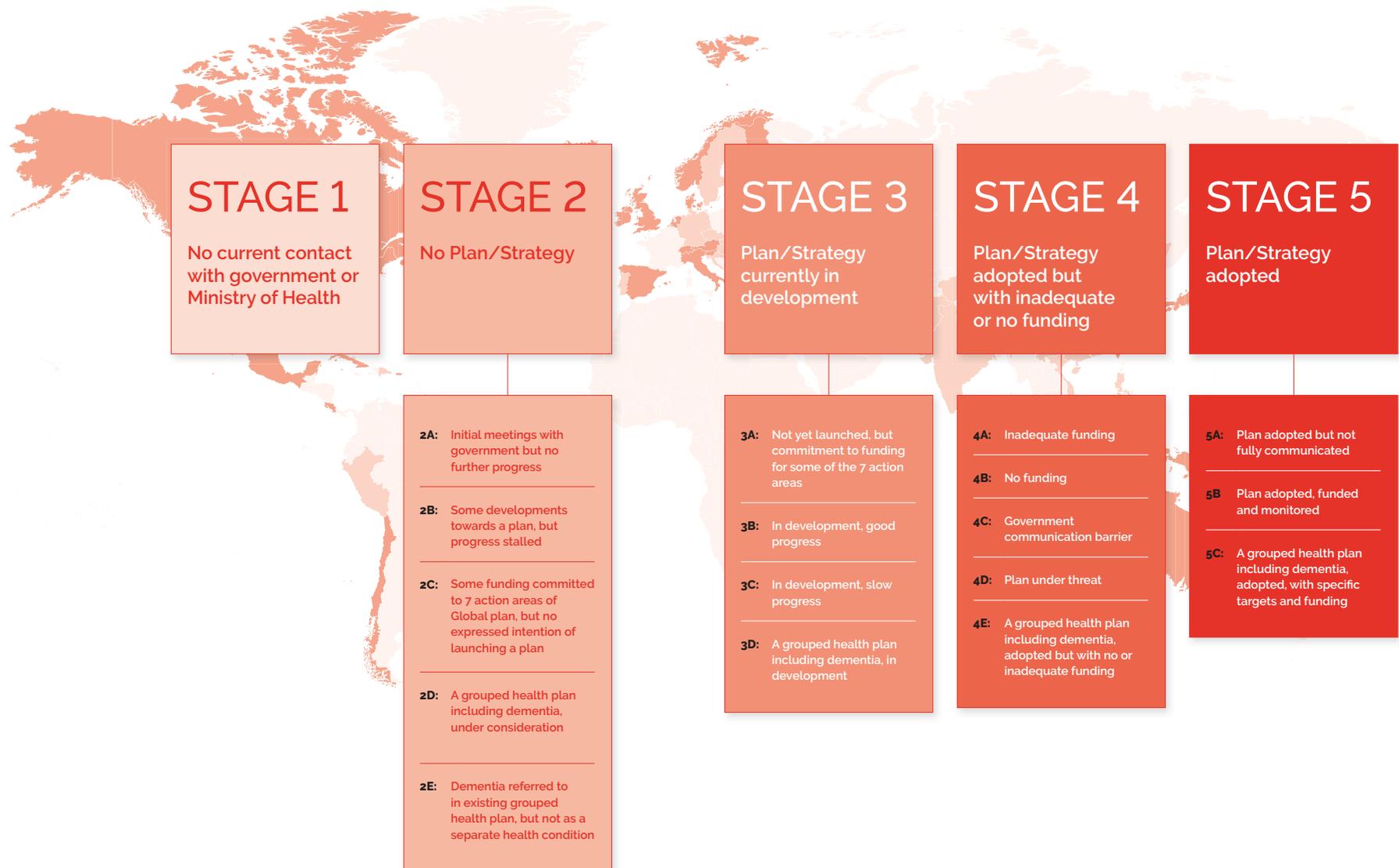
This report is structured into seven sections based on the WHO action areas. The first focuses on action area 1 with evidence from ADI member associations and leading experts who have been instrumental in the development or implementation of their national plan, or who are advocating for it in their country. The subsequent six sections provide policy and practice examples relating to actions areas 2–7. Brief case studies are included throughout that demonstrate significant global variation in developing or existing of plans. Examples are provided of good practice and challenges that have been faced, including as a result of the COVID-19 pandemic. The response of Alzheimer and dementia associations around the world to the pandemic demonstrates the extent of adaptation in support made available to people with dementia and their families. This innovation was developed in a short space of time, often with limited support from statutory services, with a range of services or activities moving online.



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

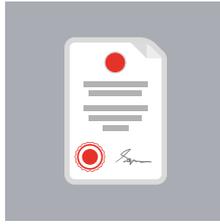
¹¹ The Membership Development programme is supported by ADI Alzheimer University; a series of workshops over three days. Participant associations set objectives at the end of the programme and are followed up on their progress after six and twelve months. <https://www.alzint.org/what-we-do/capacity-building/alzheimer-university/>

Stages of national dementia plan development



Chapter 1

Dementia as a public health priority

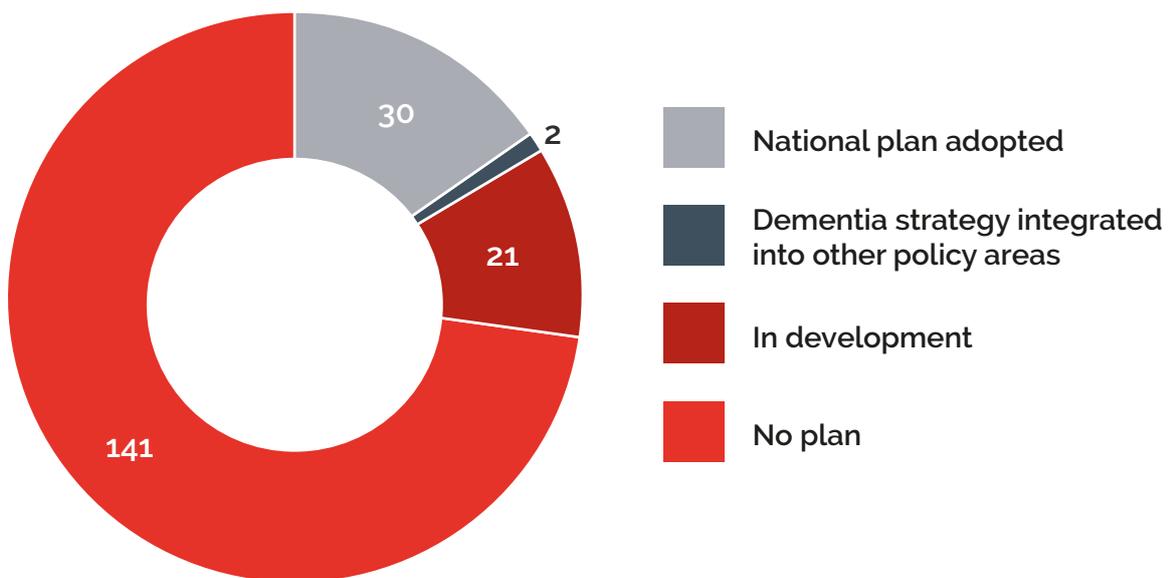


WHO target: 75% of countries (146 of 194) will have developed or updated national policies, strategies, plans or frameworks for dementia, either stand-alone or integrated into other policies/plans, by 2025

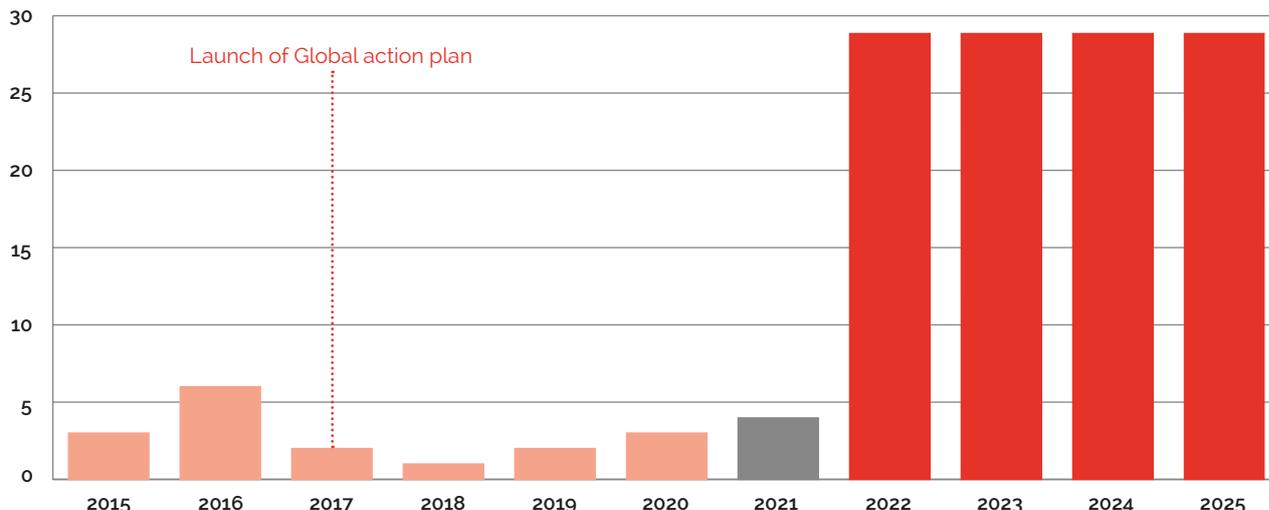
ADI continues to provide support and advice on the Global action plan and the development and implementation of national plans. This includes sub-national plans and non-governmental dementia strategies. Four years into the action plan, 32 national plans have been adopted among WHO Member States, 2 further dementia plans have been integrated into other policy areas, 21 are in development, 141 Member States have no plan. The 75% target, or 146 of 194 Member States, to develop national dementia plans by 2025 will not be met.

Currently, all G7 nations except one (France) have a national dementia plan, three of which are reported as funded. The majority of countries with a national dementia plan are in the WHO regions of Europe and North America in contrast to the region of Africa with no dementia plans, Eastern Mediterranean and South East Asia with one each, and Western Pacific with four. While there have been four new plans in the past year: China, Dominican Republic, Germany, and Iceland, 28 new plans are needed every year from 2022 to cover 75% of countries by 2025. This calculation is based on information available in April 2021 and an assumption of no additional plans launching during 2021.

WHO Member States implementation of national plans



Number of dementia plans adopted annually since 2015 (all states) and number of plans needed every year to meet WHO 2025 target of 75% of Member States.



28 new plans needed every year from 2022 to cover 75% of Member States by 2025. This calculation is based on information available in April 2021 and an assumption of no additional plans launching this calendar year.

National dementia plans – terminology explained

National dementia plans, developed by national governments, aim to address issues tailored to specific countries.

They typically include public awareness and deal with improving health and social care for people with dementia and their families.

In some countries, sub-national plans have been developed by region, province, canton, or state when deemed appropriate.

Non-governmental dementia strategies exist in India and New Zealand. Here, the strategies are generated by non-governmental groups to persuade governments to create a national or sub-national plan.

In some countries, governments have integrated dementia in plans under other areas or health issues, such as healthy ageing, mental health, neurology, or non-communicable diseases. However, in order to be considered in this report, such strategies or plans should always include the targets and indicators that relate to the seven action areas of the WHO plan with associated budgets.

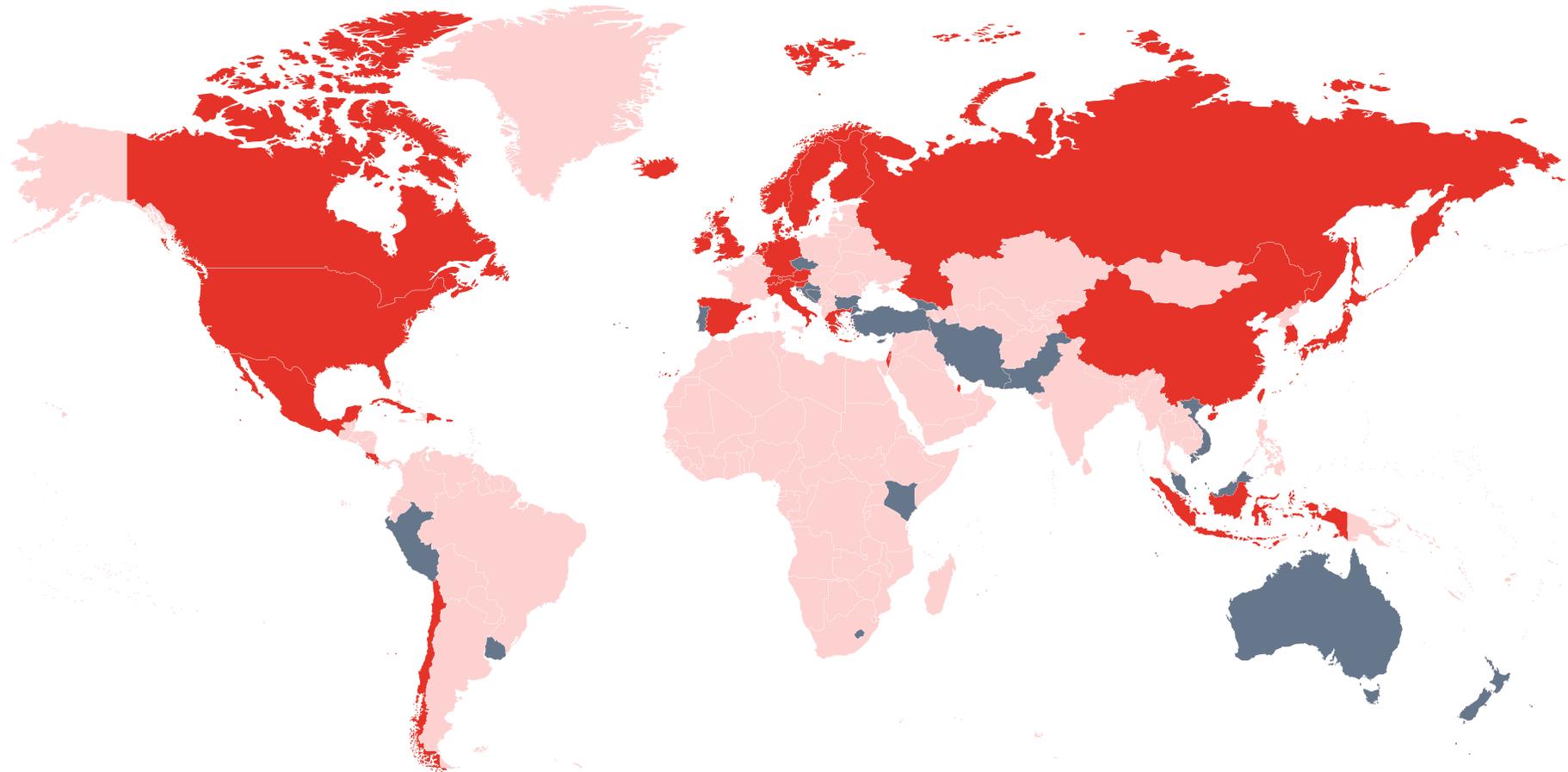
This section reviews the data provided by the ADI survey in relation to national plan development while Appendices A, B, and C provide full lists of all countries. Case studies have been provided from around the world demonstrating the importance of not only a functioning plan, but a funded plan.

Maps on the following pages provide a visual representation of the number of plans in place; that is countries with a national plan or dementia as part of an integrated health plan, countries with a national plan in development, and countries with no plan, beginning with a combined map to capture the global picture.

“People with dementia and improved services and support can help national Alzheimer’s and dementia associations develop national dementia plans if they are included equally and listened to. Too often, they are primarily engaged with to endorse projects or policies, or for the funding of projects for organisations. This means the benefit for us of working together is often inequitable, and it is not necessarily a win-win. As we work together to change dementia policy, people with dementia must be included equally.”

Kate Swaffer, CEO and Co-founder, Dementia Alliance International

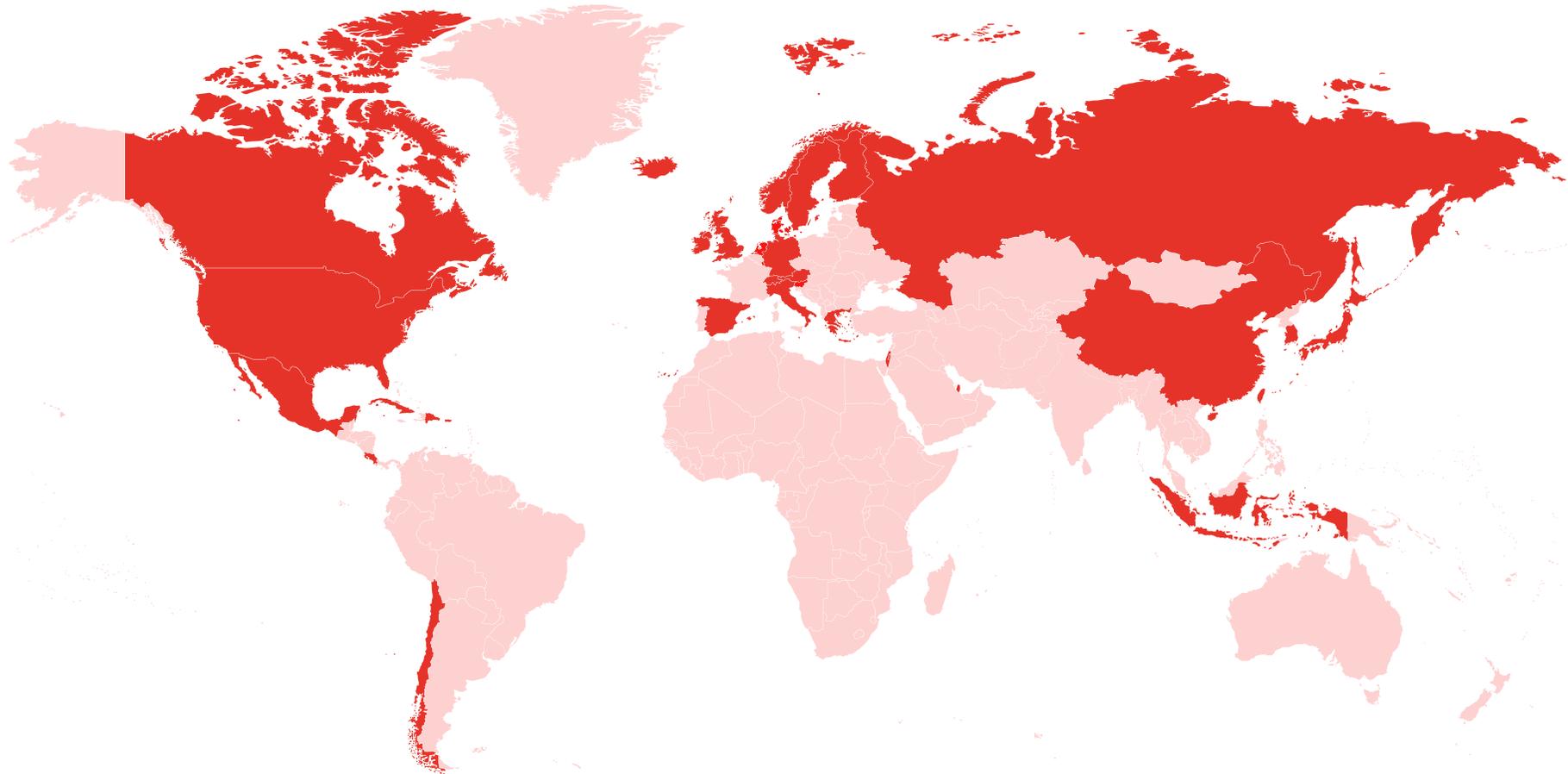
Current national dementia plans and plans in development



-  Countries with national dementia plan dementia/ dementia integrated as part of wider health plan
-  Countries with plan in development
-  Countries with no plan in existence or development

Based on information received from Alzheimer and dementia associations, April 2021

Countries and territories with national dementia plan, or with dementia integrated as part of a wider health plan

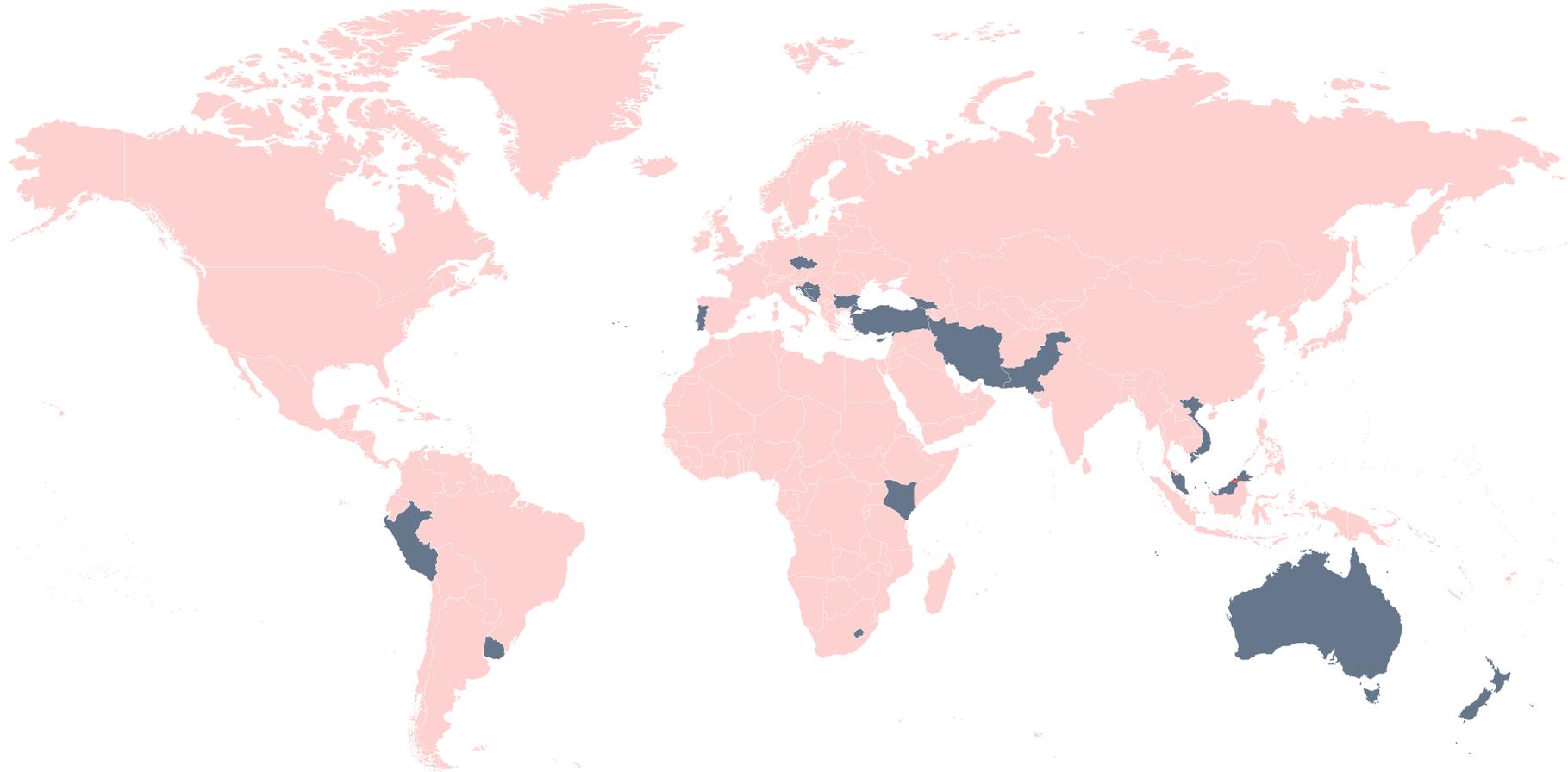


Countries and territories with national dementia plan, or with dementia integrated as part of a wider health plan

Austria	Cuba	Greece	Japan	Netherlands	Singapore	England (UK)
Bonaire	Denmark	Iceland	Republic of Korea	Norway	Slovenia	Northern Ireland (UK)
Canada	Dominican Republic	Indonesia	Luxembourg	Puerto Rico	Spain	Wales (UK)
Chile	Finland	Ireland	Macau SAR	Qatar	Sweden	United States of America
China	Germany	Israel	Malta	Russia	Switzerland	
Costa Rica	Gibraltar	Italy	Mexico	Scotland (UK)	TADA Chinese Taipei	

Based on information received from Alzheimer and dementia associations, April 2021

Countries and territories with a national dementia plan, or dementia integrated as part of a wider health plan, in development



Countries and territories with a national dementia plan, or dementia integrated as part of a wider health plan, in development

- | | | | | | |
|----------------------|----------------|---------------|-------------|----------|---------|
| Australia | Croatia | Georgia | Lesotho | Peru | Vietnam |
| Bosnia & Herzegovina | Curacao | Hong Kong SAR | Malaysia | Portugal | |
| Brunei | Cyprus | Iran | New Zealand | Turkey | |
| Bulgaria | Czech Republic | Kenya | Pakistan | Uruguay | |

Based on information received from Alzheimer and dementia associations, April 2021

Case studies

Examples are provided below from a range of contributors across WHO regions who share their experiences, reinforcing the need for urgent action to support ongoing work developing and implementing national dementia plans.



Australia STAGE 3A

The Royal Commission into Aged Care Quality and Safety in Australia reported on "A shocking tale of neglect" and has made 149 recommendations, including many for dementia care. This, in a country which has had successive dementia plans since 2003, made dementia a national health priority and invested significant funding in dementia.

Important recommendations made may be of interest to those in other nations developing dementia plans requiring strong action in respect of establishing a dementia support pathway, increased specialist dementia care services, regulation of use of restraints, dementia quality care standards, dementia related design and training for dementia care.

The Commission reported extensive and disturbing abuse.

Third, increased funding for a dementia plan is a good sign of real political commitment, but it must be linked to defined outcomes that can be monitored.

Fourth, dementia plans need to be directed at system wide reforms in health and long-term care and not just dementia-specific initiatives. Some of the most important recommendations for Australia are about directly strengthening access to primary care, mental health, allied health, and palliative care for older people and those with dementia.

Last, older people and their carers must be equal partners with government and service providers in the development and implementation of the dementia plan. Dementia advocates need to take a deeper interest in the evidence base for 'cash for service' schemes and other approaches to empower people with dementia and their carers that might work in their own cultures and health and long-term care systems.

A complex and long report cannot be distilled to a short summary; this report follows 20 other reports on aged care in the last two decades! For Alzheimer and dementia associations this is not a message of despair, but a reminder of the need for eternal vigilance and strong and ongoing advocacy to get the needed improvements in dementia care and aged care more generally. Even where an evidence base exists, as with medical and physical abuse, it has taken 10 years in Australia to get the recommendations for tough action that have been needed for so long. We know that a dementia plan is a good beginning – it is how plans are implemented and reported that matters!

Glenn Rees, Honorary Vice President and Former Chair of ADI

Important recommendations made may be of interest to those in other nations developing dementia plans requiring strong action in respect of establishing a dementia support pathway, increased specialist dementia care services, regulation of use of restraints, dementia quality care standards, dementia related design and training for dementia care.

So, based on the Australian experience what are some of the lessons for the implementation of global action area 1?

First, if there is little respect for older people and attention paid to the values and philosophy that underpin the health and long-term care system, no amount of planning and funding will necessarily deliver good quality dementia care.

Second, without a focus on care and quality of life outcomes, and effective regulation the vulnerable will be abused and receive poor care.

Indonesia STAGE 5A

As part of making dementia a public health priority, Alzheimer's Indonesia (ALZI) launched its national dementia plan in 2016, followed by a ministerial decree policy for national and district levels. ALZI has taken a lead in carers support, plus dementia awareness, training and friendliness since 2013 through its awareness-raising campaign "Jangan Maklum Dengan Pikun" (Don't underestimate memory loss). ALZI also produced leaflets on the 10 warning signs of dementia, which have since been translated into more than 10 languages including the recent South East Asian version, in collaboration with ASEAN Woman Circle Initiative. During the pandemic, ALZI continued to provide education sessions to the general public and various groups, such as the private sectors and religious communities through online platforms. Interest in dementia seemed to be increased, as demonstrated through ALZI's constantly rising numbers of website and social media viewers and followers (12,000 website views as of March 2021).

Online care skill training

Currently, ALZI and the Ministry of Health's Mental Health Department and Family Health Department have been developing a pilot project on dementia care pathways in 3 cities in Indonesia to strengthen healthcare practitioners' capacities in the area of dementia treatment, care and support. Furthermore, ALZI and Unika Atmajaya had the opportunity to be an official partner institution of the Strengthening Responses to Dementia in Developing Countries (STRiDE) project in Indonesia. Despite the challenges posed on the research activities due to the pandemic, ALZI and STRiDE Indonesia have started producing data on dementia stigma and perspectives, as well as conducting translation and adaptation of cognitive and socio-demographic questionnaires in Indonesia. Through a comprehensive situational analysis on dementia, ALZI and STRiDE Indonesia have also produced a policy brief for the Ministry of Health, providing recommendations in responding to the

need for improved dementia care, investing in healthcare workers capacity building, and an effective diagnostic and care pathway of dementia in Indonesia. To achieve this, ALZI suggested that the Ministry of Health conduct a comprehensive evaluation of the national dementia plan seven action areas to understand its success and challenges.



Since the launch of Indonesia's national dementia plan in 2016, ALZI continues to work across the action areas and advocates for an intersectoral collaboration in ensuring the impactful implementation of the plan. In February 2021, a virtual meeting between ADI, ALZI, and STRiDE Indonesia with the new Minister of Health took place. As a result of the meeting, the Ministry of Health has expressed interest in the area of risk reduction, treatment, and care. The Indonesian Minister of Health has specifically assigned his staff to work closely with ADI and ALZI, including preparation for the evaluation of the seven action areas of the Indonesian national dementia plan, with invitation to participate to be extended to stakeholders across Indonesia.

Michael Dirk Roelof Maitimoe, Executive Director, Alzheimer Indonesia, Tara Puspitarini Sani, Research Coordinator, Alzheimer's Indonesia and Yuda Turana, Senior Researcher, STRiDE-Indonesia



Lithuania STAGE 2A

Dementia is not yet seen as a public health priority in Lithuania for a number of reasons, including other public health related challenges and limited awareness of dementia in all sectors of public service. As a result, the government has limited tools, resources, and experience in developing cross-disciplinary approaches, which are so important when considering dementia related challenges.

In 2020, I invited a number of experts from dementia-related fields and people with lived experience to join our efforts in advancing the dementia field in Lithuania with two areas of particular focus:

First, in early 2021 we founded a national association Dementia Lithuania to represent people living with dementia and their carers locally and internationally. The founding members of the association are the leaders of two main communities of carers of people living with dementia in Lithuania, as well as NGOs and a number of individuals. The emergence of the association is a significant factor to fill the gap in representation of people living with dementia and their carers, at policy level and in other areas of public life.

The strength of the initiative lies within a collaborative and cross-disciplinary approach. We created a partnership which indeed aims to put the person and their wellbeing at the centre of our work.

Second, we have developed a project "Towards Dementia Strategy: Situation Analysis and Public Awareness."¹² The project, which was supported by the European Economic Area financial mechanism, will be implemented in 2021–2023. It aims to advance the national dementia strategy development and dementia advocacy in Lithuania by implementing objectives outlined by the World Health Organization:

- Undertake a situation analysis through policy, service delivery assessment, and stakeholder mapping.
- In collaboration with key stakeholders and experts, create recommendations for dementia strategy development.
- Raise awareness around dementia in Lithuania through multi-sectorial collaborations and an awareness raising campaign.

The strength of the initiative lies within a collaborative and cross-disciplinary approach. We created a partnership which indeed aims to put the person and their wellbeing at the centre of our work, be it a person living with dementia, a family member, a professional or a person who may be prevented from developing dementia.

The Ministry of Health is one of the major partners of this initiative, and their participation falls into a promising pattern of developing a mutually supportive and trustworthy partnership. For example, members of Dementia Lithuania have collaborated with the Ministry of Health at an international level in preparation of the country's profile for the Global Dementia Observatory. In February 2021, we supported the preparation and participation of Lithuanian government senior officials in the Nordic-Baltic online workshop, which focused on dementia strategies in the Nordic countries and the process of developing a national strategy, as well as implementation and assessment.

While we need to build a mutual understanding and respect when working with policy makers in Lithuania, we have to continue to strive to raise awareness about dementia at a governmental level to demonstrate how dementia is interconnected with the health and public health priorities that are already in place.

Ieva Petkute, Lead of Dementia Lithuania,¹³ Creative Director of Arts for Health Organisation "Socialiniai meno projektai", Senior Fellow of the Global Brain Health Institute (Trinity College Dublin / University of California San Francisco)

¹² Towards Dementia Strategy: Situation Analysis and Public Awareness is financed by EEA Grants 2014–2021 through the Active Citizens Fund. The project is implemented by NGO "Socialiniai meno projektai" and the Association "Dementia Lithuania." Partners are the Ministry of Health of the Republic of Lithuania, Alzheimer's Disease International, Lithuanian University of Health Sciences, Klaipėda region Alzheimer's community "Atmena", Kaunas Alzheimer Club, Alzheimer Iceland, The Lithuanian Public Broadcaster, Lithuanian Radio and Television. Supporters: The Vilnius City Municipality, The Tiltas Trust.

¹³ Dementia Lithuania website can be accessed at www.demencijalietuvoje.org



Venezuela STAGE 1

Development of the National Alzheimer's Plan in Venezuela began in 2014. The Health and Social Security Subcommittee of the Permanent Commission for Integral Social Development of the National Assembly, alongside the Ministry of Health, led six working groups to promote a national action plan against the disease and its prevention.

As part of this process, a training plan on Alzheimer's disease and other dementias was successfully delivered at the JM de los Ríos Hospital and the Concepción Palacios Maternity Hospital in the Capital District. This aims to develop the future plan with a focus on improving the quality of life of people with dementia and their carers, improving detection and motivation for those diagnosed, increasing support for carers, and improving care in homes and nursing homes for older people. It also provides training in dementia care for health professionals and promotes knowledge and research in universities and institutes, as well as promoting the importance and profile of careers working with older people and people with dementia.

In 2016, the new National Assembly pledged to provide the necessary support and asked the commission's technical team to review the draft bill, which is currently in the health sub-commission of the Permanent Commission for Integral Social Development. However, political and economic difficulties affected the development of our work.

Currently, Venezuela has been subjected to very tough international sanctions. The government does not believe in private institutions and hopes that the new National Assembly will approve the "Communal State". Already 60 countries do not recognise the current government and it has only limited support from Russia, China, Turkey, Iran, and North Korea. In contrast, the hydrocarbon and gas laws are being changed from 60% state and 40% private, to 30%



Mira Josic de Hernandez, President of the Board of Trustees of the Fundación Alzheimer de Venezuela presenting the National Plan for Alzheimer's and other Dementias in the National Assembly, which was approved by a majority in the new Assembly.

state and 70% private, in order to attract oil and gas investment and increase production, as Venezuela's only export is oil and its derivatives. Currently the Venezuelan state is bankrupt and health policies are ineffective. Additionally, 5,000,000 Venezuelans have emigrated to other countries due to the terrible economic, political, and social conditions.

Despite this, the Fundación Alzheimer de Venezuela continues to develop its national plan as far as possible with the support of volunteers and a small number of sponsors. Our relationship with Pan American Health Organization (PAHO) has been excellent, and although during the pandemic they are working with the Venezuelan Ministry of Health for the first time in years, we do not see any progress yet in the area of dementia, so we will continue to fight with what we have in the knowledge that thousands of families thank us for our work.

Mira Josic de Hernandez, President of the Board of Trustees of the Fundación Alzheimer de Venezuela



Uganda STAGE 2B

We are in the early stages of developing a national plan in Uganda and without doubt the COVID-19 pandemic has slowed proceedings. The first lockdown started in March 2020, just after our invitation to attend the NCD National Stakeholder meetings organised by the Ministry of Health's NCD Department and Uganda NCD Alliance (UNCDA). This provided us with the opportunity to discuss issues with the Assistant Commissioner, Non-Communicable Disease (Lifestyle Diseases Division). As the year progressed and lockdown eased, the country then entered the campaign period for national general elections including presidential and local council elections which continued through to early 2021.

presents the challenge that it is more difficult to develop a national plan and implement policy and practice for something that has neither a name nor policy 'home'.

With barely 2.5 % of the population in Uganda above the age of 65, Uganda has one of the youngest populations in the world. While we work alongside the Rotary Clubs of Uganda and Tanzania to raise awareness and deliver the highly influential Dementia Friends programme, we remain aware that as a low-middle income country with associated economic challenges, increased urbanisation and high levels of unemployment, a focus on dementia is unlikely to be a policy priority.

Alzheimer's disease and related dementias present a public health crisis that, left unattended, will have devastating economic consequences, especially in low- and middle-income countries where almost 60% of all cases are now.

Alzheimer's disease and related dementias present a public health crisis that, left unattended, will have devastating economic consequences, especially in low- and middle-income countries where almost 60% of all cases are now. It is for this reason, even as the world grapples with the COVID-19 pandemic and numerous other challenges, that global efforts to address dementia as a public health priority remain sustained and unrelenting. A crucial step is that associations and organisations worldwide prioritise the development of national dementia plans in collaboration with their national health authorities. It is only by doing so will we be able to systematically address the seven action areas endorsed by the World Health Assembly in 2017, as part of the 'Global Action Plan on the Public Health Response to Dementia'.

Furthermore, we have some specific challenges that have complicated the process towards a national dementia plan in Uganda. Apart from in textbooks, dementia or Alzheimer's disease remain undefined – there is no single word or phrase in any local languages to specify or describe the condition. In addition, from a policy perspective, there is no clarity over classification or categorisation of dementia as a disease. Currently it falls under mental health although by default rather than planning. This

Dr Paul Kiwanuka-Mukiibi, Executive Director, Uganda Alzheimer Association (UAA)



Russia STAGE 5C

Russia, the 9th most populous nation in the world, has seven national programmes funded from federal and regional budgets, one is Demographics (2018–2025). Within this programme is a Project for the Elderly, and the dementia plan is part of this project. It includes risk reduction, education for medical and social staff, informational support

for carers, seminars for the elderly to improve their cognitive functions, a special medical ward in polyclinics (outpatient department combined with general-practitioner health centre) and psychiatric hospitals for people with cognitive decline.

Alexandra Shchetkina, CEO, Foundation Alzrus



Netherlands STAGE 5B

In the Netherlands, we have a new national dementia plan for the next 10 years, 2021–2030. This plan is a continuation of the Delta Plan Dementia, 2013–2020. The main difference is that the government takes more responsibility in the implementation of the strategy and a new Minister will lead the plan. In the new plan there are three pillars: scientific research, dementia friendly communities, and personal care/support which follows closely the existing programmes of the Delta Plan Dementia.

Funding for research was clear from the beginning of the new strategy: the government announced growth of the budget from €8 million per year (as was the case in the Delta Plan Dementia) with €2 million per year towards an annual budget of €16 million (2024 and further). The government asked ZonMw, a national body that stimulates health research and care innovation throughout the entire knowledge chain from fundamental research to implementation, to set up a new national dementia research programme. This is a follow-up to the research programme called Memorabel and will also encompass the funding within the EU-programme on Neurodegenerative Disease Research (JPND). The new research programme will be built around research consortia and centres of excellence. Alzheimer Nederland will co-fund the new research programme, play a role in the participation of people with dementia and their carers within research projects or consortia, and supporting communication and implementation of research findings.

More recently, funding of the extension of the national dementia friendly programme has been announced (€5 million for 5 years). The government aims at doubling the number of Dementia Friends to more than 760,000 in 2025. Focus in the new

programme will be on supporting people with dementia and carers in their neighbourhood and local communities, and to reach out to younger target groups to be involved as Dementia Friends. Alzheimer Nederland will lead this programme. An additional focus will be on the development of 'Dementalent' projects: local initiatives with opportunities for voluntary work for people with dementia. The third pillar of the national plan will focus on the implementation of the existing quality guidelines, the further development of a national registration of (national and regional) care and support delivery, and quality enhancement as well as social and technological innovation.

Governance of the new national plan is in place for the first phase with the plan to be steered by a small control group led by the Minister. Representatives with a background in local government, care, research, and business will take part in the control group. A project group is about to be installed, co-ordinated by staff of the ministry with a broad range of experts invited to join the project group. They will monitor progress of the programmes and the national plan and give advice to improve the results. Alzheimer Nederland is invited to join both the control group and the project group. This reflects our commitment in the past (within the Delta Plan Dementia), our position as a major stakeholder and voice of people with dementia and carers, and our persistence in contacting the national government (during COVID-19 pandemic) and being supportive in facing this crisis. At the same time, it draws on the new national plan in the knowledge that after COVID-19, dementia is a pressing long-term challenge for our national health care and society.

Marco Blom, Scientific Director, Alzheimer Nederland

Key points



The target of the first area of the Global action plan requires the governments of 146 countries to demonstrably act on dementia. Four years into this plan it has become apparent that this target is not being met with just 32 national dementia plans and integrated plans in place in Member States, not all of which are funded, leaving an unrealistic target of 28 new plans annually.

Chapter 2

Dementia awareness and friendliness



WHO target: 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.

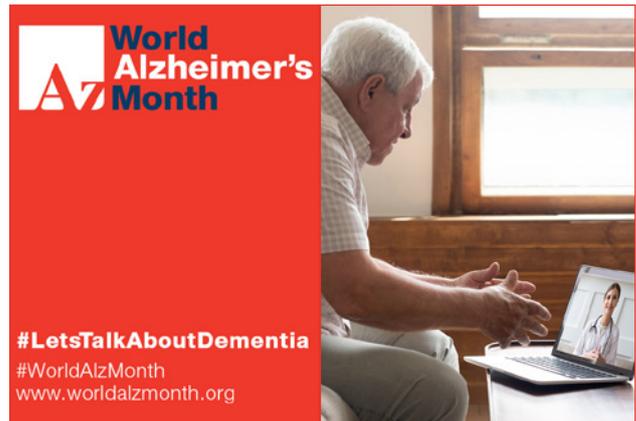
World Alzheimer's Month is a global campaign delivered by ADI every September to raise awareness and challenge the stigma surrounding dementia. A full month of activity and advocacy supports Alzheimer and dementia associations, and others with an interest in, or affected by, dementia around the world to extend their awareness programmes up to, and beyond, World Alzheimer's Day on 21st September. This is reflected in ADI's survey feedback indicating 85% of associations who responded to this question were aware of, or had participated in, a dementia awareness campaign or dementia friendly activity. This included associations taking part in World Alzheimer's Month 2020 activities, the theme of which was 'Let's Talk about Dementia'.

This section provides an overview of dementia friendly activities, including a focus on design principles for dementia, included in the *World Alzheimer Report 2020*. The range of case studies included demonstrate variety, creativity and the importance of engaging with civil society.

ADI supports Alzheimer and dementia associations through the provision of toolkits, creative materials, PR, plus digital and social media masterclasses in preparation for World Alzheimer's Month. In September 2020, events were held in over 97 countries, predominantly in a virtual format, with some socially distanced events taking place. A number of buildings were also lit up around the world, an initiative that ADI encourages associations to repeat annually by working alongside their local authorities in order to raise awareness.

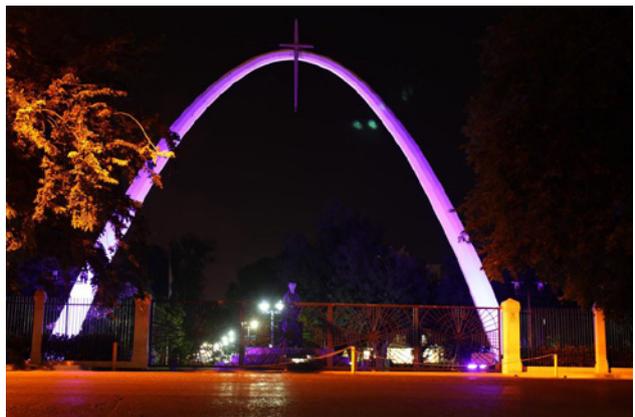
World Alzheimer's Month 2020 online

	3,400 Twitter mentions	20 million hashtag impressions	Tweets reached 432,000 people



Materials from World Alzheimer's Month 2020.

World Alzheimer's Day – Lighting up the World



ADI's first virtual conference

ADI's 34th international conference, *Hope in the Age of Dementia*, was held online in December 2020 having originally been scheduled to take place in Singapore. The conference was attended by approximately 1,600 delegates from over 120 countries and included people living with dementia, family carers, researchers, clinicians, as well as other staff and volunteers of various Alzheimer and dementia associations. Focusing on the theme of 'Hope in the Age of Dementia', the conference aimed to present hope through new science, new knowledge and new solutions around dementia. The conference programme was built around the WHO Global action plan on dementia, with diverse international keynote speakers delivering plenary sessions for each of the seven action areas of the plan. Additional sessions were also added around COVID-19 and dementia-related design.

Expert contributions and brief case studies below highlight dementia awareness or dementia friendly activities from a range of countries, some provided as part of the World Alzheimer Report 2020 and others shared by Alzheimer associations in 2021.



For the first time ADI's international conference was held virtually.

Hope is powerful, it's real, it's all we have.



Eileen and Dubhglas Taylor presenting on behalf of Dementia Alliance International.

Awareness raising

Despite restrictions due to COVID-19, awareness raising and dementia friendly initiatives remained evident as part of World Alzheimer's Month 2020. This reinforced the importance of people affected by dementia having a key role in sharing their experiences and creating a community where they feel valued and are engaged, rather than only accessing separate activities. Since Japan introduced the Dementia Friends programme in 2004, while simultaneously reducing the negative connotation associated with the word 'dementia', many other countries have followed. The concept of being 'dementia friendly' is now commonplace, whether this is in relation to communities, societies, workplaces, and individual training programmes. Currently, all countries that have a national dementia plan also have dementia friendly awareness-raising

activities, training, or campaigns often with people with dementia at the centre of these activities. ADI maintains that dementia friendly education and training should extend to all staff who work with, or support, people with dementia. This includes nursing, allied health, social care staff in residential and health facilities, home carers and also domestic and catering staff.

ADI suggests that the four essential elements needed to support a dementia friendly community are:

- **People** – people living with dementia must be included and centred.
- **Communities** – the physical and social environment must be appropriate to the needs of people living with dementia.

- **Organisations** – businesses and organisations must develop dementia friendly approaches and strategies, particularly in healthcare settings.
- **Partnerships** – cross-sectoral support and collective action are crucial to effect change.

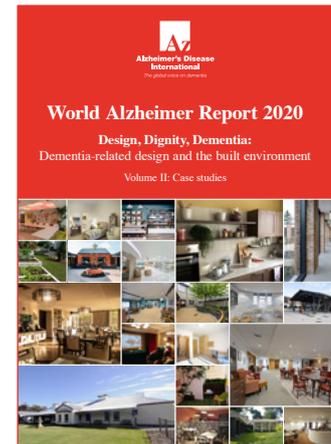
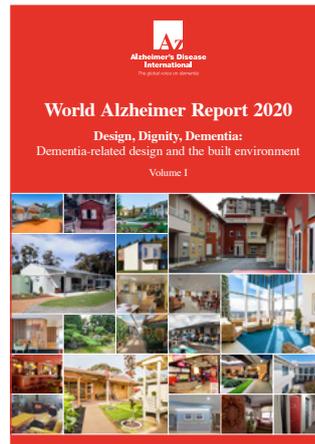
Through its Twinning¹⁴ programme, ADI supports members to share awareness raising among other good practice activities by connecting members from two associations in different parts of the world, and at different stages of developing a national dementia plan. Examples of Twinning projects include creating a newsletter and setting up a helpline.

Dementia-related design

On World Alzheimer's Day, ADI released the World Alzheimer Report 2020 'Design, Dignity, Dementia: Dementia-related design and the built environment'.¹⁵ This report, with 84 case studies and interviews with innovators in the field, is a global perspective of dementia-related design that takes a cross cultural approach, while also benchmarking progress against the physical disabilities movement.

A key element of dementia awareness and friendliness is the design of the physical environment. Many of the principles on which the report is based are known, however, governments need to view dementia as a serious health condition in order to understand the importance of design for dementia. This requires recognition of the need for flexibility in relation to principles that are applicable to some of the more diverse contexts of low- and middle-income countries where there may not be an option to adapt lighting, colour, or surroundings. There is a balance between adapting the physical environment for positive interaction and creating barriers to adequate care.

Following the launch of the *World Alzheimer Report 2020*, ADI has called upon all nations to advocate for the inclusion of the principles of design for people with dementia in national plans, and to encourage the development of effective dementia friendly initiatives that alleviate pressure on health and social care systems, and on informal carers. National dementia plans may focus on any aspect of dementia care and support but, in reality, rarely focus on the physical context of people living with dementia. Exceptions include Austria, Bavaria, Denmark, Gibraltar, and Norway who prioritise designing for people with dementia. The process of working towards an internationally accepted statement of values and principles to guide good design for people living with dementia continues with the launch of the Dignity Manifesto of Design, originating from the *World Alzheimer Report 2020*.¹⁶



Expert contributions and brief case studies below highlight dementia awareness or dementia friendly activities from a range of countries, some provided as part of the *World Alzheimer Report 2020* and others shared by Alzheimer and dementia associations in 2021.

Design Principles for Dementia

- **Unobtrusively reduce risks.**
- **Provide a human scale.**
- **Allow people to see and be seen.**
- **Reduce unhelpful stimulation.**
- **Optimise helpful stimulation.**
- **Support movement and engagement.**
- **Create a familiar place.**
- **Provide opportunity to be alone or with others.**
- **Link to the community.**
- **Design in response to vision for way of life.**

¹⁴ ADI Twinning programme <https://www.alzint.org/what-we-do/capacity-building/twinning-programme/>

¹⁵ *World Alzheimer Report 2020, Design, dignity, dementia: Dementia-related design and the built environment*, Volumes 1 and 2 can be accessed at <https://www.alzint.org/resource/world-alzheimer-report-2020/>

¹⁶ The dignity manifesto of design for people living with dementia can be accessed at <https://designdignitydementia.com/>



New Zealand STAGE 3C

It's easy, if you are not embedded in the dementia sector as we are, to forget that, in all of the debate about 'best policy settings', 'appropriate service provision' and 'health sector budget implications', that we are actually talking about people. Real, living, breathing people with family and friends, whose lives matter, who still wish, as much as possible, to live as well as possible and to be part of their community. An individual with dementia still has human rights, just like the rest of us. This is why Alzheimer's New Zealand puts people at the heart of everything we do, and it's why we continue to adhere to our long-term strategy of creating a more dementia friendly New Zealand. Despite COVID-19, 2020 was a year in which we made considerable progress. With help from the wider dementia sector, we launched New Zealand's first-ever Dementia Action Plan, which provides a blue-print for the changes our government must make to the health system to better support people with dementia and their care partners. The current Labour Government and the major opposition party have both pledged their support for the Plan which, once in place will bring about tremendous and very practical benefits for Kiwis with dementia and their care partners. We also launched the Dementia Learning Centre, the first education hub of its kind in our country and one specifically established to provide better support and information for people diagnosed with dementia and for those who provide care. Our Centre will offer evidence-based dementia education courses, workshops, and webinars to increase the skills required to care and support people with dementia and their family. Again, our goal is very much that of making a tangible difference that will impact families.

Further evidence came that we are making inroads into the public consciousness when our team of Dementia Friends almost doubled in size to around 10,000 last year. Don't forget, we are a small country, so having 10,000 of our number aware enough and concerned enough about dementia to do something meaningful about it is very pleasing. We also accredited three more major brands into our Dementia Friendly Recognition Programme, meaning awareness of dementia is also gaining meaningful traction in the corporate space. Add to that major growth in our online communities and increasing uptake of our blogs, webinars, and podcasts, and we are feeling increasingly confident that, across the board, real progress is being made turning our plan of a more dementia friendly New Zealand into a reality.



Cover of Dementia Action Plan 2020.

Last, but by no means least, we must ensure our own house is in order – that everything we do is dementia friendly and that it encourages everyone with whom we interact to be dementia friendly too. Hence, we have maintained our focus on rolling out our own Services and Standards model which has the added bonus of ensuring what we do has a tightly-focused human rights agenda. The more and better we walk the dementia friendly talk, the more others will too which, again, is all about making a real difference where it counts.

Lessons learned from all of this? "It may not happen overnight," as a famous Kiwi actress once said in a TV ad she fronted, "but it will happen". But nothing concrete will happen in New Zealand without government action. So, our major learning and key message is that while we must do everything possible to make our country more dementia friendly, we must also maintain pressure on the government to do its bit. Once our government signs the Dementia Action Plan into force, we will see a very real and very positive impact for all New Zealanders affected by dementia.

It can't come soon enough.

Catherine Hall, Chief Executive, Alzheimer's New Zealand



England STAGE 5B

Since March 2020, the Alzheimer's Society in England, Wales and Northern Ireland have developed a virtual version of their face-to-face Information Session and trained 1,327 existing volunteer Champions to deliver sessions virtually. Up to the end of February 2021, 16,672 Dementia Friends had been trained at these virtual sessions. Overall, Dementia Friends and Dementia Friendly Community activity has been lower than in previous years due

to the pandemic but up to the end of February 2021, over 66,000 Dementia Friends had been made in 2020/21. The current total number of Dementia Friends made since the beginning of the programme in England, Wales and Northern Ireland is 3,370,759. There are 507 Dementia Friendly Communities in England and Wales and 109 have continued working towards becoming Dementia Friendly in the last 12 months.



Wales STAGE 5A

The Alzheimer's Society in Wales, UK have translated Dementia Friends Champion induction resources into British Sign Language (BSL) as part of consultation with the BSL community about how best to raise awareness and support people affected by dementia who live with a sensory loss.

In addition, Alzheimer's Society co-chaired a Welsh Government Taskforce on 'Dementia and Hearing Loss' which has recently launched a policy paper with clear recommendations on how to improve care and support services across audiology and dementia.



Japan STAGE 5B

Fukuoka City has developed guidance focusing on people with dementia, called "Fukuoka City friendly design guideline for people with dementia"¹⁷ as part of their strategy to make the city more dementia friendly. Dementia design principles were implemented in one of the city's community centres as a test site. Users of the centre originally identified difficulty in finding the toilet in public spaces, whereas after dementia friendly design was implemented in the community centre, this was much easier.



Before (left) and after (right).



Malaysia STAGE 3C

The Atria shopping gallery¹⁸ included elements of good design including good lines of sight to help people with dementia to see key places, reduced stimulation, and wayfinding cues. It contains Alzheimer's Disease Foundation Malaysia's (ADFM)

community corner where anyone can walk in to receive information about dementia and sign up to the ADFM National Caregivers Support Network. The community corner also provides short mid-week respite.

¹⁷ Reproduced from World Alzheimer Report 2020, page 222

¹⁸ Reproduced from World Alzheimer Report 2020, page 248



Iran STAGE 3C

Ghasedak Day Centre,¹⁹ Maydan Bassij, North Sattari Exit is part of a larger site that provides services for up to 100 people. On a typical day between 30–40 people living with dementia attend the centre.

The places that attendees often want to go to, such as sitting areas, gardens, a toilet, or activity spaces are very easily identified with emphasis placed on reducing noise levels and clutter.

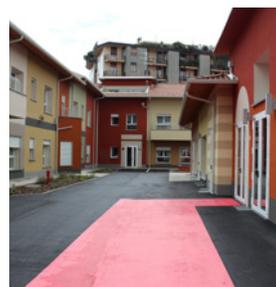


Assembly hall



Italy STAGE 4A

Il Paese Ritrovato²⁰ residential care centre ensured good lines of sight to help people with dementia to see the key places they want to go to. The garden and courtyard are easily identifiable and accessible. Residents bring in personal items, have access to places where they can be alone if they wish, and overall, there is an emphasis on designing the environment so that people living with dementia are supported.



China STAGE 5B

Zhangyou Huiyuan Memory Care Centre²¹ opened in 2019 as a residential care centre for people living with dementia. The centre accommodates 100–149 residents within a larger campus of over 500 residents. Internally and externally uneven surfaces which

present a trip hazard, steps and highly contrasting floor finishes have been almost totally avoided. Where safety features such as fences, door locks or other barriers to movement have been provided they are unnoticeable, and therefore unobtrusive.

¹⁹ Reproduced from World Alzheimer Report 2020, page 29
²⁰ Reproduced from World Alzheimer Report 2020, page 145
²¹ Reproduced from World Alzheimer Report 2020, page 184

Key points



The platform provided by ADI and member associations in September each year offers an opportunity to work with civil society. In addition, many associations stage awareness raising days, weeks and months at other times of the year, some long established and helping to raise awareness and challenge stigma throughout the calendar year.

ADI emphasises the importance of 'grassroots' activities and seeking the views of people living with dementia and families, rather than priorities and strategic plans being determined using a 'top down' approach. Following commitment from Member States, in the WHO Global action plan on dementia, national dementia plans, or integrated health plans, should include dedicated national awareness campaigns, which ADI recommends are conducted with national associations and relevant health and care organisations.

Chapter 3

Dementia risk reduction



WHO target: 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 UK, the Lancet²² launched new guidance in 2020 which revealed that addressing an extended set of 12 modifiable risk factors might prevent or delay up to 40% of dementia cases globally. This saw the inclusion of three new dementia risk factors: head injury, air pollution and excessive alcohol consumption which builds upon the nine established risk factors: less education, hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes, and infrequent social contact.

The risk reduction guidance still applies in the context of COVID-19, but with added complexities around social distancing, where opportunities to be cognitively, physically, and socially active in mid and later life have been limited. Each government must therefore take into account dementia and non-communicable disease risk factors in their COVID-19 response plans. These should also acknowledge that although individual actions to reduce the risk of dementia are recommended, to increase cognitive reserve, structural interventions and formal policies are essential.

The World Health Organization has produced guidelines on *Risk Reduction of Cognitive Decline and Dementia*²³ including evidence-based recommendations on lifestyle behaviours and interventions to delay or prevent cognitive decline or dementia.

Each government must therefore take into account dementia and non-communicable disease risk factors in their COVID-19 responses plans.

Examples are provided in this section of some of the risk reduction activity and research taking place globally, with awareness raising campaigns increasingly highlighting the importance of this topic across the lifespan.

²² Livingston, G. et al. (2020) Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *The Lancet*, 396 (10248). 413–446. [https://www.thelancet.com/article/S0140-6736\(20\)30367-6/fulltext](https://www.thelancet.com/article/S0140-6736(20)30367-6/fulltext)

²³ WHO Guidelines on Risk Reduction of Cognitive Decline and Dementia can be accessed at: https://www.who.int/mental_health/neurology/dementia/guidelines_risk_reduction/en/

12 Dementia risk factors



Impact of COVID-19 on dementia diagnosis

Deaths associated with COVID-19 have disproportionately affected older people, consisting of up to 26% of all UK COVID-19 deaths; 41% in Australia; over 20% in regions of Italy. In Canada, 85% of all COVID-19 deaths are in long term care where two-thirds of people have dementia.²⁴

While primarily known for its effect on the respiratory system, research is also showing that COVID-19 can affect the brain.²⁵ It can cause short-term symptoms such as loss of smell in approximately 5–10% of individuals; a neurological side effect with potential to cause long-term deterioration of the brain. While in the short term, numbers of people with dementia may go down due to the higher number of deaths, the numbers may rise significantly as a result of the impact of COVID-19. Chair of ADI's Medical and Scientific Advisory Panel, Alireza Atri likens the potential damage to that of a Trojan horse.

"Simply put, if you have a fortress and an enemy puts holes in your walls, you're less likely to be able to withstand future attacks. COVID-19 opens the gates in the same way that the Greek soldiers hiding in the wooden horse did. It gives easier access to things that can harm your brain. While we're faced with a long battle ahead of us, we can take a lesson from the Trojans' failure. We need to recognise the potential effects COVID-19 has on the brain now and put systems in place for what the future may bring. Now is the time to seize upon opportunities to improve dementia evaluation, care and research practices. We need to leverage digital health tools and technologies such as sensors, trackers and online platforms to enhance dementia research and care."

Dr Alireza Atri, Chair of ADI Medical and Scientific Panel

²⁴ Suárez-González A, Livingston G, Low LF, Cahill S, Hennesly N, Dawson WD, Weidner W, Bocchetta M, Ferri CP, Matias-Guiu JA, Alladi S, Musyimi CW, Comas-Herrera A. (2020) Impact and mortality of COVID-19 on people living with dementia: cross-country report. International Long-Term Care Policy Network. CPECLSE.

²⁵ Information about excess deaths associated with COVID-19 can be accessed at https://www.cdc.gov/nchs/nvss/vsrr/covid19/excess_deaths.htm#dashboard



Scotland STAGE 4A

The establishment of Brain Health Scotland,²⁶ in partnership with Alzheimer Scotland,²⁷ represents a major investment and commitment by Scottish Government, which has funded the initiative. The key objective of Brain Health Scotland is to take the leading, collaborative strategic role across public policy in Scotland to help ensure that optimal brain health is part of public health policy, clinical research, and clinical practice in order to reduce the risk of developing or preventing some forms of dementia.

We know that the brain changes caused by neurodegenerative conditions such as Alzheimer's disease begin many years before symptoms emerge. With no disease-modifying therapies currently available for the diseases that lead to dementia, our most effective approach to reducing the incidence of dementia is through proactively maintaining brain health throughout life. For this, a shift in mindset is required – away from a sole focus on later life, when symptoms predominantly show and become problematic in the dementia stage of illness, and instead adopting a focus towards reducing or eliminating known modifiable risk factors and detecting any disease processes that are present as early as possible.

Brain Health Scotland's mission is to inspire and empower everyone to protect their brain health and reduce their risk of diseases that lead to dementia. This will be achieved through two interconnected programmes of activity: Brain Health Engagement, which focuses on public health messaging and education; and Brain Health Services, a fully integrated clinical infrastructure which promotes positive brain health for prevention of disease onset and progression.

To take an effective lead and to guide best practice in these areas, Scotland's (and the world's) first National Brain Health Strategy will be released towards the end of 2021.

To better understand current public awareness levels, Brain Health Scotland launched the first National Brain Health Survey,²⁸ in summer 2020. The survey asked a representative sample of people aged 20–49 from

across Scotland for their views and attitudes towards mid-life brain health. The responses highlighted that, while most people were aware and consciously thinking of the health of their own brains, less than half were actively taking steps to protect their brain health. Indeed, a quarter of people asked could not name any actions at all that would be beneficial to look after brain health.

These findings reinforce the need for effective, understandable, and actionable public health advice, made available to all, to help people understand how best to look after their brains at all stages of life. This reading of the nation's awareness will be influential in shaping and expanding the brain health engagement programme, which is currently spearheaded by the freely available open online course: *Understanding Brain Health: Preventing Dementia*, hosted on the FutureLearn²⁹ platform. The national survey will be repeated annually to provide valuable insight into any shifting perceptions and changes in national brain health awareness over time.

Additional to a broad programme of engagement activity, Brain Health Scotland has been working closely with colleagues in the Scottish Government Dementia Policy team and Healthcare Improvement Scotland, to establish Brain Health Service demonstrator sites, embedded within the National Health Service. This collaborative approach has laid the foundations for the first wave of clinical sites to open their doors from autumn of this year. This first phase of service provision will provide a valuable opportunity to evaluate and optimise care pathways to then inform national rollout of Brain Health Services across Scotland. Designed to complement the existing memory clinic model, which is optimised for diagnosing dementia and putting in place care packages, Brain Health Services will focus on providing tailored risk profiling, early disease detection and implementation of personalised prevention plans.

The objectives of Brain Health Scotland, and the opportunity to realistically achieve these goals, has only be made possible through the commitment and backing received from Scottish Government. We would urge other nations to show similar ambition and

²⁶ Brain Health Scotland website can be accessed at: <https://www.brainhealth.scot/>

²⁷ Alzheimer Scotland website can be accessed at: <https://www.alzscot.org/>

²⁸ Findings from the National Brain Health Survey 2020, including video summary can be accessed at: <https://www.brainhealth.scot/resources>

²⁹ Information about Understanding Brain Health: Preventing Dementia can be found at: <https://www.futurelearn.com/courses/understanding-dementia-prevention>

to commit to supporting forward-thinking initiatives that focus on maintaining health and prevention of brain disease. Doing so provides our greatest opportunity to live and age well and to meaningfully reduce the incidence and impact of dementia.

Professor Craig Ritchie, Professor of the Psychiatry of Ageing, University of Edinburgh, Director of Brain Health Scotland; Anna Borthwick, Executive Lead, Brain Health Scotland; Neil Fullerton, Project and Communications Lead, Brain Health Scotland



USA STAGE 5B

In 2020, the Alzheimer's Association was selected by the U.S. Centers for Disease Control and Prevention as the nation's Public Health Center of Excellence on Dementia Risk Reduction. In this role, the Alzheimer's Association will lead a national effort to develop and disseminate public health strategies and resources aimed at addressing the risk factors for cognitive decline and dementia and will work with state, local, and tribal public health agencies to undertake activities to address those risk factors and the social determinants of health related to dementia. The aim of the Center is to increase public health agency efforts to address modifiable risk factors for dementia in their communities, including addressing risk among diverse populations.

The tasks of the Public Health Center of Excellence on Dementia Risk Reduction include:

- Reviewing, synthesising, and summarising the latest scientific evidence on modifiable risk factors for cognitive decline and dementia.
- Translating the scientific evidence into specific activities that can be undertaken by public health agencies. Identifying the public health interventions and best practices that address the risk factors for cognitive decline and dementia and dementia-related social determinants of health.
- Creating actionable tools, materials, and messaging for public health agencies to use in addressing risk factors, including social determinants of health.
- Securing action by public health agencies to undertake efforts to implement best practices and strategies on risk reduction in their communities.
- Providing technical assistance and advice to public health agencies as they work to implement these strategies.
- Evaluating the effectiveness of the work to inform future development of resources and best practices.

Because public health agencies in many smaller communities lack the resources to take on this issue, especially in the wake of the COVID-19 public health crisis, the Center is developing a plan to help build local capacity. This

includes working with smaller public health agencies to convene community stakeholders, health systems, and other community organisations to identify strategic priorities for the community, foster collaborative community partnerships, address social determinants of health, and develop joint actions to tackle dementia risk factors. In addition, the Center will hold a series of regional Learning Collaboratives, where public health officials can learn more about cognitive health and dementia, pinpoint actions they should undertake in their communities, and develop work plans to execute those actions.

Other future activities include a workshop with dementia researchers and public health officials to explore dementia social determinants of health in depth, a report on the economic benefits of addressing dementia risk factors, and the development and testing of risk reduction messaging for public health communications.

The Alzheimer's Association's Dementia Risk Reduction Center is one of three Centers named by the Center for Disease Control. The other two focus on caregiving and early detection. Funding for the Centers was made possible when the U.S. Congress passed the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act, which became law in 2018 following a strong advocacy effort by the Alzheimer's Association and its grassroots advocates. Overall, the BOLD Act is aimed at increasing the dementia public health infrastructure in the United States.

Chelsea Kline, Associate Director, Center of Excellence, Alzheimer's Association, USA



Indonesia STAGE 5A

Indonesia has made great progress in vaccinating older people for COVID-19 in the South East Asia/Asia Pacific region. Alzheimer's Indonesia (ALZI), has used the opportunity to promote 'brain gym' as a risk reduction activity and raise awareness about dementia in several vaccination centres in Indonesia.

In February 2021, ADI and ALZI representatives met with the Indonesian Minister of Health, Budi Gunadi Sadikin and his team virtually. The Minister of Health expressed interest in the area of risk reduction, care and treatment, with awareness that not acting upon this issue will have financial consequences in the longer term. Since March 2021, the ALZI Risk Reduction team have collaborated with the Indonesian Ministry of Health through activities scheduled in several COVID-19 vaccination centres in Bali and Jakarta to conduct brain gym sessions and share the 10 warning signs of dementia brochure (following all protocols). More than 10,000 copies of the brochure have been distributed to older people receiving vaccines, and 10 brain gym sessions have been conducted in 7 vaccination centres in Jakarta and Bali.

As part of the vaccination process, after an individual has been vaccinated, they are required to spend 30 minutes in the observational rooms. While waiting, ALZI offered brief educational sessions on dementia and 3–5 minutes of risk reduction brain gym activities led by ALZI's risk reduction specialists. Several centres invited the team, while other vaccination centres (including drive through) played a pre-recorded video of the brain gym exercise.

Acting now, through conducting brain gym exercise (brain training) involving younger and older people

at the COVID-19 vaccination centres, is part of the creative and innovation collaboration that Indonesia has initiated in 2021.

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



Reading the 10 warning signs of dementia brochure at the vaccination centre.



ALZI Risk Reduction team leading the brain gym session.

Key points



Alzheimer and dementia associations are reporting an increasing amount of brain health and risk reduction activities. This is welcomed as part of recognition of modifiable risk factors that may reduce the risk of dementia. ADI urges governments developing and updating national dementia plans to include risk reduction strategies, and to recognise the potential impact on individuals and society, in addition to cost-saving in the longer term and to understand the potential increased risk of dementia caused by COVID-19. This requires governments to take into account dementia and non-communicable disease risk factors in their COVID-19 response plans.

Chapter 4

Diagnosis, treatment, care and support



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

In low- and middle-income countries, as few as 10% of individuals affected receive a diagnosis of dementia. This rises to approximately half in higher income countries, but in all countries barriers have been identified to support, treatment and care. ADI believes that national dementia plans should include information about the importance of timely diagnosis and effective post-diagnostic support. The *World Alzheimer Report 2021* produced by ADI and McGill University, Montreal, Canada will be published in World Alzheimer's Month, September 2021, and will focus on the journey to a diagnosis of dementia. It

includes findings from a clinician survey with more than 1,000 responses from over 100 countries, a survey for people with dementia and informal carers, with over 2000 responses and an Alzheimer and dementia association survey.

In this section, the potential of clinical trials in developing treatment will be discussed, followed by a global snapshot over a series of pages that capture the impact of COVID-19 on dementia diagnosis. The perspective of a clinician making a diagnosis of dementia during the COVID-19 pandemic is shared.

10 Warning signs of dementia

10

warning signs of dementia

- 1

Memory Loss
- 2

Difficulty performing familiar tasks
- 3

I DEN'T ROMEDBIR

O E E

Problems with language
- 4

Disorientation to time and place
- 5

Poor or decreased judgement
- 6

Problems keeping track of things
- 7

Misplacing things
- 8

Changes in mood and behaviour
- 9

Trouble with images and spatial relationships
- 10

Withdrawal from work or social activities

[@AlzDisInt](#)

[Alzheimer's Disease International](#)

Dementia is not a part of normal ageing.

Talk to a doctor or contact the Alzheimer association in your country.

The global voice on dementia

Clinical trials

In order to progress the treatment of Alzheimer's disease, it is imperative to have robust, global and well designed clinical trials which recruit participants at all stages: preclinical (a stage of the disease where subjects are cognitively normal but are building up asymptomatic amyloid in their brain), prodromal (when early signs appear), mild, moderate and advanced, as well as trials which assess the impact of new investigational products for the treatment and management of symptoms which may include agitation, aggression, apathy or depression. An investigational product is a trial drug and most trials compare this to a placebo (a tablet with no active ingredient) when added on to standard of care treatment for the disease.

Traditionally, trials into Alzheimer's disease are very challenging; they are slow to recruit and they usually have to assess participants for 12–24 months to see if there is a response to the investigational product. This is a relatively long timeframe when compared to other trials, however progression of Alzheimer's disease can happen over a period of years, and therefore the response to the investigational therapy also takes time. However, a major challenge is identifying appropriate participants for trials. In the early stage of Alzheimer's disease, it is particularly difficult as individuals have fewer cognitive changes or only occasional memory issues as their main symptom, and at this point people rarely self-identify as having Alzheimer's disease. This is challenging for the clinical sites as they have to spend a lot of time and resources screening many people to identify the small numbers who will meet the entry requirements. The cost of such screening for the sponsoring pharmaceutical company can run into many millions of dollars.

In part, the cost is high because participants undergo a screening process which is usually completed with an amyloid PET scan (but this may alternatively be a lumbar puncture to also detect amyloid). Such scans are extremely expensive, \$10,000–\$15,000 per scan, and at least 70% of preclinical and 35–60% of prodromal potential participants will "fail" the PET scan and be

assessed as amyloid negative. The failure rate for assessing suitability for entry into trials is extremely high: 90–95% for preclinical and 80–85% for prodromal, where an amyloid positive subject is required for acceptance into the trial.

However, with an increasing number of blood-based and digital biomarkers being developed, there will be a new, and significantly more efficient means of conducting clinical trials whereby all potential participants undergo a simple blood-based or digital biomarker assessment at the very start of the screening process. This is a significantly cheaper and more globally accessible approach which could detect anyone who will not pass the screening process simply and cheaply, thus reducing the burden on the clinical site, increasing the trial recruitment rates so that trials can be concluded more quickly, and also significantly reducing the costs to the sponsoring company.

There are a number of plasma-based tests in development as well as eye tests, and urine tests to name a few. These will make a huge impact on the conduct of clinical trials as the current recruitment rates can be just 3–6 people per site per year. In a trial where at least 1500 subjects are required for each trial, being able to double or triple the recruitment rate using these accurate biomarkers will make a major difference in the timeframe required for recruitment. It should mean that potential investigational products can be assessed more efficiently, and that a successful treatment for Alzheimer's disease is brought to the global market more quickly.

The increasing use of biomarkers will herald the new era of trials, both in terms of the time required to recruit participants and conduct the trial, but will also expand the network of countries who participate in these clinical trials as the biomarkers do not require complex technology like a PET scanner, cyclotron or the availability of an amyloid PET ligand. Therefore, it will be possible to conduct global clinical trials in Alzheimer's disease in many more countries, bringing the potential benefits of an active treatment to more people, more quickly.

Davos Alzheimer's Collaborative

The Davos Alzheimer's Collaborative³⁰ (DAC) is a public-private partnership committed to a collective global response against the challenges of Alzheimer's disease. DAC are partnering with cohorts around the world to build a global cohort with high-quality, detailed data on a diverse population. This will link local discovery infrastructures in high-, middle-, and low-income countries through a standardised data system, enabling researchers to study therapeutic

targets and associated biomarkers across the world. DAC is in the foundational stage of a six-year strategy to drive progress on these three and have established several partnerships to support and bolster ongoing efforts and to reach communities across low, middle and high income countries alike. This is with the aim of coordinating research, creating momentum and engaging governments in the fight against dementia.



Japan STAGE 5B

People living with dementia globally are among those facing the most severe effects from the ongoing COVID-19 pandemic. Similarly, in Japan the COVID-19 pandemic has affected the everyday lives of people with dementia by restricting their activities or by forcing them further into social isolation. It is also causing those most affected to experience worsening of cognitive function and greater symptom severity. At the same time, opportunities for people with dementia to receive consultations has decreased with the number of outpatient visits and dementia diagnoses fewer than the average year. It may be safe to say that the effects of the pandemic have been just as bad or worse on some of us, and people with dementia in particular, than COVID-19 itself. In time this will change, however public awareness campaigns to promote consultation and diagnosis will not be enough in isolation, just as having a national dementia plan in itself will not bring about change. This requires intervention,

communication and financial support from governments that take a longer-term perspective. Kobe City in Japan has made a local government ordinance for dementia and introduced the "Kobe Model", an early diagnosis subsidy system whereby those 65 years of age and older can receive a two-step diagnosis at no cost; a first stage cognitive functional examination and a second stage detailed examination if required. For individuals with a diagnosis of dementia an accident relief system is in place where the city covers insurance premiums for those who have pre-registered should a person with dementia be liable for damages due to an accident. In order to help prevent accidents, for a small monthly usage fee, a global positioning system (GPS) can be used enabling family to find the location of the person with dementia using a smartphone.

Mr. Shunichiro Kurita, MPM, Manager, Health and Global Policy Institute (HGPI)

³⁰ Blog from Davos Alzheimer's Collaborative can be read on the ADI website <https://www.alzint.org/news/the-davos-alzheimers-collaborative-a-global-preparedness-plan-for-dementia/>

Disrupted Diagnosis – COVID 19

In early 2021, ADI conducted a survey with members of their Medical and Scientific Advisory Panel which raised concern about the impact of COVID-19 on dementia diagnosis. This led to a question being added to the association survey that informed this report. Perspectives and experiences from Alzheimer and dementia associations are provided which confirm the disruption in diagnosis experienced on a global scale.

Argentina



“ More than 90% of the patients reported neuropsychiatric disturbances. 63% of caregivers showed signs of caregiver overload and about half of them severe caregiver overload. However, despite the high prevalence of behavioural problems, only 50% of the respondents were able to make at least one medical consultation during this period and only 9% were able to use the video consultation system to communicate with the doctor ”

Australia



“ COVID-19 impacted where diagnosis was already under way ”

Bermuda



“ The memory clinic where diagnosis takes place was closed, the hospital was also closed to non-essential healthcare ”

Bonaire



“ The COVID-19 pandemic is affecting our Government's priorities, especially the Public Health Department, which has caused a delay in the implementation process of the dementia plan so far ”

Cameroon



“ There are no memory centres here, but doctors working in the fight against Alzheimer's disease noticed a slight decrease in consultations ”

Brazil



“ There is no doubt there was a reduction in referrals, the impact is difficult to measure ”

China



“ Neuropsychological assessment that needs more than one hour face-to-face interpersonal contact was suspended in most memory clinics or dementia centres. Some memory clinics closed for a while ”

Brunei



“ Non-urgent clinics or services were temporarily suspended during the COVID-19 crisis situation ”

Croatia



“ There were 20% less procedures in hospitals and clinics in general during the COVID-19 pandemic period ”

Canada



“ There has been a decrease in referrals reported by memory clinics, family physicians and specialists for new diagnoses ”

Czech Republic



“ In spring 2020, some clinics were closed with no access to diagnosis. Phone calls were available for support and medication ”

Costa Rica



“ Suspension of face-to-face consultations clearly has had an impact on the diagnostic approach. Our Dementia Friends model was suspended ”

Cuba



“ The pandemic has meant a decrease in referrals for diagnosis and follow-up care; the state and the national health system have focused their actions on limiting the effects of COVID-19. As part of the FINGERS research project in Cuba we have observed a decrease in the practice of physical activities and activities of cognitive stimulation and social support. We have seen increased loneliness, anxiety and depression in older people ”

Dominican Republic



“ There has been significant disruption as relatives do not want to take family members to health centres or take them out of their homes for fear of becoming infected. This population was more affected by social isolation than by COVID-19. There has been a lot of deterioration due to the change of routine and an increase in many psychiatric symptoms ”

England



“ There has been a significant disruption to the process of referrals; the current estimate is that there is a shortfall of approximately 30,000 diagnoses ”

Finland



“ Nurses at memory clinics have been redeployed to COVID-19 testing and tracing, which has led to delays in assessments and the associated risk that diagnosis is delayed ”

Gibraltar



“ Access to health and care professionals has been limited and diagnosis interrupted. People with dementia in long-term care have been disproportionately impacted and severely disrupted. During lockdown families have not been allowed to visit their loved ones and this was understandably difficult. Isolation has been a heavy burden faced by our most vulnerable and many people living with dementia have endured extended time alone without fully understanding why ”

Greece



“ The vast majority of memory clinics in large hospitals did not work during the COVID-19 period, but the Alzheimer associations and day care centres continued their operation. The only problem is the home visits because the patients and their caregivers are afraid of the virus ”

Guatemala



“ Our clinic and day centres were closed from March 2020 to January 2021, which negatively affected health and caused deterioration of our patients leading to serious problem in care provision ”

India



“ Access to care and referrals were curtailed due to restrictions...persons with dementia and their family members faced lots of difficulties and there was a decline in referrals ”

Indonesia



“ There has been disruption to the referrals of people for diagnosis, the public in general are afraid to go to hospitals during the COVID-19 pandemic ”

Iran



“ After years of hard work, and advocacy, COVID-19 has slowed progress towards a plan ”

Italy



“ We have become aware, especially in the first phase of the pandemic, of delays and missed referrals at the memory clinic. A lot of family caregivers told us that the person with dementia could not visit the memory clinic ”

Ireland



“ People with dementia are experiencing cancelled health care appointments for diagnosis, speech and language therapy, occupational therapy and other services ”

Jamaica



There is disruption in referrals. The country has just received the first shipment of vaccinations (March 2021) so until distribution, referrals to the health centres and memory clubs are declining. The only Dementia Clinic on the island at the University Hospital of the West Indies was suspended in March 2020 due to the pandemic and as far as is known remains closed, older persons remained under a stay at home order

Japan



The number of new patients has been decreasing during the pandemic. Amyloid PET testing can only be conducted in urban areas due to movement restrictions

Lebanon



It has been very difficult to administer neuropsychological testing. Also, day care centres have been closed since the beginning of the pandemic. Several other programs have also closed in the last year

Lithuania



The people were afraid to travel, leave their homes and seek out medical help. The change was noticed both in ambulatory services and in-patient services there were significantly less hospitalisations for testing (lumbar puncture and cerebrospinal fluid tests were delivered in much fewer numbers). There is a clear indication that the diagnosis of new cases and the treatment was delayed or protracted

Lesotho



We do not have a psychiatrist in the country, so diagnosis was always a problem. Meetings have been delayed by COVID-19

Madagascar



When people/families called us during pandemic, especially during lockdown, many showed great hesitation when being recommended to see a doctor for diagnosis, especially in public hospitals due to fear of being exposed to COVID-19

Malaysia



The pandemic caused delays in discussion of the draft dementia plan. There are cases of deterioration that were not brought to light until many months later due to postponement of their appointments, so diagnosis is delayed. Many care homes were not admitting new residents leading to increase in caregiver burden. There are partial closures of the memory clinics

Malta



Services for individuals with dementia were hugely impacted by the pandemic. Dementia day centres had to close down, and community visits were reduced significantly. Although Memory Clinics did not shut down, people were reluctant to use them in fear of going out and catching the virus. Dementia Cafes had to stop as well due to social distancing and restrictions on gatherings

Mexico



It has been stated that people who have stopped attending the centres have deteriorated a lot

Montenegro



During the pandemic we have a lockdown and a curfew which is keeping us away from regular check-ups in hospitals and clinics. People are strongly advised to stay at home and only in the case of utmost emergency to come to ask for a help

Morocco



Requests for diagnosis for mild cognitive impairment and early Alzheimer's Disease have decreased, there have been more dementia cases with behavioural disorders

Nepal



“Hospitals were closed for several months, as a result people couldn't visit memory clinics for diagnosis or follow up visits for those with a diagnosis”

Netherlands



“People were not referred to memory clinics, or appointments for assessments were cancelled. Sometimes this was done by the people with suspicion of dementia or the caregivers themselves”

Nicaragua



“The number of people living with dementia referred to both public and private centres and clinics has decreased”

New Zealand



“New Zealand has had only one national lockdown and that was March/April 2020. During that lockdown, assessment and diagnosis services continued to be available although some people with dementia were nervous about using them”

Northern Ireland



“The pandemic has meant a change across a range of services including General Practice, which had to rapidly change its working patterns. This however had a detrimental impact on the number of people receiving a timely diagnosis”

Pakistan



“COVID-19 disrupted the healthcare system, the normal functioning of the health facilities stopped. Out-patient departments were closed, operations postponed, and only emergency services provided. Similarly, the people with dementia and families have also not been seeking the normal healthcare services (non-emergency) due to COVID-19 fear”

Peru



“Due to the small availability of hospital beds in the country, the significant increase in COVID-19 patients has saturated capacity. The memory clinics have had to suspend their activities completely”

Poland



“Diagnoses were and continue to be made online. Access to neurological tests was limited as some hospitals were converted to COVID-19 hospitals. There was a drop by over 50% of new patient reports, for fear of infection. Overall, there has been a regression in diagnosis (from March 2020) of over 65%”

Puerto Rico



“The association have received calls about the lack of access to health services in general for people with dementia. Consultation has been limited to video conferencing, and isolation has negatively affected cognitive functions and mood”

Slovenia



“Referrals for many different conditions, dementia included, were disrupted. The situation improved after the first wave and health services operated, however, the referrals were hindered due to individuals' and families' fear of COVID-19 infection”

Scotland



“In the early period of lockdown there was disruption to memory clinics and a subsequent decline in diagnosis and referral for post-diagnostic support. We anticipate a substantial decline in the number of people accessing a dementia diagnosis and post-diagnostic support. The Scottish Government would have been due to publish Scotland's fourth National Dementia Strategy in 2020, however, that has been understandably delayed in the face of the global pandemic”

South Africa



“Our memory clinic in Eastern Cape could not deliver services due to lockdown and government services were scaled down”

South Korea



“ Due to the COVID-19 epidemic, the number of dementia diagnoses is estimated to have decreased by about 20% in university hospitals and 60% in dementia safety centres ”

Spain



“ There has been a slowdown in referrals and, simultaneously, a worsening of cognitive symptoms. Also, many older family caregivers have begun to show previously undetected cognitive impairment ”

Sri Lanka



“ Appointments to see doctors was difficult for new referrals, second or repeat appointments may be by telephone or online but only if families had the technical facilities to do so ”

Suriname



“ There is a huge decline in new referrals, almost 75%, because the GP's aren't seeing the elderly. Those already in the system only visited the geriatrician in crisis situations ”

TADA (Chinese Taipei)



“ We notice that the people with dementia degenerate quickly due to taking part in fewer activities ”

Tanzania



“ There was a decline in referrals, we had to resort to online service delivery by establishing a 24-hours landline phone for family carers ”

Thailand



“ Hospitals will ask patients whose symptoms are stable to follow telemedicine procedures and new care will be postponed. Sometimes, the family themselves don't want to take their senior member who has suspected dementia to hospital ”

Tunisia



“ Families refused to go to the Alzheimer's centre for fear of infection. Others tried to find doctors who could see them at home ”

Turkey



“ In the process of combating the COVID-19 pandemic, it may be difficult to prioritize chronic disease management and strategy ”

Vietnam



“ Carers indicated that they delayed their loved ones hospital visits for diagnosing and routine dementia checking ”

Wales



“ Alzheimer's Society Cymru has been made aware of a backlog of people awaiting diagnosis as a result of the COVID-19 pandemic. Our memory assessment services were suspended, and staff were re-deployed throughout the NHS in order to help during the pandemic ”

Zambia



“ We have seen a general decline in referrals to our neurology outpatient clinic, which is the only neurology clinic in Zambia. There are fewer referrals from outside of the capital city of Lusaka where our clinic is located ”

Zimbabwe



“ Most people stayed away (from hospitals) for fear of COVID-19 ”



Perspective of conducting virtual consultations during COVID-19

The global pandemic of COVID-19 has meant that face to face communication had to be cut to a minimum to reduce the risk of viral transmission. It soon became clear that older people and people with underlying health problems were at particular risk of dying from COVID-19. People with dementia were clearly at risk as they are in the main older and most often have other physical illnesses. There was also a question as to whether having dementia itself was an additional risk factor for COVID-19 mortality. Suddenly most consultations had to become virtual, either by phone or by video conference because of the very real and dangerous risk of infection of face-to-face consultations, particularly in health service settings.

We had to ask if this was one of the very few effects of COVID-19 which we may want to keep for the future. One early pandemic study of staff perspective about the delivery of mental health services to older people in the UK (which is where most people with dementia are seen in the UK) found some positives in remote consultations.³¹

I work in a memory clinic and have discussed this with colleagues, and we are struck by both negative and positive aspects of remote consultations compared to face to face. The positive includes that no-one needs to travel for consultations with a health or social care professional which means it is more convenient, cheaper, in theory quicker, much easier for people with mobility difficulties, and usually people are seeing without waiting.

However, many clinicians whom I have talked to have found that teleconsultation is frequently problematic for those with most needs. Many older people living with dementia are not accustomed to using video devices and do not have them, or if they have access are unable or unwilling to learn to use them. One of the disabilities of dementia is that people are less able to learn new skills. Consultations are therefore often by phone. Whether video, or as is more often the case entirely audio, these consultations reduce communication particularly in people with difficulty in hearing or those who are less fluent in English. Many people find the lack of body language in phone consultation and the reduction of more subtle visual clues in video consultation can lead to less accessible or useful consultations.

In memory clinics, many of my colleagues and I find the information given is much more limited over the phone and,

for example, detailed testing of cognition to establish which if any areas are impaired is almost impossible. Family carers and people living with possible or confirmed dementia are often unable to discuss their concerns separately or indicate by gesture that they do not agree with what is being said in the assessment. They do not wish to have conflict within the consultation or their relationships but there is no safe separate space to discuss and try to reconcile differing viewpoints. Early in the pandemic, several of our memory clinic nurses began wearing personal protective equipment and visited people at home as they found that they could make a therapeutic relationship or alliance, avoid crises and conflict, and work out ways forward much more easily, as the person with dementia and the nurse understood each other better.

When clinicians knew the person living with dementia and their family, they were more able to use remote communication well and often did not need to have face-to-face consultations. They could judge well whether the remote consultation was sufficient or superior and they were able to fit in consultations more rapidly. Interestingly, in line with these staff experiences recent research including interviews with adults of all ages about their experiences of virtual mental health consultations found similar concerns. While remote ways to access mental health care enabled some people who would otherwise not have had access to professional help to enjoy continuity of care, others found they presented substantial obstacles.³² Concern was particularly high for people who were members of United Kingdom minority groups.

Telehealth has a place to reduce infection and for communication with those who can use technology. Clinicians and people affected by dementia who have a pre-existing relationship with, and knowledge of, each other are most likely to find it useful; and be able to judge whether it meets their needs in an individual consultation. Overall, people living with suspected or confirmed dementia with the most needs are more likely to be unable to use or to access technology, and may be excluded if it is used as the only means of diagnosis therefore worsening existing inequalities.³³

Professor Gill Livingston, Professor of Psychiatry of older People, UCL, London

- ³¹ Bhome, R., Huntley, J., Dalton-Locke, C., San Juan, VN., Oram, S., Foye, U., Livingston, G. (2020) Impact of the COVID-19 pandemic on Older Adults Mental Health Services: a mixed methods study medRxiv
- ³² Gillard, S., Dare, C., Hardy, J. et al. (2021) Experiences of living with mental health problems during the COVID-19 pandemic in the UK: a coproduced, participatory qualitative interview study. *Soc Psychiatry Psychiatr Epidemiol.* <https://doi.org/10.1007/s00127-021-02051-7>
- ³³ Liu, K., Howard, R., Banerjee, S., Comas-Herrera, A., Goddard, J., Knapp, M., Livingston, G., O'Brien, JT., Paterson, RW., Polignano, R., Robinson, L., Rossor, M., Rowe, J., Sharp, D., Sommerlad, A., Suárez-González, A. & Burns, A. (2021) Dementia wellbeing and COVID-19: review and expert consensus on current research and knowledge gaps OSF Preprints <https://osf.io/2bq4u>

ADI COVID-19 response

Having identified that the majority of Alzheimer and dementia associations reported significant disruption to diagnosis, this section explores strategies that have been put in place by associations during the global pandemic, followed by case studies demonstrating the importance of support and training as part of coordinated care for people affected by dementia.

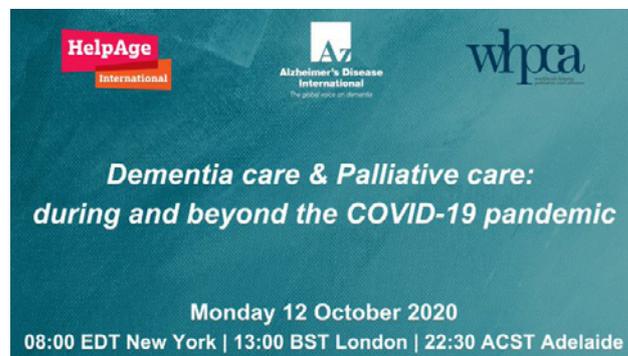
Support from ADI members includes:

- Online dementia care training for families and healthcare professionals.
- Food deliveries to families.
- Advocacy to arrange COVID-19 vaccination at home for people with dementia.
- Purchase of IT equipment to support people with dementia at home.
- Mobile dementia service including an outreach team to give support to people with dementia and caregivers, including training at home.

- Association volunteers distributing activities to people with dementia to engage with at home such as arts and crafts, and sharing online videos with familiar songs.
- Increased use of social media and the development of apps.
- Telephone helpline, including 24/7 availability.

Additionally, over the past year, ADI has developed member and public webinars, including a series around COVID-19, has advocated for people with dementia to be given priority for vaccinations, and has collated a range of resources, blogs, and updates from member associations. For example, in October 2020, ADI delivered a webinar 'Dementia risk reduction in the age of COVID-19' where findings from the Lancet report (see page 34) were discussed along with implications for individuals and governments calling for them to introduce dementia risk reduction policies.

ADI webinars during the COVID-19 pandemic



Examples of member association COVID-19 responses

Dominican Republic



The national dementia plan in Dominican Republic was launched in the middle of the pandemic which led to a lot of publicity. Priority is given to people with dementia in the vaccination programmes. In vaccination centres it is possible to hear people with dementia being called over the microphone to avoid the queues or long waits. The association has been successful in securing vaccination at home for people with dementia who cannot travel.

Asociación Dominicana de Alzheimer

England



The Dementia Programme Board has produced a Dementia COVID-19 action plan to tackle issues including:

- Drop in national diagnosis rates.
- Increase in use of antipsychotic drugs.
- Increased or blanket use of Do Not Attempt Cardiopulmonary Resuscitation orders.
- Accompanying people living with dementia to appointments.
- Tackling the impact of social isolation for people with dementia.

Alzheimer's Society, UK

Guatemala



At Asociación Grupo Ermita, in order to continue operating, we had to reinvent ourselves and be able to support patients and their families in their homes with all the necessarily protection and protocols. We created the Ermita en Casa programme and since June we have been visiting, accompanying, supporting, and attending to people in their homes for four hours. We also made the transition to move our Diploma in Care of the Elderly, with an emphasis on Alzheimer's, 100% online, offering a new experience in caregiver training. We also put our Medical Consultation service online.

Asociación Grupo Ermita, Guatemala

Turkey



The work we started in 2019 continued online in 2020. In order to support all the older people and caregivers staying at home during the pandemic period, the state established support teams under the name of 'Fidelity'. Examples of support include for older people with Alzheimer's disease and their caregivers to be vaccinated at home. In addition, medication was provided, with online support available before patients came to the medical centres.

Turkish Alzheimer Society and Foundation

Dementia Alliance International (DAI)

Dementia Alliance International (DAI) is a registered non-profit organisation whose membership is exclusively for people with a medically confirmed diagnosis of dementia from all around the world. DAI is the global voice of more than 50 million people currently living with dementia.

COVID-19 has affected all countries hard, but its impact has been hardest on those communities that were already most vulnerable, especially people living with dementia and other disabilities, and their families or care partners. During the pandemic, DAI increased the number of freely available services for people living with dementia by providing additional online support groups,

educational webinars, cafés, and other activities for our members in 49 countries.³⁴

DAI has also continued with its global efforts on claiming the human and disability rights for all people with dementia through our international advocacy and policy work and will continue to call on leaders to monitor inequalities experienced by people with dementia and our families, continuing our work towards ensuring that all are able to access quality health services.

Kate Swaffer, CEO and Co-founder, Dementia Alliance International

01 Join a DAI online peer-to-peer support group today. www.join dai.org

02 Facetime, Zoom, or Skype with family and friends.

03 Follow ADI's up to date advice and resource page. www.alz.co.uk

04 Follow the World Health Organisation daily updates. www.who.int

05 Join your peers, family and friends at DAI's monthly Café Lé Brain & Webinars.

06 Contact your national Alzheimer's organisation.

07 Exercise daily.

08 Maintain physical distancing and stay safe.

FOR PEOPLE WITH DEMENTIA DURING THE COVID-19 PANDEMIC

DAI has a 24/7 open access Zoom room available for members, family and friends. www.infodai.org | email: info@infodai.org

DAI Vision: A world where all people are valued and included

Key points

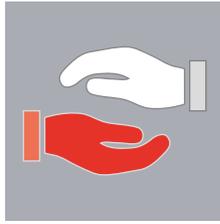


The past year has been an unprecedented challenge as a result of the COVID-19 pandemic and the real impact in terms of diagnosis, care and support is still emerging. Urgent action is needed to understand and mitigate the impact of COVID-19 on dementia diagnosis, and to fully understand the impact of restrictions on cognitive decline and the need for additional or enhanced support going forwards.

³⁴ Reproduced with permission from <https://www.dementiaallianceinternational.org/world-health-day/>

Chapter 5

Support for dementia carers



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

In the continued absence of a disease modifying treatment breakthrough, it is vital to extend the availability of, and improve post-diagnostic support. This includes learning from innovative approaches used elsewhere in order to help improve the quality of life of people living with dementia and their families. Unpaid care equates to 40 million full time equivalent jobs, forecast to rise to 65 million by 2030.³⁵ We call on all nations to support informal care, recognising that women make up a disproportionate amount of informal carers, a role that often reflects cultural norms.

We call on all nations to support informal care, recognising that women make up a disproportionate amount of informal carers, a role that often reflects cultural norms.

While the extent and availability of training programmes for carers and people with dementia remains difficult to quantify, the focus remains on training for paid staff and professionals. The shift towards online and virtual ways of working and communicating during 2020 and early 2021 has offered opportunities for some carers to engage in ways that may not have been previously available or considered. For example, Understanding Brain Health: Preventing Dementia (see page 36) was designed for healthcare professionals, but has also been accessed by family carers with positive outcomes.

WHO's iSupport Lite³⁶ consists of a set of practical support messages for carers of people with dementia extracted from iSupport. To complement the generic version of iSupport (available as a hardcopy manual and e-training), iSupport Lite offers easy read tips for carers of people with dementia that can be drawn upon when, and as, needed. For carers who have already completed the comprehensive iSupport programme, iSupport Lite acts as a refresher, reinforcing previously acquired caregiving skills and knowledge. iSupport Lite is available in the form of posters, a short video, and Question and Answers on WHO's website.

³⁵ World Alzheimer Report 2018, *The state of the art of dementia research: New frontiers* <https://www.alzint.org/resource/world-alzheimer-report-2018/>

³⁶ iSupport lite can be accessed from the iSupport website at <https://www.who.int/publications/i/item/g9789241515863>

ADI accreditation programme

Ensuring people living with dementia receive high quality care and support, provided by appropriately trained professionals and carers is a priority for ADI. This is achieved through the delivery of educational training programmes that offer a structured approach to the knowledge and skills of participants, in addition to establishing standards of care. Through successful completion of an evaluation, providers of training programmes can earn ADI Accreditation. This means that the training and learning activities have reached the required ADI standard, ensuring integrity and quality at all levels.

The ADI Accreditation programme launched in 2021.³⁷

In regular times, carers of people with dementia experience stress due to social isolation and time spent caring, resulting in mental and physical health deterioration as well as loss of productivity and income. This report has demonstrated how the COVID-19 pandemic significantly disrupted carer access to much needed services and support, placing additional strain on carers and accentuating isolation from social networks. The breakdown of community-based services emphasised the importance of providing carers with

accessible public health messages to reduce stress and improve their mental health and well-being. The WHO's existing iSupport programme provides evidence-based knowledge and skills training to carers of people with dementia. It aims to prevent or decrease mental and physical problems associated with caregiving.

The target of action area 5 to provide support for carers of people with dementia is rooted in inclusion, and listening to what people want. Whilst COVID-19 has dominated activities and impacted diagnosis, care and treatment, an established carer group at Alzheimer Scotland have continued in their advocacy role and are using their experience to join a team of researchers to share their voices, rather than being research participants. Alzheimer Scotland's National Dementia Carers Action Network (NDCAN) is a national campaigning and awareness raising group for carers of people with dementia. In 2019, representatives of the group came together with academic staff to plan how they wished to be involved in future research. Reflections from the group on planning their role as co-researchers in their selected area of advanced dementia care are captured below, reproduced with permission of the group from blogs written for the Scottish Dementia Research Consortium.³⁸ This is followed by an overview from Dementia Australia of their Roadmap for Quality Dementia Care emphasising the importance of support and training for carers. This comes at a time, May 2021, when the Australian Government has just announced a \$229 million investment in dementia care as part of their Federal Budget.



Scotland STAGE 4A

Real research involvement is only possible when people who have 'lived it' agree to be involved. This delivers new understanding and meaning, allows us to define and refine, and most importantly helps people affected by dementia. NDCAN is often asked to take part in research, but this time we are learning how to be co-researchers, not just 'the researched'. Not knowing what to expect initially, it was refreshing to be part of what felt like a real conversation. We talked about how our various experiences with research and researchers had made us feel. We were encouraged to think about what we wanted from research and what we were interested in contributing. Over time the idea of actually being researchers ourselves surfaced.

It feels good to be able to be a part of decision making and know that the opinions of carers really do matter.

At NDCAN we were new to the world of research and are learning all the time, for example, how funding is explored, different theories used and what they mean, and the necessity of involving an ethics committee. It is all fascinating and we thoroughly enjoy being part of this collaboration. It feels amazing to have a chance to be involved, especially when experiences of research among the group have not always been positive.

"When my husband was first diagnosed with Vascular Dementia he took part in a drug trial that involved him taking for various health and mental tests to monitor any deterioration or changes in his dementia, but he also took medication without knowing if it was a new drug, or a placebo. I was also committed to attending with him and completing forms and online assessments regarding my perception of his condition and recording any changes I became aware of. After two years funding was withdrawn and the project stopped. We were never

³⁷ Information about ADI accreditation can be accessed at <https://www.alzint.org/what-we-do/accreditation/>

³⁸ NDCAN blogs can be viewed on the Scottish Dementia Research Consortium website at <http://www.sdrc.scot/news/research-involvement-blogs>

told whether he took a trial drug or placebo, and the experience made my husband more stressed because he was aware during the practical assessments of his continuing decline. It was two years in our lives which I feel were wasted and we can't ever get back. I also have no idea if the research was valuable or even published'.

In NDCAN, we know a thing or two about crying out. It matters that researchers understand that those who engage in their projects may still be crying and crying out. When researchers work with family carers, they are working with people who have lived with and through tears and have more tears to shed. With such cumulative and practical knowledge among family carers, it is no wonder that the mantra "Nothing about us, without us" is used.

The idea of a bicycle springs to mind when we talk about research, specifically a tandem. Working in tandem means doing things at the same time. Yet, someone has to be at the front of the bike to steer and the person behind has to believe they are going in the right direction, especially as they are providing

half of the impetus. In relation to research, this means having a clearer idea about what true collaboration means; working together at the same general speed and definitely going in the same direction. As we are gaining in confidence and experience, we are now riding the tandem with a little more ease and speed and maybe we need to take turns at the front. That will be the continued challenge.

"I was compelled to arise to my feet, at the Alzheimer's Disease International Conference in Puerto Rico in 2014, as a founding member of the National Dementia Carer's Action Network, I said 'In Scotland we have a simple philosophy, it's about the right people, doing the right thing, at the right time. To make a change, be the change'."

NDCAN Research Group in collaboration with Professor Debbie Tolson, University of the West of Scotland and Scottish Dementia Research Consortium, and Dr Margaret Brown, University of the West of Scotland.



Australia STAGE 3A

Support and training for carers has an integral part in the Australian roadmap for dementia care. Since September 2018, thousands of Australians of all ages living with all forms of dementia, and their families and carers have shared their very personal, often traumatic, and confronting experiences directly with the Royal Commission into Aged Care Quality and Safety. The culminative Final Report: Care, Dignity and Respect³⁹ released in March 2021 captures the essence of those issues and demonstrates the Commissioners have listened to Australians impacted by dementia. The response to the Royal Commission's findings is a rare opportunity to make a once in a lifetime difference to the experience of people impacted by dementia in Australia. In Australia, a diagnosis of dementia takes 3 years and up to 7 years for younger onset dementia. Many are not diagnosed at all.

Dementia Australia has a clear roadmap for quality dementia care. It is based on the views of people living with dementia and their families and carers. It addresses the gaps and possible solutions outlined by the Royal Commission into Aged Care Quality and

Safety. Working with people impacted by dementia, as well as some important sector partners, we have developed an integrated "Roadmap for Quality Dementia Care."⁴⁰ Quality dementia care needs to become a core element of aged care, both in Australia and globally. The Roadmap outlines three key areas of transformation that collectively would make a significant difference to the delivery of quality dementia care:

1. Dementia support pathways.
2. Transformed dementia workforce capability.
3. Dementia-friendly design.

We see these three focus areas, along with a set of underpinning principles such as integration, continuous improvement, and ongoing consumer engagement, combining to form a 'roadmap' for the future of dementia care and support in Australia.

The roadmap presents a connected, integrated dementia care system, where people living with

³⁹ Care, Dignity and Respect is available at: <https://agedcare.royalcommission.gov.au/publications/final-report>

⁴⁰ Roadmap for Quality Dementia Care is available at: <https://www.dementia.org.au/sites/default/files/2021-03/PFOD-Roadmap-paper-noPrev-March-2021.pdf>

dementia, their families and carers, and their care providers can access the information that they need and be supported to navigate to the most appropriate services. In conjunction with this, the sector, and people working within it, will have the capacity and capability to consistently deliver quality care for people living with dementia, their families and carers, and the physical settings within which people receive care will also be fit for purpose.

The first focus area in our Roadmap for Quality Dementia Care: 'Dementia support pathways' proposes an integrated and specialist service response with a single access point through a centralised, national telephone and online service that complements existing aged care, carer, and disability helplines. By expanding on our existing National Dementia Helpline, Dementia Australia will offer a more comprehensive and integrated service pathway that includes the kind of service, social and psychological support that people need. This will ensure people of any age experiencing symptoms of dementia, living with dementia, and their carers and families have timely access to diagnosis and a direct and clear pathway to early and ongoing support and treatment services.

Focus area two of our roadmap is all about 'Transformed dementia workforce capability' consistent with action area 5, and proposes a comprehensive approach to building the dementia capability of the aged care workforce to ensure the skills and knowledge to provide quality care and support to people living with dementia. This will focus on addressing the most immediate deficits in workforce capacity, along with implementing initiatives to support the sustainable transformation of dementia practice in the longer term.

Focus area three, 'Dementia-friendly design', proposes developing and embedding a set of robust, evidence-based, and practice-informed dementia-friendly standards. This will enable



Dementia Australia Consumer Summit attended by Dementia Advocates, plus observers including leaders from aged care organisations and the Department of Health.

physical environments that support people living with dementia to be as independent as possible.

It is a global imperative that we improve our dementia diagnosis rates. Consumers tell us that accessing support services early improves their understanding of dementia, their relationships and planning for the future, and with the time it takes to diagnose dementia on average, it is critical that this is improved. We must significantly reduce the time it takes to diagnose dementia and increase the number of people accessing support without delay.

Maree McCabe, Chief Executive Officer, Dementia Australia.

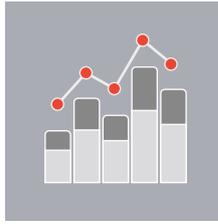
Key points



The COVID-19 pandemic has significantly disrupted carer access to much needed services and support, placing additional strain on carers and increasing isolation from social networks. Many Alzheimer's and dementia associations deliver training for carers, with some developed in consultation with carers. ADI recognises the importance of training and support for all carers, and welcomes the creative and inclusive approaches demonstrated in this report. This is equally relevant in countries where no national dementia plan is yet in place, and demonstrates the importance of governments engaging with civil society to facilitate change and instigate plan development at national level.

Chapter 6

Information systems for dementia



WHO target: 50% of countries routinely collect a core set of dementia indicators through their national health and social information systems every two years by 2025.

Systematic monitoring and evaluation of data provides evidence for policy development in addition to improving accessibility to and coordination of care for people with dementia. It provides understanding and detection of population-level changes. However, this section highlights that such data is missing from both policy and practice at national level.

Dementia registries

A core component of a national data collection system is a dementia registry collecting data on quality of care for patients with dementia, which is based on a core set of quality indicators. This provides measurable evidence which is used to assess and improve the quality of care provided to patients.⁴¹

Dementia registries collecting data on quality of care already successfully operate in Scandinavian countries.⁴² For instance, the Swedish Dementia Registry, SveDem, a national quality registry has been operating since 2007. In 2021, 100% of memory clinics in Sweden provided data to SveDem, and in August 2020 over 94,000 patients with dementia disorders were registered. The Norwegian national registry of persons assessed for cognitive symptoms (NorCog) was established in 2013. At the end of 2018, 42 hospitals were participating in the NorCog data collection, with over 10,000 registered patients. A dementia clinical quality registry is being piloted in Australia where the Australian Dementia Network Registry (ADneT) aims to collect data on people diagnosed with dementia or mild cognitive impairment

in memory clinics and dementia diagnostic services across the country.

Dementia registries are important tools for monitoring the uptake and quality of implementation of clinical guidelines. For instance, significant improvements in the quality of dementia care have been reported in relation to the SveDem registry. From 2011 to 2016, in primary health care centres which joined the registry, the Swedish Dementia Registry Annual report noted that the percentage of complete basic investigations increased by 24% and diagnosis of "dementia not otherwise specified" decreased by 16%.

Due to differences in the national health systems and the diagnostic processes and procedures, there is variation in the quality indicators used in existing dementia registries. Nonetheless, a study using data from SveDem and the Danish Dementia Registry⁴³ found six quality indicators used in both registries: evaluation time, assessment of cognitive status, laboratory data, brain imaging, aetiological diagnosis, and dementia medication. The shared indicators allowed for a

⁴¹ Campbell, SM., Braspenning, JA., Hutchinson, A., and Marshall, M. (2002) Research methods used in developing and applying quality indicators in primary care. *Quality and Safety in Health Care*. 11(4):358–64.

⁴² Krysinska, K., Sachdev, PS., Breitner, J., Kivipelto, M., Kukull, W., Brodaty, H. (2017) Dementia registries around the globe and their applications: A systematic review. *Alzheimer's & Dementia*. 13(9):1031–47.

⁴³ Fereshtehnejad, SM., Damangir, S., Cermakova, P., Aarsland, D., Eriksdotter, M., Religa, D. (2014) Profile in dementia with Lewy bodies versus Alzheimer's disease: a linkage study between the Swedish Dementia Registry and the Swedish National Patient Registry. *Alzheimer's research & therapy*. 6(5):1–4.

comparison of diagnostic work-up characteristics and the quality of dementia care across the two countries.

As much as possible and feasible, standardisation of registries and quality indicators is essential for truly international initiatives. Understandably, most dementia registries are set up as national data collection systems, designed to operate independently and not with the explicit aim of international comparisons. Nonetheless, harmonisation of registry datasets will allow for comparisons between countries and regions, providing the much needed, and currently limited, data on the indicators of health and social systems and resources related to the quality of dementia care. International

collaborations are facilitated by standardising and integrating existing datasets and defining international data-sharing guidelines, including the challenges of informed consent. The European Prevention of Alzheimer's Dementia (EPAD) project is an example of an initiative which aims to integrate existing international dementia datasets.⁴⁴

Professor Henry Brodaty, Scientia Professor of Ageing and Mental Health and Co-Director, Centre for Healthy Brain Ageing, University of New South Wales, Sydney, and Dr Karolina Kryszynska, Adjunct Research Fellow, School of Public Health and Preventative Medicine, Monash University, Australia.

Key points



The importance of dementia registries is clear in terms of supporting health and social care systems and providing data on incidence of dementia, treatment, and management. Despite the GDO offering a platform to provide easy access to dementia data from member states across policies, service delivery and information and research, it is not clear if this target will be met. Information currently available to Alzheimer and dementia associations globally suggests that considerably less than 50% of countries routinely provide core dementia indicators every two years. While 23 of 83 who responded to this question indicated that their country had submitted data, a further 23 associations said that their country had not provided figures, with some noting that data previously submitted to WHO was not available to check or review.

⁴⁴ Ritchie, CW., Molinuevo, JL., Truyen, L., Satlin, A., Van der Geypen, S., Lovestone, S. (2016) Development of interventions for the secondary prevention of Alzheimer's dementia: the European Prevention of Alzheimer's Dementia (EPAD) project. *Lancet Psychiatry*. (2):179–86.

Chapter 7

Dementia research and innovation



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

Research that provides an evidence base for practice is essential at all stages of dementia care regardless of where the person calls home. Innovation is often demonstrated through technology which has become more user-friendly for people with dementia and may be high-tech such as robotic devices, or low-tech such as adapted cutlery or utensils. Examples of both research and innovative technology are included in this section.

Dementia research encompasses bio-medical studies into the pathophysiological and clinical manifestations

of dementia, and social research aimed at improving quality of life and quality of care. While clinical research seeks to delay symptoms and progression, psycho-social and social research provides evidence of innovative approaches to care and support. Assistive technology may help people living with dementia to remain safe or active, however, it should work for the individual and must be used with their consent alongside, rather than replacing, face-to-face contact. Examples of assistive technology include automated reminders, medication aids, and locator devices.

Clinical trials

Finding an effective, disease modifying treatment continues to evade researchers as trial after trial is unsuccessful, thus preventing an effective treatment for Alzheimer's disease. There are many reasons for unsuccessful trials and researchers often openly share their trial data and the "lessons learned" from such trials in order to advance the field, and prevent other companies making similar mistakes. It is important to ensure that the appropriate participant population is recruited into a trial which will maximise the likelihood of seeing a positive or therapeutic response to the investigational product being tested. For example, before there was a robust method for detecting amyloid in the brain, trials would include a range of participants, usually at a mild to moderate stage. Further evaluation determined that up to 30% of these subjects did not have amyloid in their brain in sufficient concentration at baseline in order for an anti-amyloid investigational product to have an effect on the overall population. Due to these findings, researchers then 'enriched' the participant population (identified representatives for whom a drug effect is more likely be apparent) and assessed for the appropriate amount of amyloid in their brain as an entry criterion for the trial. Any amyloid

negative subjects, even with other symptoms of Alzheimer's disease would not be admitted to a trial.

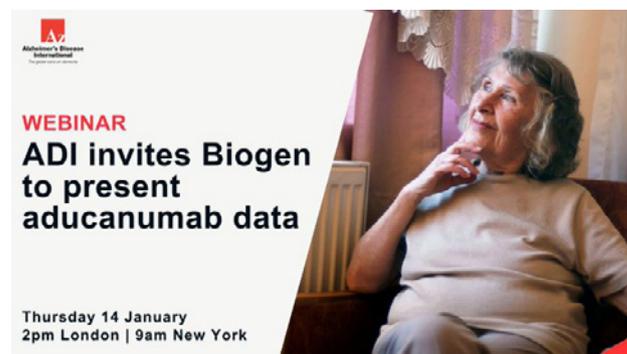
As trials continue to evolve, the science and learning from each negative trial can result in increased knowledge and understanding, and subsequent clinical trials can be designed and implemented using this enhanced knowledge. For example, Eli Lilly and Company is now implementing their acquired knowledge base of biomarkers, both tau and amyloid, in their Trailblazer trials using donanemab. In these trials, participants are not only required to have a threshold level of amyloid in their brain, but also an appropriate level of tau protein, thus creating a more personalised medicine approach to clinical trials. All previous Alzheimer's disease trials, although unsuccessful in developing a therapeutic agent, need not be considered as "failed" trials if learning can be applied to the next generation of trials.

The complexity seen in clinical trials across Alzheimer's disease are also demonstrated by Biogen's aducanumab. Based on a pre-specified futility analysis which predicted the trials would not meet their primary

endpoint, Biogen discontinued their Phase 3 studies (EMERGE and ENGAGE) in early Alzheimer's disease in March 2019. However, after reviewing additional data it was acknowledged that the pre-specified futility analysis, while valid at the time of its design, was incorrect. It was based on a smaller, earlier dataset with less exposure to high dose aducanumab. The additional data showed the pharmacologically and clinically active nature of aducanumab in patients with a longer average exposure to the high dose, determined by dose-dependent effects in reducing brain amyloid and in reducing clinical decline.

At the time of writing, there has been an extension to the Food and Drug Administration's (FDA) regulatory review of aducanumab with a decision expected in June 2021. Biogen has also submitted regulatory filings in Australia, Brazil, Canada, Switzerland, Japan and the EU.

In 2021, to enable a broad audience to gain a better understanding of this complex development and approval process, ADI collaborated with Biogen to deliver a webinar around aducanumab. The webinar explored Biogen's Phase 3 clinical studies ENGAGE and EMERGE with discussion of why Phase 3 clinical trials were prematurely terminated in 2019, and how the full data set provides evidence of clinical effectiveness.



World Health Organization Dementia Blueprint

Despite growing international attention focused on healthy ageing, global dementia research remains highly fragmented, with broad variability in investment levels and quality of research efforts. Dementia research and innovation costs are higher than in other therapeutic areas due to lower success rates, longer development times, and low patient recruitment into clinical trials. Consequently, market incentives for dementia research and innovation investment remain low. Additionally, the vast majority of dementia research is conducted in high-income settings.

Global prioritisation is necessary to ensure that ongoing dementia research covers critical areas within the full care pathway, including prevention, treatment, cure, and implementation science. Moreover, research efforts must be rooted in equity, diversity, and inclusiveness, be person-centred, and family inclusive. This necessitates building greater research capacity in all income settings, as well as developing mechanisms to ensure the inclusion of people with dementia and their carers across all research activities.

To this end, WHO is developing *WHO's Dementia Research Blueprint* which aims to accelerate global dementia research and innovation, and make research more productive and efficient, as well as promote research capacity building in low-resource settings and ensure inclusiveness in all stages from generation to implementation.

Being developed with the active contribution from a diverse group of stakeholders, the blueprint will catalyse processes for increased investment in dementia research and innovation, increase capacity-building in all income settings, and foster uptake and equitable dissemination of effective interventions in both policy and programme planning. By leading such coordination mechanism for dementia research, WHO's Dementia Research Blueprint can provide direction to funders for research investment, increase the profile of dementia research and innovation in the global agenda and ultimately enable and facilitate policy making for dementia research.

Brain Health Unit, WHO

Reflections on international progress from World Dementia Council

In 2013, at a dementia summit hosted in London by the UK government, as part of their G8 (now G7) presidency, the international community committed to accelerate progress by 2025 on dementia research, improving care, raising awareness, and preventing dementia. To review what international progress has been made towards the 2025 dementia goals, the World Dementia Council has launched the dementia landscape project,⁴⁵ a global initiative to assess the advancements that have been made and to identify how governments, international organisations and the dementia community can help accelerate progress further. As part of this we are holding a number of global dialogues covering a range of themes, such as ones we have already held examining the development of biomarkers and the progress in clinical trials. In the coming months we will hold dialogues looking at data sharing for dementia research, dementia and an ageing society, as well as health system readiness and dementia.

While there are some symptomatic treatments for dementia, we still cannot slow, or stop, the development of Alzheimer's disease and other dementias any more than we could have over a hundred years ago when Alois Alzheimer first described the condition. But that stark and depressing fact can obscure the story of last decade, which is one of accelerating progress towards the development of disease-modifying treatments. Our understanding of the underlying biology of the brain has improved considerably. The development of biomarkers over the last decade has had a huge impact on research, clinical trials, and practice. This is a very similar trajectory to oncology, and like the development of cancer treatments, funding has been key to growing the field. It is these building blocks, aided by new technology, big data and artificial intelligence that is advancing knowledge. We may very soon have the first approved treatments for Alzheimer's disease, but because of the progress in the field in the last decade, we will have treatments (in the plural) over the next decade. That will of course bring with it new challenges, not least ensuring equitable access to treatments, but this is a moment of hope.

If the story of the last decade is one of accelerating progress in research, the story in care is more mixed. Almost everyone living with dementia will need some help and support as the disease progresses. People's

care experience can not only be radically different between countries, but within them as well. There is a lot more evidence about how good quality personal care can improve the lived experience of someone with dementia and their informal carers. There is a lot of encouraging new technology being developed that can help support independent living and the quality of care. Yet, in many countries care is under-funded, and this results in poor quality care being far too common. Societies everywhere are ageing. Thanks to medical advances, there are many more individuals of working age living today with complex medical needs.

Awareness of dementia is a patchwork. There are many examples of progress but, as ADI has previously highlighted, there are equally many examples of societal or professional stigma towards people with dementia and their caregivers. One measure of this is how few people living with dementia have a diagnosis. There are obviously complex reasons why someone with dementia might be reluctant to get a formal diagnosis, but the wide disparity in diagnosis rates, again between countries and within them, needs to be addressed.

Finally, on primary prevention of dementia, over the last decade there has been accumulating evidence that the incidence of dementia in some high-income countries is lower than expected, and this is a consequence of long-term lifestyle changes that has reduced the number of people developing dementia. Healthy lifestyles, a better educated population and the treatment of diabetes, hearing loss or high blood pressure appear to be the explanation. Of course, the reasons for poor diet, or a lack of exercise, or even the absence of childhood education are complex and public policy interventions to address them are not easy. Even if you took dementia out of the equation there is regardless a very strong, indeed overwhelming, argument for childhood education for all! Whether later-life interventions are as successful at slowing the development of dementia is less clear. But as our understanding of the basic science improves, so will our understanding of how to prevent dementia.

The story of the last decade is one of progress. For all the challenges, and for all the frustrations, there are reasons to be optimistic.

Lenny Shallcross, Executive Director, World Dementia Council

⁴⁵ Information about the dementia landscape project can be accessed at: <https://worlddementiacouncil.org/DLP>

STRiDE (Strengthening Responses to Dementia in Developing Countries)

Strengthening responses to dementia in developing countries (STRiDE) is a four-year (2018–2021) project to build capacity in dementia research in seven developing countries, led by the London School of Economics and Political Science in partnership with the University of Cape Town, Brighton and Sussex Medical School, Alzheimer's Disease International and Dementia Alliance International. The project aspires to strengthen capacity to conduct research in each country and 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 works with local teams made up of senior and early-career researchers and Alzheimer associations in seven countries: Brazil, India, Indonesia, Jamaica, Kenya, Mexico, and South Africa. There are 10 work packages across the project, focusing on areas such as stigma, unpaid care, cost and prevalence, care models, and knowledge exchange and impact. Work package 8, led by ADI and members in each of the seven countries, directly addresses the WHO Global action plan by providing recommendations for national dementia plans across all seven countries. The COVID-19 pandemic required project teams to pause face-to-face data collection and although local teams were quick to innovate and find ways to engage virtually, this has impacted and delayed analysis in some of the work packages. The effects continue as a result of the UK government's reduction in budget for Official Development Assistance (ODA); the knock-on

effects include significant cuts to UK Research and Innovation (UKRI), whose Global Challenges Research Fund funds the STRiDE project.

Despite delays and funding cuts, the STRiDE project pushes forward in 2021 to deliver project outputs. As part of work package 8, ADI is working with each country team to use both qualitative and quantitative data and evidence generated across the work packages, identifying gaps, but also opportunities, that can be formulated into policy recommendations. This work will be underpinned by stakeholder engagement and advocacy.

STRiDE teams remain agile and ready to take advantage of opportunities to engage with policy makers such as in Kenya and Indonesia, where STRiDE is collaborating with Ministries of Health to develop dementia policies aligned with the action areas of the WHO Global action plan. The dementia action plan in Kenya will be the first for Africa. In Brazil, the city of Sao Paulo has just developed a city-wide dementia strategy and it is hoped that STRiDE-Brazil team can contribute vital data and evidence to help replicate such a strategy on a wider basis as well as, importantly, to support the development of a nascent national dementia plan. As data and evidence becomes available, policy work will gather momentum in India, Jamaica, Mexico and South Africa.

Wendy Weidner, Research and Policy Project Lead, ADI

The World-Wide FINGERS network; an update on global multidomain trials for dementia prevention

World-Wide FINGERS⁴⁶ is the first global network of clinical trials to assess the impact of multidomain interventions for reducing the risk of cognitive impairment and dementia in older individuals. This randomised control trial was the first of its kind to demonstrate that a two-year multidomain intervention consisting of nutritional guidance, exercise, cognitive training, social stimulation, and control of vascular and metabolic risk factors can improve cognitive functioning in older adults at risk of dementia. The intervention also had positive effects on other outcomes such as mobility and functional status, development of chronic disease and health-related quality of life.

After the successful results of the FINGER study, a global network was launched in 2017 to further test, adapt, and optimize the FINGER multidomain model in different populations and settings.⁴⁷ The network currently includes around 40 countries, bringing together studies with key methodological features based on the FINGER trial, namely: i) assessment of multidomain interventions that target several factors associated with an increased risk of cognitive decline and dementia such as vascular, metabolic, and lifestyle-related factors; ii) trials designed with individual and group sessions to personalise the interventions as well as provide social support; and iii) harmonised outcomes based on cognitive changes

⁴⁶ Information about WW-FINGERS can be accessed at www.wwfingers.com

⁴⁷ Kivipelto, M, et al. (2020) World-Wide FINGERS Network: A global approach to risk reduction and prevention of dementia. *Alzheimers Dement.* 2020 Jul;16(7):1078–1094. doi: 10.1002/alz.12123

and other outcomes such as functional status or disease development. These trials aim to adapt the original FINGER multidomain model to specific cultural and economic settings world-wide including several European countries, North and South America, China, Singapore, Japan, Malaysia, India, South Korea, and Australia. Work is ongoing, in collaboration with ADI and the WHO, to increase the participation of low and middle-income countries. Innovative methodologies tested within the network include additional intervention components, for example interventions targeting sleep or mood disorders, and the use of digital health technologies which supports remote (rather than face-to-face) intervention delivery and monitoring.

The WW-FINGERS network has responded to the COVID-19 pandemic in two ways: first, by focusing on ways to adapt trial methodologies in ongoing studies and second, by developing a harmonised survey for assessing the impact of the COVID-19 pandemic on persons at risk of cognitive impairment. All countries in the WW-FINGERS network have been affected by the COVID-19 pandemic, which has caused disruption to ongoing studies at different stages of implementation, particularly due to the risk of infection to participants and research staff and the need to adapt study protocols to align with public health recommendations. The WW-FINGERS network initiated a series of virtual meetings to discuss the various methodological challenges related to the pandemic and share solutions to enable studies to move forward. The second activity of the network has focused on the need for research on the effects that the pandemic and related public health recommendations have had on older people. The FINGER model focuses on modifiable factors such as cognitive and social stimulation, nutrition, and control of vascular and metabolic risk factors, many of which may be affected

by quarantines and lockdowns. The WW-FINGERS COVID-19 survey was developed by a multinational team from the network; a core survey was created to allow for cross-national comparison, while also providing the opportunity to adapt specific parts of the survey to account for local, cultural, and economic factors.

The first results from the WW-FINGERS COVID-19 survey have been published⁴⁸ suggesting that the majority of participants (three quarters) adopted some distancing practices during the first months of the pandemic, but this had negative effects on their lifestyle and health, specifically a decrease in physical activity and contact with friends and family, and increased feelings of loneliness. However, some positive results were also noted; their self-rated health generally remained stable, and individuals were able to use digital tools to keep in contact with family and friends, while many increased their vegetable and fruit consumption. As the COVID-19 pandemic continues, the WW-FINGERS network strives to maintain its goal of preventing cognitive decline through multidomain interventions, while adapting to the ongoing challenges of the COVID-19 pandemic.

Miia Kivipelto, Professor in Clinical Geriatrics at Karolinska Institutet, Center for Alzheimer Research, and Director for Research & Development of Medical Unit Aging at Karolinska University Hospital in Stockholm, Sweden. Director, Chair in Neuroepidemiology at Imperial College London, UK, and Principal Investigator in the FINGER Study and of the World-Wide FINGERS network

Francesca Mangialasche, MD, PhD, Center for Alzheimer Research, Karolinska Institute Stockholm, Sweden; Katie Palmer, PhD, Center for Alzheimer Research, Karolinska Institutet, Stockholm, Sweden

⁴⁸ Lehtisalo, J., Palmer, K., Mangialasche, F., Solomon, A., Kivipelto, M., Ngandu, T. (2021) Changes in Lifestyle, Behaviors, and Risk Factors for Cognitive Impairment in Older Persons During the First Wave of the Coronavirus Disease 2019 Pandemic in Finland: Results From the FINGER Study. *Front Psychiatry*. 12:624125. doi: 10.3389/fpsy.2021.624125



Scotland STAGE 4A

Many governments have made changes to the statutory retirement age and pensions which encourage people to work in later life. While economic and social benefits may include retaining skills in the workplace and enhancing teams and productivity, with this comes an increased risk of developing a chronic illness, such as dementia, while still in employment. Earlier diagnosis, coupled with policy changes that extend working years, means that the number of people with dementia in employment is likely to increase. This leads to a critical impetus to understand the needs and experiences of people with dementia in the workplace, and to improve the support available within employment settings.

A programme of research led by the University of the West of Scotland was the first in the UK to explore the experiences of people who have been diagnosed with dementia while still in employment. Case study research, funded by the Alzheimer's Society (UK) found that people with dementia can, and do, continue to work after a diagnosis with support. However, the research highlighted that there are inequalities in employment experiences, with many losing employment pre- or at the point of diagnosis or unable to access support in the workplace.

Additionally, there are gaps in knowledge of dementia and its effects in the workplace among employers. A study exploring employers' responses to dementia, funded by the Carnegie Trust, found a tendency to make assumptions about the capabilities of people living with dementia, often resulting in decisions being made to offer early retirement or redundancy post-diagnosis.⁴⁹ Emerging evidence about the employment experiences of people living with dementia suggests that while there is potential for continued employment, there is an urgent need to develop interventions and supports for the workplace. This includes helping people to recognise and maintain skills and to develop supportive work policies, practices and environments.⁵⁰

A range of evidence-informed resources funded by the Alzheimer's Society have been developed to provide guidance and support for people who have concerns about dementia and employment.⁵¹ Additionally, organisations across the UK have responded to our research findings and have developed training, support and resources with the aim of supporting people with dementia in the workplace. The Scottish Trade Union Congress have to date trained over 100 workplace trade union representatives in supporting an employee with dementia. Similarly, Age Scotland have developed guidance and training for organisations and have trained more than 700 people in organisations across Scotland in how to create dementia inclusive workplaces.

Despite such increased awareness there is still a lack of understanding about the practical support that can help people in the workplace. Additionally, it is recognised that not all people with dementia will want to continue employment after a diagnosis. Some will need support with making decisions about leaving employment and finding alternative activities post-diagnosis. Our new research project, also funded by the Alzheimer's Society, aims to co-produce a workplace intervention to support people with dementia to make decisions around their employment post-diagnosis. Working closely with people affected by dementia, as well as health and social care practitioners and career guidance practitioners, the project will develop an intervention to support choices around continued employment, leaving employment, or identifying alternative forms of work. It is hoped that an innovative strategy of combining careers guidance approaches with an understanding of dementia will help to create more inclusive opportunities for people with dementia around their employment in the future.

Dr Louise Ritchie, Reader, Alzheimer Scotland Centre for Policy and Practice, University of the West of Scotland, Scotland

⁴⁹ Egdell, V., Cook, M., Stavert, J., Ritchie, L., Tolson, D., and Danson, M. (2019). Dementia in the workplace: are employers supporting employees living with dementia? *Aging & Mental Health*. <https://doi.org/10.1080/13607863.2019.1667299>

⁵⁰ Ritchie, L., Egdell, V., Danson, M., Cook, M., Stavert, J., and Tolson, D. (2020). Dementia, Work and Employability: Using the Capability Approach to Understand the Employability Potential for People Living with Dementia. *Work, Employment and Society*. <https://doi.org/10.1177/0950017020961929>

⁵¹ Alzheimer's Society resources can be accessed at: <https://www.alzheimers.org.uk/sites/default/files/2018-10/Employment.pdf>

Examples of assistive technology



Republic of Korea STAGE 5B

SK Telecom and Seoul National University College of Medicine have developed an artificial intelligence (AI) tool⁵² to help identify dementia earlier. The tool has a ten minute conversation with an individual and then analyses their voice to determine if they may

have dementia. It is reported that the AI tool works by analysing the sound emitted by the vibrating vocal cords as it passes through the vocal tract, recognising differences in voices of those with and without dementia.



England STAGE 5B

The Accelerator Programme works with entrepreneurs to develop promising new technology designed to support people affected by dementia. Current examples are: Konnect by Kraydel which provides video conferencing hardware through the main screen in most homes to increase social interaction and allow remote service delivery. Sibstar is a financial tool for people

living with dementia to allow more independence in financial decision making once diagnosed and HUG by LAUGH is a sensory product designed for people living with dementia which has a beating heart within its soft body and can play music from a favourite playlist. HUG has been shown to increase wellbeing of people with later stage dementia.



Uganda STAGE 2B

Uganda Alzheimer's Association is collaborating with Memory Lane Games (UK) Limited to develop Ugandan specific, culturally appropriate memory games in three local languages featuring simple quiz-style games on

familiar topics, points of interest and cities, towns, and villages across Uganda. The digital health apps turn memories into games and is part of the Memory Lane Games Country Pilot Programme.

Key points



Although there is understanding of different types of dementia and the mechanisms involved, much more research is required to further understand the causes, diagnoses, treatments and risk reduction as highlighted in ADI's World Alzheimer Report 2018 *The state of the art of dementia research*. Alongside this is the importance of qualitative research that has seen a shift to capturing the experiences of people affected by dementia whether through their own diagnosis or that of a relative, friend or colleague. A key message is still to call on all governments to invest a minimum 1% of the societal cost of dementia in research, and it is vital that governments include research in their national dementia plans, with an identified budget.

⁵² Artificial intelligence in South Korea available at <https://www.zdnet.com/article/sk-telecom-offers-ai-voice-analysis-for-dementia-diagnosis/>

Summary

The work and activities of Alzheimer and dementia associations globally, working alongside a plethora of committed people and organisations dedicated to the cause, has improved the wellbeing of, and support for, people with dementia and their families.

Benefits have been demonstrated of making dementia a national priority and having a national dementia plan. Such benefits span the WHO action areas including public awareness, advocacy, improvements to health, social and long-term care, increased research, and development of risk reduction strategies, however so much more still needs to be done. This is evidenced in that only 32 of 194 WHO Member States have developed a national dementia plan at this pivotal mid-way point of the WHO Global action plan on dementia.

COVID-19 has had a devastating effect on people with dementia and their families. Diagnosis and provision

of services have been disrupted globally with an increase in social isolation experienced by older people generally. Even accounting for this, it is clear that the majority of targets in the WHO Global action plan on dementia will not be met.

ADI remains aware of the importance of grass roots work, advocacy, and the civil society movement that has undoubtedly enabled good progress to this point, but Member States must now make good the commitment made when they approved the WHO Global action plan on dementia.

This is a pivotal moment. Only four national plans were launched in the last year and we must now find ways to increase momentum, galvanise the dementia community, collaborate, innovate, and accelerate action towards achieving the goals of the Global action plan on dementia.

This is a pivotal moment. Only four national plans were launched in the last year and we must now find ways to increase momentum, galvanise the dementia community, collaborate, innovate, and accelerate action towards achieving the goals of the Global action plan on dementia.

References

- Alzheimer's Disease International (2018) *World Alzheimer Report 2018. The state of the art of dementia research: New frontiers*. London, Alzheimer's Disease International.
- Alzheimer's Disease International (2018) *From plan to impact: Progress towards targets of the Global action plan on dementia*. Available at: <https://www.alzint.org/resource/from-plan-to-impact/>
- Alzheimer's Disease International (2019) *From plan to impact II The urgent need for action*. Available at: <https://www.alzint.org/resource/from-plan-to-impact-ii/>
- Alzheimer's Disease International (2020) *From plan to impact III: Maintaining dementia as a priority in unprecedented times*. Available at: <https://www.alzint.org/resource/from-plan-to-impact-iii/>
- Bhome, R., Huntley, J., Dalton-Locke, C., San Juan, VN., Oram, S., Foye, U., Livingston, G. (2020) Impact of the COVID-19 pandemic on Older Adults Mental Health Services: a mixed methods study *medRxiv*
- Campbell, SM., Braspenning, JA., Hutchinson, A., and Marshall, M. (2002) Research methods used in developing and applying quality indicators in primary care. *Quality and Safety in Health Care*. 11(4):358–64.
- Egdell, V., Cook, M., Stavert, J., Ritchie, L., Tolson, D., and Danson, M. (2019). Dementia in the workplace: are employers supporting employees living with dementia? *Aging & Mental Health*. <https://doi.org/10.1080/13607863.2019.1667299>
- Fereshtehnejad, SM., Damangir, S., Cermakova, P., Aarsland, D., Eriksdotter, M and Religa, D. (2014) Profile in dementia with Lewy bodies versus Alzheimer's disease: a linkage study between the Swedish Dementia Registry and the Swedish National Patient Registry. *Alzheimer's research & therapy*. 6(5):1–4.
- Fleming, R., Zeisel, J. and Bennett, K. (2020) *World Alzheimer Report 2020: Design Dignity Dementia: dementia-related design and the built environment Volume 1*. London, England: Alzheimer's Disease International. Available at <https://www.alzint.org/resource/world-alzheimer-report-2020/>
- Fleming, R., Zeisel, J. and Bennett, K. (2020) *World Alzheimer Report 2020: Design Dignity Dementia: dementia-related design and the built environment Volume 2: Case Studies*. London, England: Alzheimer's Disease International. Available at: <https://www.alzint.org/u/WorldAlzheimerReport2020Vol2.pdf>
- Gillard, S., Dare, C., Hardy, J. et al. (2001) Experiences of living with mental health problems during the COVID-19 pandemic in the UK: a coproduced, participatory qualitative interview study. *Soc Psychiatry Psychiatr Epidemiol*. <https://doi.org/10.1007/s00127-021-02051-7>
- Krysinska, K., Sachdev, PS., Breitner, J., Kivipelto, M., Kukull, W. and Brodaty, H. (2017) Dementia registries around the globe and their applications: A systematic review. *Alzheimer's & Dementia*. 13(9):1031–47.
- Liu, K., Howard, R., Banerjee, S., Comas-Herrera, A., Goddard, J., Knapp, M., Livingston, G., O'Brien, JT., Paterson, RW., Polignano, R., Robinson, L., Rossor, M., Rowe, J., Sharp, D., Sommerlad A, Suárez-González A. & Burns, A. (2021) Dementia wellbeing and COVID-19: review and expert consensus on current research and knowledge gaps *OSF Preprints* <https://osf.io/2bq4u>
- Livingston, G., Huntley, J., Sommerlad, A., Ames, D., Ballard, C. and Banerjee, S. et al. (2020) *Dementia prevention, intervention, and care: 2020 report of the Lancet Commission, The Lancet*. 396(10248), 413–446. Available at: [https://www.thelancet.com/article/S0140-6736\(20\)30367-6/fulltext](https://www.thelancet.com/article/S0140-6736(20)30367-6/fulltext)
- Ritchie, CW., Molinuevo, JL., Truyen, L., Satlin, A., Van der Geyten, S. and Lovestone, S. (2016) Development of interventions for the secondary prevention of Alzheimer's dementia: the European Prevention of Alzheimer's Dementia (EPAD) project. *Lancet Psychiatry*. (2):179–86.
- Ritchie, L., Egdell, V., Danson, M., Cook, M., Stavert, J. and Tolson, D. (2020). Dementia, Work and Employability: Using the Capability Approach to Understand the Employability Potential for People Living with Dementia. *Work, Employment and Society*. <https://doi.org/10.1177/0950017020961929>
- Suárez-González, A., Livingston, G., Low, LF., Cahill, S., Hennesly, N., Dawson, WD., Weidner, W., Bocchetta, M., Ferri, CP., Matias-Guiu, JA., Alladi S., Musyimi, CW. and Comas-Herrera, A. (2020) *Impact and mortality of COVID-19 on people living with dementia: cross-country report*. International Long-Term Care Policy Network, CPECLSE.
- World Health Organization (2018) *Towards a national dementia plan: a WHO Guide*. Geneva, World Health Organization.
- World Health Organization (2019) *Risk reduction of cognitive decline and dementia: WHO Guidelines*. Geneva, World Health Organization.

Appendix A

ADI member nations that are WHO Member States, with dementia plans represented by income group, plan stage, and status

Country	WHO region	WHO status	ADI status	Income group	Plan stage	Plan status comment
Albania	European region	WHO	MDP	UMIC		
Argentina	Region of the Americas	WHO	Member	HIC	STAGE 2B	Some developments towards a plan, but progress stalled
Armenia	European region	WHO	Member	UMIC	STAGE 2B	Some developments towards a plan, but progress stalled
Australia	Western Pacific region	WHO	Member	HIC	STAGE 3A	Not yet launched, but commitment to funding for some of the action areas.
Austria	European region	WHO	Member	HIC	STAGE 4A	Inadequate funding
Bahamas	Region of the Americas	WHO	Potential	HIC		
Bangladesh	South-East Asian Region	WHO	MDP	LMIC	STAGE 2E	Dementia referred to in existing grouped health plan, but not as a separate health condition
Barbados	Region of the Americas	WHO	Member	HIC	STAGE 2B	Some developments towards a plan, but progress stalled
Belarus	European region	WHO	Potential	UMIC		
Belgium	European region	WHO	Member	HIC	STAGE 2	No plan/strategy
Bolivia	Region of the Americas	WHO	Member	LMIC	STAGE 2A	Initial meetings with government, but no further progress
Bosnia and Herzegovina	European region	WHO	Member	UMIC	STAGE 3D	A grouped health plan including dementia, in development
Brazil	Region of the Americas	WHO	Member	UMIC	STAGE 2B	Some developments towards a plan, but progress stalled
Brunei	Western Pacific region	WHO	Member	HIC	STAGE 3B	In development, good progress
Bulgaria	European region	WHO	Member	UMIC	STAGE 3D	A grouped health plan including dementia, in development
Burundi	African region	WHO	MDP	LIC		
Cambodia	Western Pacific region	WHO	Potential	LMIC		
Cameroon	African region	WHO	Member	LMIC	STAGE 1	No current contact with government or Ministry of Health
Canada	Region of the Americas	WHO	Member	HIC	STAGE 5A	Plan adopted but not fully communicated
Chile	Region of the Americas	WHO	Member	HIC		
China	Western Pacific region	WHO	Member	HIC	STAGE 5B	Plan adopted, funded and monitored
Colombia	Region of the Americas	WHO	Member	UMIC	STAGE 2C	Some funding committed to 7 action areas of Global plan, but no expressed intention of launching a plan
Costa Rica	Region of the Americas	WHO	Member	HIC	STAGE 4A	Inadequate funding
Croatia	European region	WHO	Member	HIC	STAGE 2E & 3C	In development, slow progress & Dementia referred to in existing grouped health plan, but not as a separate health condition

Country	WHO region	WHO status	ADI status	Income group	Plan stage	Plan status comment
Cuba	Region of the Americas	WHO	Member	LMIC	STAGE 5A	Plan adopted but not fully communicated
Cyprus	European region	WHO	Member	HIC	STAGE 3B	In development, good progress
Czech Republic	European region	WHO	Member	HIC	STAGE 3C	In development, slow progress
Democratic Republic of the Congo	African region	WHO	Potential	LIC		
Denmark	European region	WHO	Member	HIC		
Dominica	Region of the Americas	WHO	MDP	UMIC	STAGE 2B	Some developments towards a plan, but progress stalled
Dominican Republic	Region of the Americas	WHO	Member	UMIC	STAGE 4B	No funding
Ecuador	Region of the Americas	WHO	Member	UMIC	STAGE 1	No current contact with government or Ministry of Health
Egypt	Eastern Mediterranean region	WHO	Member	LMIC	STAGE 2A	Initial meetings with government but no further progress
El Salvador	Region of the Americas	WHO	Member	LMIC	STAGE 2B	Some developments towards a plan, but progress stalled
Estonia	European region	WHO	MDP	HIC	STAGE 2C	Some funding committed to 7 action areas of Global plan, but no expressed intention of launching a plan
Finland	European region	WHO	Member	HIC	STAGE 4E	A grouped health plan including dementia, adopted but with no or inadequate funding
France	European region	WHO	Member	HIC	STAGE 2C	Some funding committed to 7 action areas of Global plan, but no expressed intention of launching a plan
Georgia	European region	WHO	Member	LMIC	STAGE 3C	In development, slow progress
Germany	European region	WHO	Member	HIC	STAGE 5B	Plan adopted, funded and monitored
Ghana	African region	WHO	Member	LMIC		
Greece	European region	WHO	Member	HIC	STAGE 5B	Plan adopted, funded and monitored
Grenada	Region of the Americas	WHO	MDP	UMIC	STAGE 2A	Initial meetings with government but no further progress
Guatemala	Region of the Americas	WHO	Member	UMIC	STAGE 2E & 2A	Initial meetings with government but no further progress & Dementia referred to in existing grouped health plan, but not as a separate health condition
Honduras	Region of the Americas	WHO	Member	LMIC	STAGE 2A & 2B	Initial meetings with government but no further progress & Some developments towards a plan, but progress stalled
Iceland	European region	WHO	Potential	HIC		
India	South-East Asian Region	WHO	Member	LMIC	STAGE 2C	Some funding committed to a few of the seven action areas of Global plan, but no assurance or commitment given for launching a plan
Indonesia	South-East Asian Region	WHO	Member	LMIC	STAGE 5A	Plan adopted but not fully communicated
Iran	Eastern Mediterranean region	WHO	Member	UMIC	STAGE 3C	In development, slow progress
Ireland	European region	WHO	Member	HIC	STAGE 4A	Inadequate funding

Country	WHO region	WHO status	ADI status	Income group	Plan stage	Plan status comment
Israel	European region	WHO	Member	HIC	STAGE 4A	Inadequate funding
Italy	European region	WHO	Member	HIC	STAGE 4A	Inadequate funding
Jamaica	Region of the Americas	WHO	Member	UMIC	STAGE 2A	Initial meetings with government but no further progress
Japan	Western Pacific region	WHO	Member	HIC	STAGE 5B	Plan adopted, funded and monitored
Jordan	Eastern Mediterranean region	WHO	MDP	UMIC	STAGE 2D	A grouped health plan including dementia, under consideration
Kenya	African region	WHO	Member	LMIC	STAGE 3A & 3B	Not yet launched, but commitment to funding for some of the 7 action areas & In development, good progress
Korea, Republic of	Western Pacific region	WHO	Member	HIC	STAGE 5B	Plan adopted, funded and monitored
Lao People's Democratic Republic	Western Pacific region	WHO	Potential	LMIC		
Lebanon	Eastern Mediterranean region	WHO	Member	UMIC	STAGE 2B	Some developments towards a plan, but progress stalled
Lesotho	African region	WHO	Member	LMIC	STAGE 3D	A grouped health plan including dementia, in development
Liberia	African region	WHO	Non-member	LIC		
Libya	Eastern Mediterranean region	WHO	Non-member	UMIC		
Lithuania	European region	WHO	Potential	HIC	STAGE 2A	Initial meetings with government but no further progress
Macedonia	European region	WHO	Member	UMIC		
Madagascar	African region	WHO	Member	LIC	STAGE 2E & 2A	Dementia referred to in existing grouped health plan, but not as a separate health condition & Initial meetings with government but no further progress
Malawi	African region	WHO	Potential	LIC		
Malaysia	Western Pacific region	WHO	Member	UMIC	STAGE 3C	In development, slow progress
Mali	African region	WHO	Potential	LIC	STAGE 2E	Dementia referred to in existing grouped health plan, but not as a separate health condition
Malta	European region	WHO	Member	HIC	STAGE 4A	Inadequate funding
Mauritius	African region	WHO	Member	UMIC	STAGE 2B	Some developments towards a plan, but progress stalled
Mexico	Region of the Americas	WHO	Member	UMIC	STAGE 4B	No funding
Montenegro	European region	WHO	Member	UMIC	STAGE 2E & 2B	Dementia referred to in existing grouped health plan, but not as a separate health condition & Some developments towards a plan, but progress stalled
Morocco	Eastern Mediterranean region	WHO	MDP	LMIC	STAGE 2A	Initial meetings with government but no further progress
Myanmar	South-East Asian Region	WHO	Member	LMIC		

Country	WHO region	WHO status	ADI status	Income group	Plan stage	Plan status comment
Nepal	South-East Asian Region	WHO	Member	LIC	STAGE 2E & 2B	Dementia referred to in existing grouped health plan, but not as a separate health condition & Some developments towards a plan, but progress stalled
Netherlands	European region	WHO	Member	HIC	STAGE 5B	Plan adopted, funded and monitored
New Zealand	Western Pacific region	WHO	Member	HIC	STAGE 3C	In development, slow progress
Nicaragua	Region of the Americas	WHO	Member	LMIC	STAGE 2B	Some developments towards a plan, but progress stalled
Nigeria	African region	WHO	Member	LMIC	STAGE 2D	A grouped health plan including dementia, under consideration
Norway	European region	WHO	Member	HIC	STAGE 4A	Inadequate funding
Oman	Eastern Mediterranean region	WHO	Member	HIC	STAGE 2A	Initial meetings with government but no further progress
Pakistan	Eastern Mediterranean region	WHO	Member	LMIC	STAGE 3C	In development, slow progress
Panama	Region of the Americas	WHO	MDP	HIC	STAGE 2A	Initial meetings with government but no further progress
Paraguay	Region of the Americas	WHO	Potential	UMIC		
Peru	Region of the Americas	WHO	Member	UMIC	STAGE 3C	In development, slow progress
Philippines	Western Pacific region	WHO	Member	LMIC	STAGE 2E	Dementia referred to in existing grouped health plan, but not as a separate health condition
Poland	European region	WHO	Member	HIC	STAGE 2B	Some developments towards a plan, but progress stalled
Portugal	European region	WHO	Non-member	HIC	STAGE 3C	
Qatar	Eastern Mediterranean region	WHO	Member	HIC	STAGE 4A	Inadequate funding
Rep. of Moldova	European region	WHO	Non-member	LMIC		
Romania	European region	WHO	Member	UMIC		
Russian Federation	European region	WHO	Member	UMIC	STAGE 5C	A grouped health plan including dementia, adopted, with specific targets and funding
Saint Kitts and Nevis	Region of the Americas	WHO	Member	HIC	STAGE 2A	Initial meetings with government but no further progress
Saudi Arabia	Eastern Mediterranean region	WHO	Member	HIC		
Senegal	African region	WHO	MDP	LIC	STAGE 2E	Dementia referred to in existing grouped health plan, but not as a separate health condition
Seychelles	African region	WHO	Potential	LIC		
Singapore	Western Pacific region	WHO	Member	HIC	STAGE 5A	Plan adopted but not fully communicated
Slovak Republic	European region	WHO	Member	HIC		
Slovenia	European region	WHO	Member	HIC	STAGE 4D	Plan under threat

Country	WHO region	WHO status	ADI status	Income group	Plan stage	Plan status comment
South Africa	African region	WHO	Member	UMIC	STAGE 2E & 2A	Dementia referred to in existing grouped health plan, but not as a separate health condition & Initial meetings with government but no further progress
Spain	European region	WHO	Member	HIC	STAGE 4B	No funding
Sri Lanka	South-East Asian Region	WHO	Member	LMIC	STAGE 2E	Dementia referred to in existing grouped health plan, but not as a separate health condition
Suriname	Region of the Americas	WHO	Member	UMIC	STAGE 2B	Some developments towards a plan, but progress stalled
Sweden	European region	WHO	Member	HIC		
Switzerland	European region	WHO	Member	HIC	STAGE 4A	Inadequate funding
Syrian Arab Republic	Eastern Mediterranean region	WHO	Member	LIC		
Tanzania, United Republic of	African region	WHO	Member	LIC	STAGE 4E	A grouped health plan including dementia, adopted but with no or inadequate funding
Thailand	South-East Asian Region	WHO	Member	UMIC	STAGE 2C	Some funding committed to 7 action areas of Global plan, but no expressed intention of launching a plan
Togo	African region	WHO	Potential	LIC		
Tonga	Western Pacific region	WHO	Member	UMIC	STAGE 2E & 2B	Dementia referred to in existing grouped health plan, but not as a separate health condition & Some developments towards a plan, but progress stalled
Trinidad and Tobago	Region of the Americas	WHO	Member	HIC	STAGE 1	No current contact with government or Ministry of Health
Tunisia	Eastern Mediterranean region	WHO	Member	LMIC	STAGE 1	No current contact with government or Ministry of Health
Turkey	European region	WHO	Member	UMIC	STAGE 3B	In development, good progress
Uganda	African region	WHO	Member	LIC	STAGE 2B	Some developments towards a plan, but progress stalled
United Arab Emirates	Eastern Mediterranean region	WHO	Member	HIC	STAGE 2	No Plan/Strategy
United Kingdom (England)	European region	WHO	Member	HIC	STAGE 5B	Plan adopted, funded and monitored
United Kingdom – Wales	European region	WHO	Member	HIC	STAGE 5A	Plan adopted but not fully communicated
United States of America	Region of the Americas	WHO	Member	HIC	STAGE 5B	Plan adopted, funded and monitored
Uruguay	Region of the Americas	WHO	Member	HIC	STAGE 2E & 3C	Dementia referred to in existing grouped health plan, but not as a separate health condition & In development, slow progress
Venezuela	Region of the Americas	WHO	Member	UMIC	STAGE 1	No current contact with government or Ministry of Health
Vietnam	Western Pacific region	WHO	MDP	LMIC	STAGE 3D	A grouped health plan including dementia, in development
Yemen	Eastern Mediterranean region	WHO	MDP	LIC	STAGE 2A	Initial meetings with government but no further progress

Country	WHO region	WHO status	ADI status	Income group	Plan stage	Plan status comment
Zambia	African region	WHO	MDP	LMIC	STAGE 2A	Initial meetings with government but no further progress
Zimbabwe	African region	WHO	Member	LIC	STAGE 2E & 2A	Dementia referred to in existing grouped health plan, but not as a separate health condition & Initial meetings with government but no further progress

Definitions

Membership status	
Member	Full member of ADI. There is one member per country, which is the national Alzheimer's association who have completed ADI's 2-year Membership Development Programme and meet certain criteria
MDP	Member of ADI's 2-year Development Programme
Potential	Due to commence ADI Membership Development Programme
Income classification	
LIC	Low Income Country
LMIC	Lower-Middle Income Country
UMIC	Upper-Middle Income Country
HIC	High Income Country

Appendix B

ADI members (that are not WHO Member States) with dementia plans, represented by plan stage and status

Country	ADI member	Plan stage	Plan status
Bonaire	Yes	5A	Plan adopted but not fully communicated
Gibraltar	Yes	5B	Plan status Plan adopted, funded and monitored
Macau SAR	Yes	5A	Plan adopted but not fully communicated
Northern Ireland	Yes	4A	Inadequate funding
Puerto Rico	Yes	4B	Inadequate funding
Scotland	Yes	4A	Inadequate funding
TADA Chinese Taipei	Yes	5A	Plan adopted but not fully communicated
Wales	Yes	5A	Plan adopted but not fully communicated

Appendix C

Non-ADI members that are WHO Member States with no dementia plan

Country	WHO region	WHO status	ADI status	Income group
Afghanistan	Eastern Mediterranean region	WHO	Non-member	LIC
Algeria	African region	WHO	Non-member	UMIC
Andorra	European region	WHO	Non-member	HIC
Angola	African region	WHO	Non-member	LMIC
Antigua and Barbuda	Region of the Americas	WHO	Non-member	HIC
Azerbaijan	European region	WHO	Non-member	UMIC
Bahrain	Eastern Mediterranean region	WHO	Non-member	HIC
Belize	Region of the Americas	WHO	Non-member	UMIC
Benin	African region	WHO	Non-member	LIC
Bhutan	South-East Asian Region	WHO	Non-member	LMIC
Botswana	African region	WHO	Non-member	UMIC
Burkina Faso	African region	WHO	Non-member	LIC
Cape Verde	African region	WHO	Non-member	LMIC
Central African Republic	African region	WHO	Non-member	LIC
Chad	African region	WHO	Non-member	LIC
Comoros	African region	WHO	Non-member	LIC
Congo	African region	WHO	Non-member	LMIC
Cook Islands	Western Pacific region	WHO	Non-member	UMIC
Côte d'Ivoire	African region	WHO	Non-member	LMIC
Democratic Peoples Republic of Korea	South-East Asian Region	WHO	Non-member	LIC
Djibouti	African region	WHO	Non-member	LMIC
Equatorial Guinea	African region	WHO	Non-member	UMIC
Eritrea	African region	WHO	Non-member	LIC
Ethiopia	African region	WHO	Non-member	LIC
Fiji	Western Pacific region	WHO	Non-member	UMIC
Gabon	African region	WHO	Non-member	UMIC
Gambia	African region	WHO	Non-member	LIC
Guinea	African region	WHO	Non-member	LIC
Guinea-Bissau	African region	WHO	Non-member	LIC
Guyana	African region	WHO	Non-member	UMIC
Haiti	Region of the Americas	WHO	Non-member	LIC
Hungary	European region	WHO	Non-member	HIC
Iraq	Eastern Mediterranean region	WHO	Non-member	UMIC
Kazakhstan	European region	WHO	Non-member	UMIC
Kiribati	Western Pacific region	WHO	Non-member	LMIC
Kuwait	Eastern Mediterranean region	WHO	Non-member	HIC
Kyrgyzstan	European region	WHO	Non-member	LMIC
Latvia	European region	WHO	Non-member	HIC
Luxembourg	European region	WHO	Non-member	HIC
Maldives	South-East Asian Region	WHO	Non-member	UMIC
Marshall Islands	Western Pacific region	WHO	Non-member	UMIC
Mauritania	African region	WHO	Non-member	LMIC
Micronesia	Western Pacific region	WHO	Non-member	LMIC
Monaco	European region	WHO	Non-member	HIC

Country	WHO region	WHO status	ADI status	Income group
Mongolia	Western Pacific region	WHO	Non-member	LMIC
Mozambique	African region	WHO	Non-member	LIC
Namibia	African region	WHO	Non-member	UMIC
Nauru	Western Pacific region	WHO	Non-member	UMIC
Niger	African region	WHO	Non-member	LIC
Niue	Western Pacific region	WHO	Non-member	UMIC
Palau	Western Pacific region	WHO	Non-member	HIC
Papua New Guinea	Western Pacific region	WHO	Non-member	LMIC
Rwanda	African region	WHO	Non-member	LIC
Saint Lucia	Region of the Americas	WHO	Non-member	UMIC
Saint Vincent and the Grenadines	Region of the Americas	WHO	Non-member	UMIC
Samoa	Western Pacific region	WHO	Non-member	UMIC
San Marino	European region	WHO	Non-member	HIC
Sao Tome And Principe	African region	WHO	Non-member	LMIC
Serbia	European region	WHO	Non-member	UMIC
Sierra Leone	African region	WHO	Non-member	LIC
Solomon Islands	Western Pacific region	WHO	Non-member	LMIC
Somalia	Eastern Mediterranean region	WHO	Non-member	LIC
South Sudan	African region	WHO	Non-member	LMIC
Sudan	Eastern Mediterranean region	WHO	Non-member	LMIC
Swaziland	African region	WHO	Non-member	LMIC
Tajikistan	European region	WHO	Non-member	LIC
Timor-Leste	South-East Asian Region	WHO	Non-member	LMIC
Turkmenistan	European region	WHO	Non-member	UMIC
Tuvalu	Western Pacific region	WHO	Non-member	UMIC
Ukraine	European region	WHO	Non-member	LMIC
Uzbekistan	European region	WHO	Non-member	LMIC
Vanuatu	Western Pacific region	WHO	Non-member	LMIC

About ADI

Alzheimer's Disease International (ADI) is the international federation of Alzheimer associations throughout the world. Each of our 105 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 and dementia 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.
- Deliver ADI accreditation programme to ensure people living with dementia receive high quality care and support provided by appropriately trained professionals and carers.
- 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.alzint.org

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

Published 2021

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



**Alzheimer's Disease
International**