

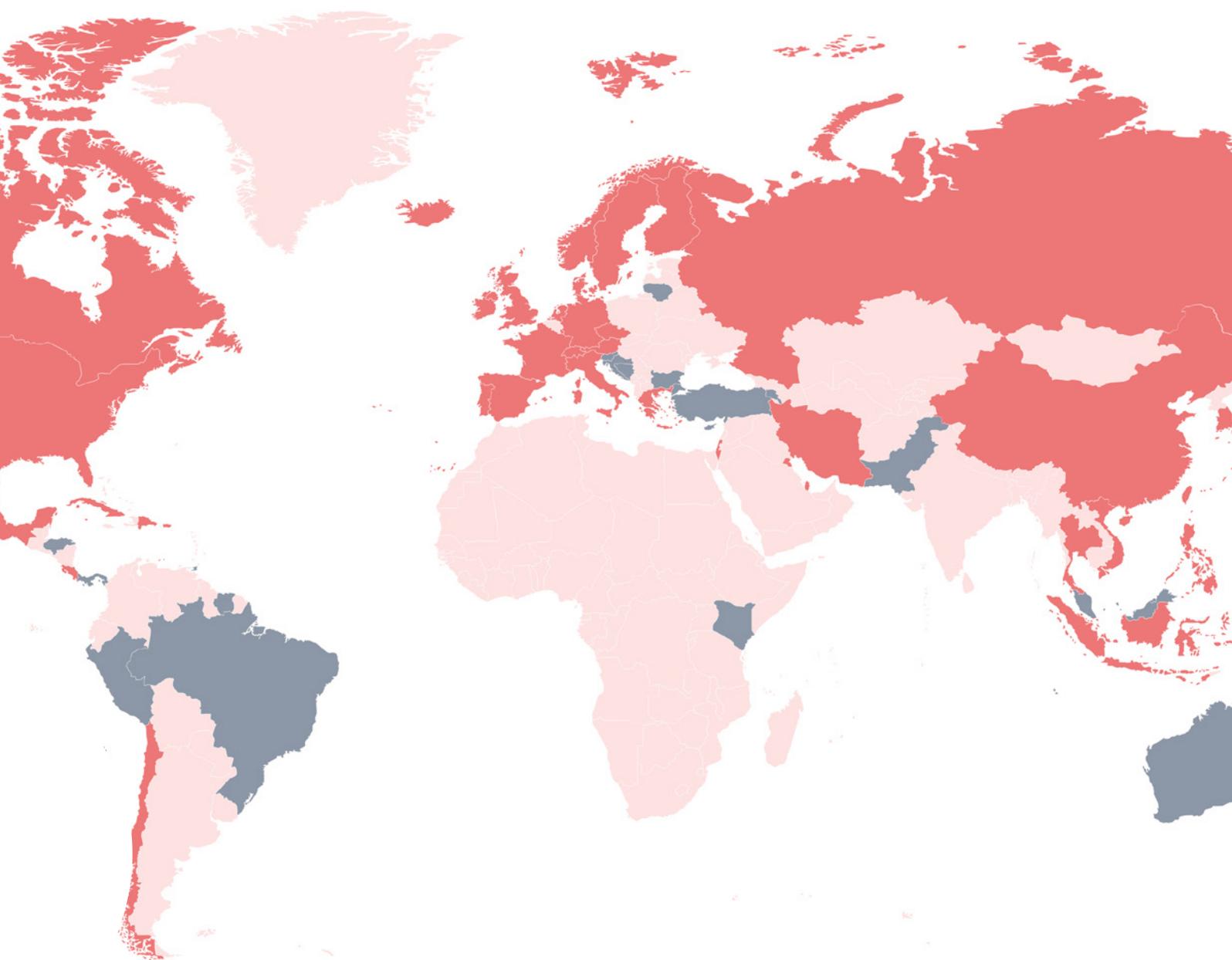


**Alzheimer's Disease  
International**

*The global voice on dementia*

# From Plan to Impact V

*WHO Global action plan:  
The time to act is now*



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## Foreword



Welcome to the fifth edition of this report, which Alzheimer's Disease International (ADI) has produced every year since the approval of the World Health Organization's (WHO) Global action plan on dementia. The WHO member states unanimously committed to translating the Global action plan into national plans. However, back then, I was concerned that we could end up with

no national plans or with words on paper, rather than real improvements on the ground for people living with dementia and their families worldwide.

Member states feed data on the progress of their national plans to the WHO Global Dementia Observatory (GDO). This report is intended to verify that data against real-life observations by our member associations. In the last four years, we have observed little or no progress, especially in low- and middle-income countries. As of May 2022, the number of WHO member states with national dementia plans stands at 39. This equates to around 27% of the 146 target.

Last year, I lamented that GDO data had not been updated since inception, but this has now completely changed. In September 2021, the WHO updated GDO data and launched its own status report looking at the progress of the Global action plan on dementia. Unfortunately, the Global status report came to the same conclusion as every single edition of From Plan to Impact, including this one – which is that, sadly, we need a lot more action if the Global dementia plan is to translate into a better life for people with dementia and their families.

From where I stand, it is obvious that a lot of governments are using COVID-19 as an excuse to kick the can down the road a bit further – and this despite the pandemic making the largest number of victims precisely among people with dementia and those living in long-term care. As Sube Banerjee states so eloquently in his essay in Chapter 4:

People with dementia both living in care homes and at home have had the highest mortality of any group, partly because of the frailty inherent in many with dementia. However, it is also driven by the lives of people with dementia being accorded a lower value than the lives of those without dementia. The Elizabethan Poor Law created the concept of the "deserving poor", whose needs should be met, and the "undeserving poor", whose needs could be ignored. When presented with the COVID-19 crisis the system reverted reflexively to a mindset of, often unconscious, discrimination against older adults and people with dementia, creating a class of the "undeserving ill". In this time of crisis, they could be deprioritised from treatment, not only for COVID-19 but for other conditions requiring hospital care.

*Sube Banerjee, executive dean and professor of dementia, Faculty of Health, University of Plymouth, United Kingdom*

Dementia is the seventh leading cause of death globally, but still too many governments refuse to acknowledge this.

This is why we launched our new #WhatsYourPlan campaign in November, the product of our frustration by this lack of action, especially in Africa. You will read about the campaign in the report. As ever, it is a hands-on, action- and outputs-oriented exercise. We have identified with our member associations the governments that need a nudge to get draft plan delivery accelerated, and the governments that need to start thinking about a plan from scratch. So far, 40 countries have answered our call, and we are currently interacting with a substantial number of those ministries. More in Chapter 1 of the report.

It has been great to see how many countries have been interested in starting to work on a dementia plan and were only too glad of our offer to provide some help and support. Once the campaign was under way and ministries started to engage with us, the WHO, and the Pan American Health Organization (PAHO) in particular, as well as the Interamerican Development Bank, have been extremely helpful in providing intelligence and technical support. We are very hopeful that the campaign will yield concrete results and we will report back on that in late 2022/early 2023.

With only three years left on the Global action plan on dementia, it felt timely to give our chances an extra push. We can do this now because we know that our movement is growing exponentially. In the span of four years, we have gone from 900,000 social media impressions for World Alzheimer's Month to 45 million. This gives us a much wider base of support to draw on and to call for politicians the world over to start working in this issue that is so critical to the economics of a nation.

And since we are talking of economics, it is important to highlight that all the figures on prevalence and incidence were updated in the last year, twice. The latest figures were published by the Institute of Health Metrics and Evaluation (IHME) and the WHO. You will find a succinct history of how we got there in the report, but it is important to note that not much has changed since our World Alzheimer's Report 2015, authored by Martin Prince and many others. In a nutshell, the number of people living with dementia in the world is high and only getting higher.

As this report states, most governments worldwide, especially in low- and middle-income countries, are doing absolutely zilch to help those living with dementia and Alzheimer's and their families. Indeed, in some high-income countries the situation is stalled or worsening. The cost to society is huge, as you can read in the eloquent essay by Anders Wimo in Chapter 1, so it is mindboggling that we are getting less, rather than more, action.

It is not all doom and gloom. In this report, you will find a lot of uplifting stories and, in some cases, examples of incredible resilience, such as Ukrainian association Nezabutni:

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The conflict has had an undeniable impact on the wellbeing of people with dementia in Ukraine. Some have died, while others have seen their memory worsen and agitation increase in response to the high levels of stress around them.

Dementia does not know borders nor geopolitics. The current situation in Ukraine has highlighted the importance of having resources to support people with dementia in times of crisis – such as the informational cards devised by ADI – as well as better awareness of the disease globally so people living with dementia, like many others with so-called “hidden disabilities”, are not left behind.

***Irina Shevchenko, founder, Nezabutni, Ukraine***

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Indeed, examples of excellence abound and remind us that there is so much great work out there and so few people who know about it yet:

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The small cottages in our dementia care homes each come with their own kitchen, where staff prepare wholesome and tasty meals. While many people living with dementia struggle with loss of appetite or interest in food, the smells, sounds and sights of cooking tempt even the most reluctant diner.

***Professor Colm Cunningham, executive director of research, international and dementia design for HammondCare Dementia Centre***

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Overall, I feel that there is a lot more awareness this year amongst policymakers – for whom this report is compiled – about dementia and its consequences on families all over the world. This is thanks to all of us working day and night in this field.

There is also more understanding of its costs and impacts on society but still, in my opinion, not enough action. Too many health systems are still wholly unprepared to address dementia and its impact, and COVID-19 risks to derail the process further. It will be up to all of us to keep our sleeves firmly rolled up for another year of hard work, but I have no doubt that we will succeed in the end.

**Paola Barbarino**  
Chief Executive Officer  
London, May 2022



## Executive summary

Dementia is the seventh leading cause of death in the world,<sup>1</sup> yet access to information, services, support, and care is deeply uneven – especially for people with dementia living in low- and middle-income countries, despite them making up nearly two-thirds of cases.

Dementia is a growing issue globally: The number of people living with dementia – estimated to stand at 55 million in 2019 – is expected to rise to 139 million in 2050, according to most recent WHO figures. The costs associated with dementia, meanwhile, are expected to rise from US\$1.3 trillion per year in 2019 to \$2.8 trillion dollars by 2030.

The World Health Organization (WHO) Global action plan on the public health response to dementia 2017–2025<sup>2</sup> was created with the aim of improving the lives of people with dementia and their carers, all while decreasing the impact of dementia on communities and countries through a series of seven action areas with defined targets. WHO member states, 194 in total, committed to the global plan and to reporting their progress through the Global Dementia Observatory (GDO).

The COVID-19 pandemic has taken its toll on people living with dementia – among the most vulnerable to the disease. But beyond the most immediate impact of COVID-19, the past two years have seen a marked drop in access to diagnosis and post-diagnosis care, while the isolation of lockdowns has had a significant impact on cognition and carer burden. Meanwhile, evidence of cognitive impairment in some individuals who contracted COVID-19 also raises the possibility that the pandemic may have a long-term impact on the number of people developing dementia in the future – further emphasising the need for a public health response.

Alzheimer's Disease International (ADI) has produced its From Plan to Impact report annually to monitor progress and provide critical updates on the status of the Global action plan. This fifth edition, the first past the halfway mark, continues to show that member states are lagging behind the goals set by the plan. A WHO status report published in September 2021 also took stock of the gains made four years into the Global action plan on dementia.<sup>3</sup> Based on self-reporting by member states, this report also found that targets are not being met quickly enough.



With three years left before the scheduled end of the plan in 2025, ADI urges governments to answer the calls to action set by the Global action plan to which they committed in 2017. ADI notably stresses the importance of committing to and implementing national dementia plans, which serve as a solid foundation for integrating dementia into policy in a multipronged, holistic way. To aid in this process, ADI has launched its #WhatsYourPlan campaign in order to support governments seeking to develop dementia plans. As discussed in this report, the aim of the campaign is to galvanise collaborative efforts between governments and key stakeholders, using tangible tools and promoting cross-sector dialogue to develop and implement solid national dementia plans that meet the needs of people living with dementia and those that support them.

<sup>1</sup> <https://www.who.int/news-room/fact-sheets/detail/dementia>

<sup>2</sup> Global action plan on the public health response to dementia 2017–2025. Geneva: World Health Organization; 2017. Licence: CC BY-NC-SA 3.0 IGO. (p 32)

<sup>3</sup> Global status report on the public health response to dementia. Geneva: World Health Organization; 2021. Licence: CC BY-NC-SA 3.0 IGO (pp 219–235)

## Key messages

- As of May 2022, 48 countries or territories have national dementia plans, 39 of which are WHO member states. This equates to around 27% of the 146 target and only around a fifth of all member states, despite all 194 agreeing to implement a plan in 2017.
- Dementia plans across WHO regions include 21 in Europe, seven in the Americas, six in the Western Pacific, three in the Eastern Mediterranean and none in Africa.
- 21 countries are currently developing a national dementia plan or have integrated dementia within a wider health plan that is also in development.
- 35 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 May 2022 and assumes no additional plans are launched this calendar year.
- 40 countries across all six WHO regions are taking part in ADI's #WhatsYourPlan campaign, with marked success so far, with commitments and progress in countries including Brazil, Lithuania and Trinidad and Tobago.
- The costs associated with dementia are expected to rise from US\$1.3 trillion per year in 2019 to \$2.8 trillion dollars by 2030. An investment now can have cost-saving impacts in the future, for example by delaying onset, delaying, or avoiding acute hospitalisation or residential care admittance, and in the case of emerging treatments, the positive impact of enabling people with dementia and carers to remain in work, making a positive economic contribution.
- The global contribution of informal carers is worth 133 billion unpaid hours each year (about eight hours a day per carer). The fact that nearly three-quarters of informal carers are women – often preventing them from entering the labour market to pursue paid work or receive education – highlights the need to address equal opportunities for women.
- The COVID-19 pandemic continues to impact both the lives of people with dementia and the prioritisation of dementia policies. Political and economic woes also play a huge role in whether people with dementia receive adequate – or any – services from their own governments. Nonetheless, dementia knows neither borders nor geopolitics, and people living with the condition deserve adequate treatment and support wherever they may be.

“With three years left before the scheduled end of the plan in 2025, ADI urges governments to answer the calls to action set by the Global action plan to which they committed in 2017.”

## Recommendations

- **We need more national dementia plans.** ADI urges member states to accelerate their progress in developing, funding, and deploying national dementia plans, if they are to achieve their 2017 commitment. National dementia plans are the best framework for governments to structure health- and long-term care systems to provide best practice care and support for people with dementia and their families.
- **ADI urges governments to take advantage of our #WhatsYourPlan campaign.** There are only three years left to achieve the WHO target and ADI's #WhatsYourPlan campaign offers tailored support to governments seeking to develop a dementia plan – bringing together key stakeholders including ministries, WHO regional and country offices and Alzheimer and dementia associations to work collaboratively towards the creation and implementation of national dementia plans.
- **Integrated plans need to include targets and ringfenced budgets for dementia.** ADI recognises that in some countries, dementia action plans have been integrated under other policy areas, such as healthy ageing, mental health, neurology, or non-communicable diseases (NCD). In these cases, strategies or plans should always include the targets, indicators and, critically, ringfenced budgets that relate to the seven action areas of the WHO global action plan.
- **ADI calls on all nations to recognise the role of women in providing informal care and to address the costs associated with their role.** Three-quarters of informal carers are women, with their role often preventing them from entering the labour market to pursue paid work or to receive education. ADI urges governments to address equal opportunities for women when developing and implementing national plans.
- **We encourage more governments to provide information to the WHO Global Dementia Observatory (GDO).** There has been a significant upsurge in the number of contributions to the GDO, enabling important data collection on incidence, treatment, and management of dementia. These data are crucial to improving planning, accessibility and coordination of research, care, and support for people with dementia.
- **Continued consideration of the impact of COVID-19 is crucial.** Two years on, the reverberations of the pandemic continue to be felt across the globe. ADI recognises that governments must explore the potential increased risk of dementia caused by COVID-19, understand and mitigate its impact on dementia diagnosis. As each government updates their COVID-19 response plans, they must consider dementia and non-communicable disease risk factors and build in resilience for future pandemics to ensure equity of access to treatment, care, and support and to avoid disruptions to the diagnostic pathway.
- **ADI calls on governments to invest in dementia research and risk reduction.** ADI persists in calling on governments to invest a minimum of 1% of the societal cost of dementia into research. While much attention is focussed on biomedical and pharmacotherapeutic research, there is also an urgent need to produce more research into care and risk reduction interventions that can improve quality of life and reduce future incidence.
- **ADI endorses collaboration between civil society and government in policy change.** In the absence of a coordinated government strategy, Alzheimer and dementia associations often step in to provide valuable care, activities, and support. ADI encourages governments to recognise the vital role of civil society and to work alongside them to facilitate change and instigate national plan development.

## 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



## Introduction

**This fifth edition of the From Plan to Impact report surveys the progress of the World Health Organization's (WHO) eight-year Global action plan on dementia adopted in May 2017.**

At least 55 million people are believed to have been affected by dementia in 2019, 60 percent of whom were living in low- and middle-income countries. The number of people living with dementia – estimated to stand at 55 million in 2019 – is expected to rise to 139 million in 2050, according to most recent WHO figures. With the annual cost of dementia standing at US\$1.3 trillion in 2019, the financial impact of dementia is expected to grow to \$2.8 trillion dollars by 2030, while many lack adequate support in navigating the condition.

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“ADI calls on governments to reinvigorate their efforts, recognise the urgency in prioritising dementia and fulfil their commitments when in 2017 the Global action plan was universally adopted. The time for action is now.”

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The WHO Global action plan sets a framework for the organisation's 194 member states to improve the lives of people with dementia, their families and communities by 2025 through a series of seven action areas with defined targets, requiring periodic reporting from governments on their progress. In each edition of From Plan to Impact, ADI has made the distinction between countries and territories that have Alzheimer and dementia associations affiliated with ADI, and WHO member states, as not all

territories that have national plans for dementia are part of the WHO and bound to the Global action plan.

The views and data presented in this report are intended to represent an up-to-date (as of May 2022) and holistic view of progress towards the targets of the WHO Global action plan. Through the report, ADI seeks to measure the data provided by governments against the lived experience of people living with dementia, their carers, and ADI member associations in these countries. The figures used here and on the ADI website are subject to ongoing revision, in order to include new information from Alzheimer and dementia associations and partners globally as it becomes available.

The ongoing pandemic has continued to disrupt the prioritisation of other public health concerns during the reporting period of May 2021 to April 2022, even with the dissemination of vaccines. Older people with dementia continue to be vulnerable to COVID-19, and many, including carers, have experienced increased isolation as a result of pandemic management policies. Meanwhile, evidence of cognitive impairment in some individuals who contracted COVID-19<sup>1</sup> also raises the possibility that the pandemic may have a long-term impact on the number of people developing dementia in the future – further emphasising the need for a public health response to address a condition that will affect more and more people across the globe, with unequal access to prevention, diagnosis, care and support.

With the timeline for the Global action plan on dementia past its halfway point, the targets set by the WHO are far from being reached. ADI calls on governments to reinvigorate their efforts, recognise the urgency in prioritising dementia and fulfil their commitments when in 2017 the Global action plan was universally adopted. The time for action is now.

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<sup>1</sup> Hampshire, Adam et al., 'Cognitive deficits in people who have recovered from COVID-19', EClinicalMedicine, September 2021, [https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370\(21\)00324-2/fulltext](https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(21)00324-2/fulltext).

## Calculating dementia prevalence

Since the last From Plan to Impact report, two new sets of dementia prevalence data have been made available by the World Health Organization (WHO) and the Institute of Health Metrics and Evaluation (IHME). These figures represent the first substantive update to the global figures since ADI commissioned figures revealed in the World Alzheimer Report 2015, entitled "The global impact of dementia: An analysis of prevalence, incidence, cost and trends"<sup>1</sup> and its subsequent update in 2020.

The first set, commissioned from IHME by WHO and published in the WHO's Global status report on the public health response to dementia, estimated that 55.2 million people around the world were living with dementia in 2019. The highest number were predicted to be residing in the WHO's Western Pacific, standing at 20.1 million, followed by the European region (14.1 million), the region of the Americas (10.3 million), South-East Asia (6.5 million), the Eastern Mediterranean (2.3 million) and the African region (1.9 million).

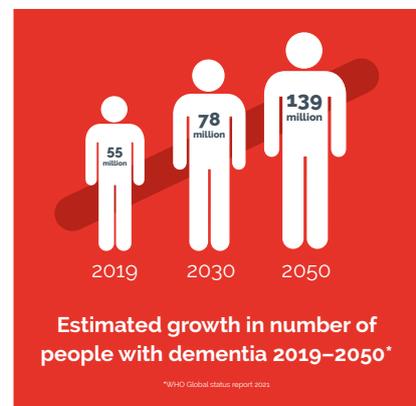
Using United Nation population data and assuming there is no change in age-specific prevalence rates, the WHO forecasted that 78 million people are likely to be living with dementia by 2030 and 139 million by 2050. The report also seeks to update global economic burden data for dementia, finding that the global cost of dementia was USD \$1.3 trillion in 2019, forecast to rise to USD \$2.8 trillion by 2030.

The second set of data were published in early 2022, when IHME revised its dementia prevalence data and methodology in *The Lancet: Public Health*.<sup>2</sup> The prevalence figures differed marginally for 2019 (56 million), and 2030 (83 million), estimating a wider difference for 2050 (153 million) from the WHO Global status report figures, but aligned more closely with ADI's previous estimates.

While the projections remain similar, the difference can be largely explained by the fact that different parameters were used when calculating projections. For example, IHME used forecasts of upward trends in obesity, smoking, and high blood sugar – all risk factors for dementia – when calculating its new projections. IHME does also make country-level data available for 195 countries or territories, which have proved invaluable for advocacy and national dementia plan work in this area. The country-level prevalence estimates have been reproduced in Appendix D of this report, with permission from the IHME.

The target for Action area 6 of the Global action plan on dementia states that 50% of countries should be routinely collecting a core set of dementia indicators through their national health and social information systems every two years by 2025. Despite this, too few WHO member states and non-member countries are recording these data, even those who have implemented a national dementia plan.

In the absence of real-world data, these global and country-level projections produced by the WHO and IHME are important instruments to highlight the global burden of dementia. They also add weight to our advocacy and the importance of implementing national dementia plans, with the ultimate aim of improving the lives of people with dementia and their carers.



<sup>1</sup> Wimo A et al. 2015. World Alzheimer Report 2015: The global impact of dementia: An analysis of prevalence, incidence, cost and trends. London, England: Alzheimer's Disease International.

<sup>2</sup> Nichols, Emma et al. 'Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: an analysis for the Global Burden of Disease Study 2019', *Lancet Public Health* 2022; 7: e105–25 Published Online January 6, 2022 [https://doi.org/10.1016/S2468-2667\(21\)00249-8](https://doi.org/10.1016/S2468-2667(21)00249-8)

## What is a national dementia plan?

Those living with dementia and their carers require specialised and multisectoral support, which can change over the course of their lifetime; identifying and addressing these needs requires action across all levels of society, including at a global, regional, national and community level.

In 2017, the World Health Organization developed the Global action plan on the public health response to dementia, aimed to improve the lives of those living with dementia and their carers, whilst mitigating the impact of dementia on communities and countries. Action area 1 of the global action plan encourages member states to implement national dementia plans or strategies.

### The WHO characterises a national dementia plan as the following:

A dementia plan recognises the value of older people and those with dementia in society. It also asserts the need for policy change aimed at enhancing prevention, treatment and care for people with dementia and their carers through better integration of health and social sectors (i.e. long-term care). A dementia plan is a written document that provides the basis for action to be jointly taken by government and nongovernmental partners.

A comprehensive dementia plan identifies a vision for the future and a strategic framework, which highlight a common set of principles and objectives that guide action. It defines and prioritises action areas, identifies coordination responsibilities and mechanisms, and delineates targets to direct resources towards achieving objectives and measuring impact. Together, the main components of a dementia plan act to raise public awareness and create mutual understanding about dementia, address population needs, reduce the burden of dementia, and protect the human rights of people with dementia, their carers and families.

### *World Health Organization: Towards a dementia plan: a WHO guide (2018)*<sup>1</sup>



There are typically two broad types of dementia plans: stand-alone and integrated plans. A standalone national dementia plan or strategy typically focusses solely on dementia. An integrated dementia plan includes dementia into the context of other areas such as aging, non-communicable diseases or neurodegenerative disorders. Both strategies should be funded and following all seven action areas of the global action plan to be effective.

Due to the unparalleled global burden that dementia presents, alongside the complexities associated with care and support for those living with dementia and their carers, ADI strongly advocates for stand-alone national dementia plans encompassing all seven action areas of the global action plan. National dementia plans should also be created by expert, multidisciplinary teams, including people living with dementia and their carers, as the best and most robust way to manage the multifaceted challenges of dementia to healthcare systems, to governments and, of course, to those people directly impacted by the condition.

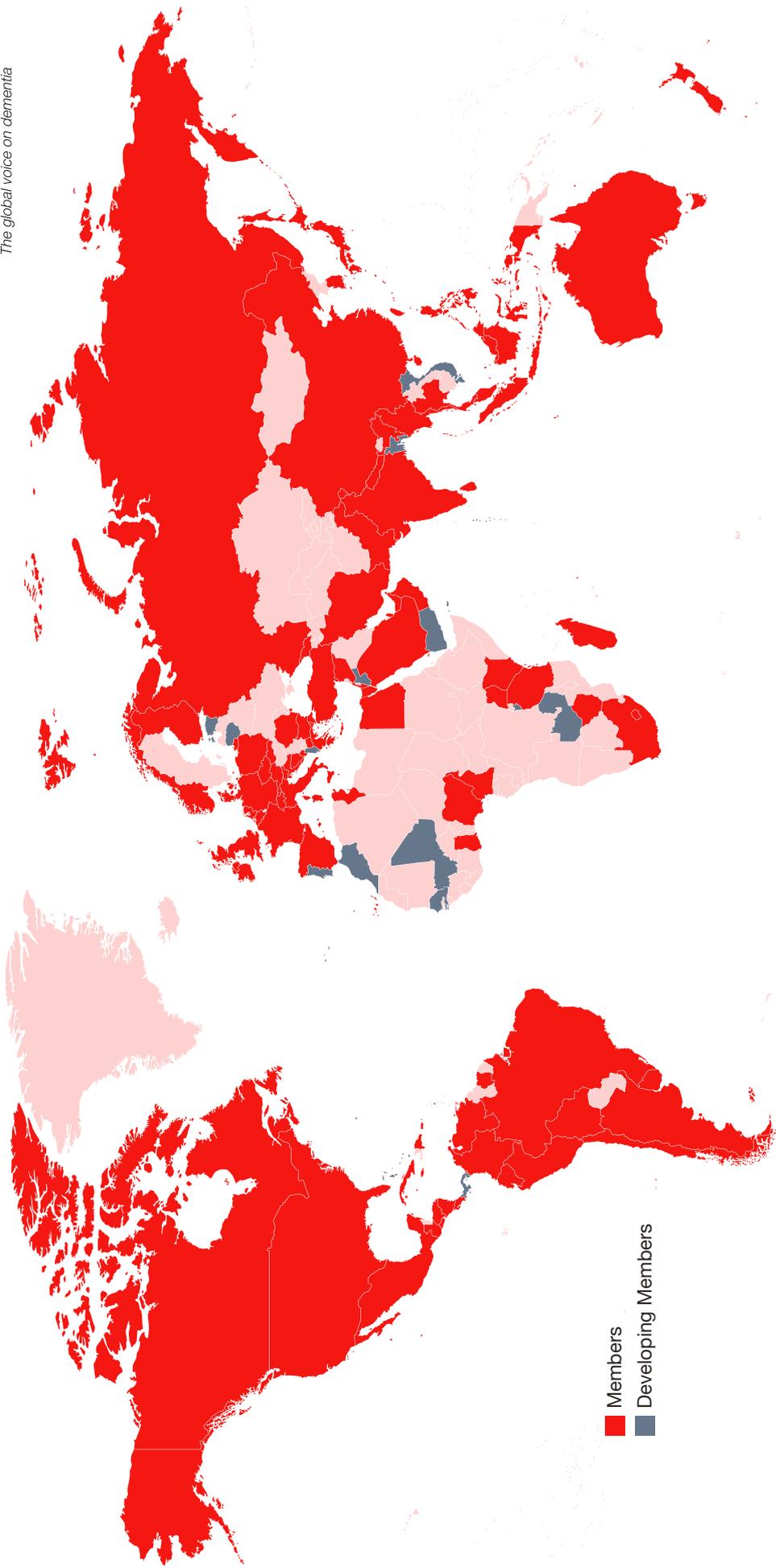
<sup>1</sup> Towards a dementia plan: a WHO guide. Geneva: World Health Organization; 2018. Licence: CC BY-NC-SA 3.0 IGO.



ADI Members and Developing Members



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## Methodology

In order to measure states' activity against the WHO Global action plan, ADI distributed a survey in January 2022 to our 105 member associations, 19 developing associations on the Membership Development Programme, and 9 other associations preparing to join the Development Programme. The survey received an 83.5% response rate, with a total of 111 replies. Each member association is a national Alzheimer or dementia organisation in that country. A developing association refers to organisations 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 (Action area 1) in their respective countries based on five stages. The survey also asked for examples of policy, research, and practice in relation to the remaining six action areas, and how the COVID-19 pandemic has affected diagnosis of dementia and access to support some two years on.

## Report structure

This report is divided into seven chapters based on the WHO action areas. The first section, focussed on Action area 1, is based on evidence obtained 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 one in their country.

The subsequent six sections provide policy and practice examples relating to Actions areas 2 to 7. Expert commentary and case studies are included throughout, showing the significant global variation in the development and/or application of policies related to dementia through examples of good practice and challenges that have been faced.

Stages of national dementia plan development

**STAGE 1**  
No current contact with government or Ministry of Health

**STAGE 2**  
No Plan/Strategy

**STAGE 3**  
Plan/Strategy currently in development

**STAGE 4**  
Plan/Strategy adopted but with inadequate or no funding

**STAGE 5**  
Plan/Strategy adopted

- 2A:** Initial meetings with government, but no further progress
- 2B:** Some developments towards a plan
- 2C:** Some funding committed to 7 action areas of Global plan, but no expressed intention of launching a plan
- 2D:** Grouped health plan including dementia under consideration
- 2E:** Dementia referred to in existing grouped health plan, but not as a separate health condition

- 3A:** Not yet launched, but commitment to funding for some of the 7 action areas
- 3B:** In development, good progress
- 3C:** In development, slow progress
- 3D:** Grouped health plan including dementia in development

- 4A:** Inadequate funding
- 4B:** No funding
- 4C:** Government communication barrier
- 4D:** Plan under threat (e.g., is coming to an end and could be terminated or replaced by a general health plan)
- 4E:** Grouped health plan including dementia, adopted but with no or inadequate funding
- 4F:** Plan adopted, but not implemented

- 5A:** Plan adopted but not fully communicated
- 5B:** Plan adopted, funded and monitored
- 5C:** Grouped health plan including dementia adopted, with specific targets and funding

# Chapter 1

## Dementia as a public health priority



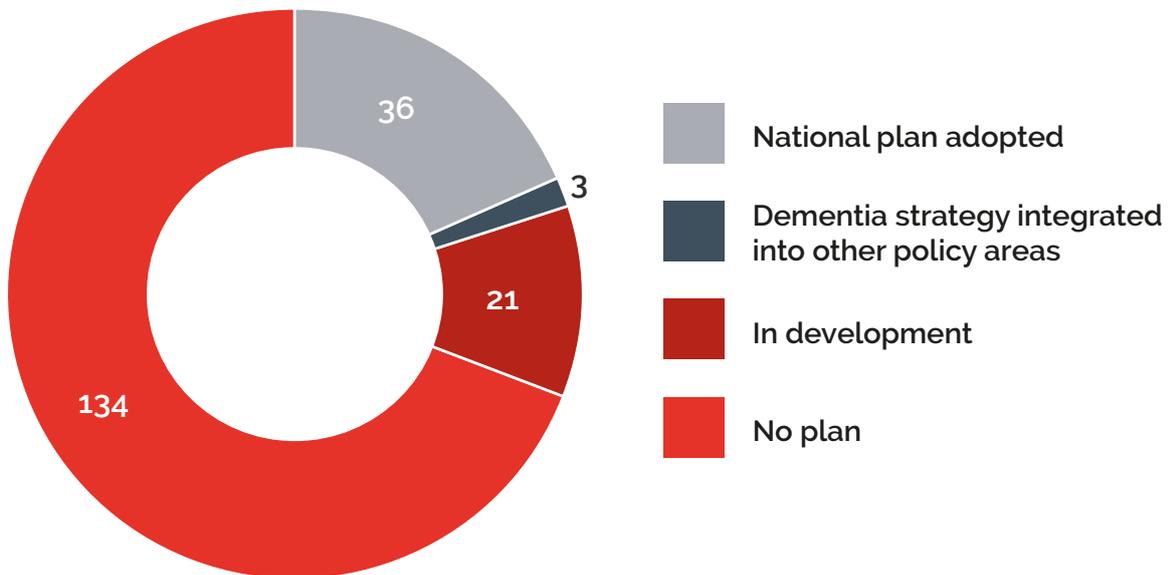
**WHO target: 75% of countries (146 of 194) will have developed or updated national policies, strategies, plans or frameworks for dementia, either stand-alone or integrated into other policies/plans, by 2025.**

Following the introduction of the WHO Global action plan in May 2017, firmly establishing dementia as a global priority, ADI shifted its own strategy to reflect this pivotal moment to advocate and to work closely with governments, associations and partners worldwide, in order to progress Action area 1 on the development of national dementia plans. Without a doubt, national dementia plans are the best tool a government has available to tackle the multifaceted challenges of dementia. As we cross the halfway mark of the 2025 goals of the Global action plan, ADI is working collaboratively across all regions to find ways to advocate, to support governments to accelerate the development of their plans, and to fulfil their commitment in 2017 to deliver robust and well-funded national strategic responses.

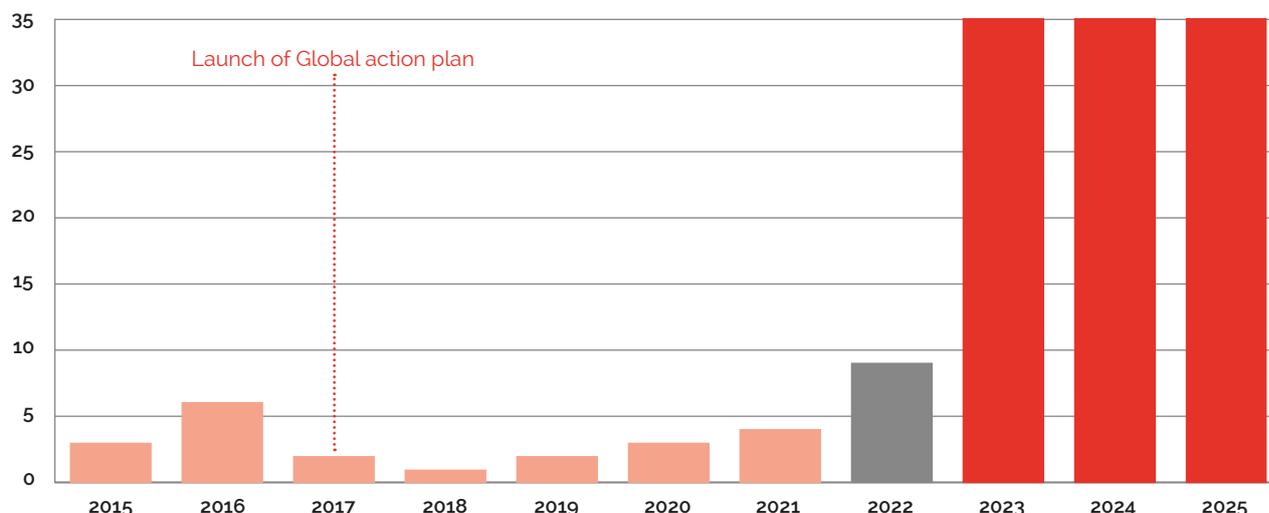
As of May 2022, the number of WHO member states with national dementia plans stands at 39. This equates to around 27% of the 146 target, and only around a fifth of all member states, despite all 194 agreeing to implement a plan in 2017.

ADI also supports and monitors national plan development, progress and implementation in non-WHO countries and territories. In total, at the time of publication, we proffer that there are currently 48 national plans in place. Non-WHO member state plans include Bonaire, Gibraltar, Macau, Puerto Rico, TADA Chinese Taipei, and individual country plans within the United Kingdom. It is important to share these plans as part of our global coverage, highlighting their development process, impact, effectiveness and sharing examples of good practice.

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.



**35 new plans needed every year from 2023 to cover 75% of member states by 2025.** This calculation is based on information available in April 2022 and an assumption of no additional plans launching this calendar year.

ADI's collaborative approach to the development of national dementia plans manifested itself in the launch of the #WhatsYourPlan campaign in late 2021. Working with WHO global, regional and country office teams, alongside our member associations, we are engaging ministries directly with the aim of governments committing to the development of plans and to creating working groups to progress them. In the initial phase of the campaign, ADI is working with associations in 40 countries across all six WHO regions, with marked success so far, with commitments and progress in countries including Brazil, Lithuania and Trinidad and Tobago.

The African region – especially sub-Saharan Africa – the Eastern Mediterranean region, and the Southeast Asia region are still the most under-represented in terms of plans, but with some promising developments. The STRiDE (Strengthening responses to dementia in developing countries) project, covering seven low- and middle-income countries, may have come to an end, but it has put in place strong foundations for influencing and supporting future national plan development in Brazil, India, Jamaica, Kenya and South Africa. STRiDE has also added vital context for plan evolution in Indonesia and re-established the plan in Mexico as a priority.

We have been made aware of 10 new or re-established plans (stand-alone and integrated) in the last 12 months, including Czech Republic, France, Iran, Kuwait, Philippines, Portugal, Thailand, Vietnam, and Curaçao, and we are aware of plans under development in 22 countries.

Leveraging the influence of key bodies and organisations must remain at the forefront of national plan responses. G7 and G20 agendas have been focussed on pandemic response and recovery, but only through robust national dementia plans can governments build future resilience. The same is true of humanitarian crises, as evidenced in many countries, where support for people with dementia is lacking or missing, with an urgent need for crisis support and humanitarian response to be factored into national dementia plans. In 2022, ADI and partners are aiming to influence a return in focus by G20 to the Okayama declaration, delivered under Japan's presidency in 2019, to ensure that the six dementia-specific action areas highlighted in that outcome document are delivered against, including leading on the development of national dementia plans.

A perspective on cost must also be taken for the development and effective deployment of national dementia plans. We are often asked, especially by government departments: "What is the cost of a plan?" More research is required in this area, but costs will vary greatly across regions and countries, as well as the scope and scale of the plan itself. Interpretation is also important – an investment now can have cost-saving impacts in the future. For example, by delaying onset, slowing down cognitive decline, delaying or avoiding acute hospitalisation or residential care admittance. In the case of emerging treatments, investment can have the positive impact of enabling people with dementia and carers to remain in work, making a positive economic contribution.

## Determining the number of national dementia plans

In September 2022, the World Health Organization (WHO) released the Global status report on the public health response to dementia marking the halfway point of the Global action plan on the public health response to dementia 2017–2025. This important and much needed assessment sought to take stock of the progress made towards the implementation of the global action plan by the WHO itself, member states, civil society and all those with an interest in delivering solutions for people with dementia, their carers and families all over the world. The status report identified progress, highlighted barriers and aimed to galvanise the dementia community to accelerate towards the targets of the global plan.

The WHO also quantified the number of member states that have implemented national dementia plans, using its monitoring and accountability mechanism for the global action plan known as the Global Dementia Observatory (GDO). The GDO collects data from member states across 35 indicators and sub-indicators to assess the progress of member states towards achieving the targets of the seven action areas of the global action plan. Analysing the data from the GDO, the WHO concluded that there are currently 50 national dementia plans in existence, across all 194 member states.

As the federation of Alzheimer and dementia associations from around the world, ADI used a slightly

different methodology for the development of From Plan to Impact V and its assessment of the number of national dementia plans, through utilising the insight of our members and their contacts within their respective countries. As such, at the time of publication of this edition of From Plan to Impact, ADI proffers that there are currently 48 countries with national dementia plans (39 of which are WHO member states\*).

Whilst there is a variance in the estimated number of national dementia plans, and acknowledging that plan development is a fluid process, with plans both being created and lapsing, both WHO and ADI figures show clearly that most member states are not on track to achieve the targets of the global action plan by 2025. The target for action area one states that "75% of countries will have developed or updated national policies, strategies, plans or frameworks for dementia, either stand-alone or integrated into other policies/ plans, by 2025". Three years from the target end date of the global action plan, current estimates by WHO and ADI suggest that we are under a third of the way to achieving this target. Member states must accelerate their progress if they are to achieve their 2017 commitment to implementing a national dementia plan and the promises they have made to those living with dementia, carers and the people they serve.

## #WhatsYourPlan

In November 2021, ADI officially launched the #WhatsYourPlan campaign, aiming to galvanise governments to develop, fund and implement national dementia plans in their countries. ADI is working with its member associations and partners to reach out directly to governments, with 40 countries currently engaged in the campaign. The campaign utilises formal letters of engagement with government ministries, plus awareness raising through traditional and social media, using the hashtag #WhatsYourPlan, engaging member associations, advocates and colleagues working in the fields of dementia and Alzheimer's disease to take part in adding their voices to help the campaign gain further traction.

As Chris Lynch, ADI's deputy CEO and director of policy, states *"The rapidly approaching deadline of 2025 is the reason why ADI launched the #WhatsYourPlan campaign, with the aim of advocating to member states and working*

*with partners globally, regionally and nationally, to develop robust and well-funded national strategies. Time is running out and it is vital we galvanise as a community to ensure that we deliver on this global plan."*

A key aim of the campaign is to bring the stakeholders together, including ministries, WHO regional and country offices and Alzheimer and dementia associations, to work collaboratively towards the creation and implementation of national dementia plans.

Six months since the initial campaign launch, ADI has seen improved relationships between many ministries and local Alzheimer and dementia associations, as well as positive movements towards national dementia plans in certain countries. The triangular relationship between ministries, associations and country WHO offices is a strong foundation and a key aspiration of the campaign, inspired

\* ADI also monitors plan development and progress in non-WHO member states, sharing insights and progress in national plan response.

by the ADI and Pan American Health Organization (PAHO) region awareness raising campaign in 2019.

Forty associations and countries are currently engaging in the first phase of ADI's #WhatsYourPlan campaign. The stages depicted above reflect their current progress towards the development of a national dementia plan. Further information on staging can be found on page 16. Appendices A-B lists the current stages or presence of a national dementia plan, as determined to the best of ADI's knowledge.

**#WhatsYourPlan: Phase I Participating Countries**

	Stage 1	Stage 2	Stage 3	Stage 4	Stage 5
Azerbaijan	█				
Bosnia Herzegovina	█				
Botswana	█				
Brazil	█				
British Virgin Islands	█				
Cameroon	█				
Cayman Islands	█				
Costa Rica	█				
Dominica	█				
Ecuador	█				
Guatemala	█				
Honduras	█				
India	█				
Iran	█				
Jamaica	█				
Jordan	█				
Kuwait	█				
Lithuania	█				
Mauritius	█				
New Zealand	█				
Nigeria	█				
Oman	█				
Panama	█				
Peru	█				
Philippines	█				
Poland	█				
Portugal	█				
Puerto Rico	█				
Senegal	█				
Seychelles	█				
South Africa	█				
St Lucia	█				
The Bahamas	█				
Trinidad and Tobago	█				
United Arab Emirates	█				
Uruguay	█				
Venezuela	█				
Yemen	█				
Zambia	█				
Zimbabwe	█				

Here are a few select examples of the impact of the #WhatsYourPlan campaign:

### Brazil

In November 2021, the Brazilian Senate unanimously passed the National Law of Care of People with Alzheimer's and other dementias, with a joint letter from ADI and our member: Federação Brasileira das Associações de Alzheimer (FEBRAZ), being read during the debate. ADI, FEBRAZ, and the STRiDE-Brazil team are continuing their advocacy as the proposed law moves to the Lower House/Chamber of Deputies.

### Panama

The ministry is interested in starting the process of developing a national dementia plan and has a meeting with PAHO scheduled to request technical support in getting a consultant to help the Ministry draft a national dementia plan.

According to Ingrid Wellington from Asociación de Apoyo a los Familiares de Pacientes con Alzheimer y Otras Enfermedades Demenciales (AFAPADEA): "AFAPADEA had had very little engagement with the Ministry of Health in the past, but the meeting kickstarted the process and we are hopeful for the future. We are happy to have since been invited to the 'Vº Foro Regional Intersectorial de Salud Mental' organised by the Ministry in April and hope to be included in upcoming meetings regarding the development of the national dementia plan."

### Puerto Rico

Ana Gratacos from Asociación de Alzheimer y Desórdenes Relacionados de Puerto Rico shared: "The support offered by ADI to advance the National Dementia Plan in Puerto Rico has been extraordinary. The letter sent by Paola Barbarino to the Secretary of Health of our government, together with meetings between local Ministry of Health officials, the PAHO representative on the island, Paola Barbarino, Laura Dabas and myself, have created spaces for dialogue in which the urgency with which this plan must be put into operation has been emphasised – as soon as possible in order to benefit people living with dementia, their families and carers in Puerto Rico."

**The campaign has gained considerable momentum so far, including but not limited to:**

- **Official responses received so far:** British Virgin Islands, Honduras, Lithuania, Poland, Seychelles, Trinidad and Tobago and Uruguay.
- **Key ministry meetings:** Azerbaijan, Bahamas, Botswana, Cameroon, Panama, Puerto Rico, St Lucia and Zimbabwe, with imminent meetings scheduled with Ecuador and Jordan.

## The global economic burden of dementia

A part of WHO's Global Dementia Observatory project was to calculate estimates of the global economic burden of dementia in 2019. The figures presented here are derived from the Global status report on the public health response to dementia<sup>1</sup>, launched by WHO in September 2021.

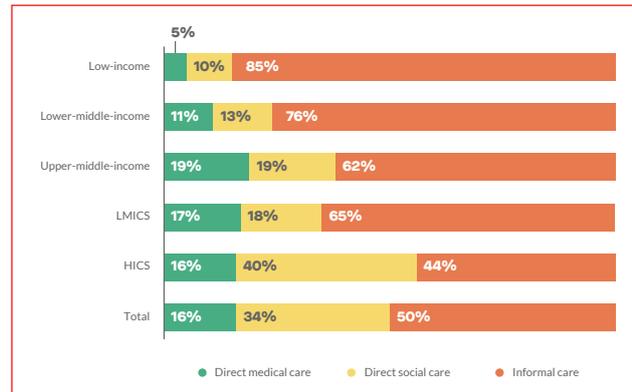
In 2019, the global societal costs of dementia were estimated to be US\$ 1.3 trillion for 55.2 million people with dementia, or around US\$ 24,000 per person with dementia. There is a strong relationship between costs and severity of dementia: about US\$ 16,000 in mild dementia, US\$ 27,000 in moderate dementia and US\$ 36,000 in severe dementia. Some 50% of these costs were related to informal care, 34% to the social care sector (including long-term institutional care) and 16% associated with direct medical care (e.g. hospital care etc).

More than 60% of the global dementia population lives in low- and middle-income countries (LMIC) but represent only some 25% of global costs. The proportion of costs represented by informal care is also much greater in LMIC: 65% in LMIC and 44% in high-income countries (costs per person with dementia, see figure above).

The contribution of informal carers is perhaps better expressed in terms of global hours: 133 billion hours (about 8 hours per day), of which some 89 billion hours constitute support in care and 44 billions hours to supervision. There is a clear gradient along income levels: 12 hours per day on average in low-income countries and 7.6 hours per day in high-income countries. Some 70% of the informal carers are women (wives, daughters, daughters-in-law); 77% in low-income countries.

If hours of informal care are translated to full-time workers, it corresponds to about 67 million workers, of which 45 million are related to care activities.

It is obvious that the economic burden of dementia has a significant impact on any country and care system in the world. Given the expected increase in the number of people with dementia worldwide, all countries need an action plan for dementia care and support to families. There are also great imbalances in how resources for dementia care are distributed worldwide. The financing of dementia care is a great challenge for any country, but an extra challenge for most LMIC is the lack of long-term care infrastructure, in addition to the fact that long-term care in LMICs may be organised and financed differently from high-income countries.



Percentage distribution of the cost per person with dementia by types of care and by World Bank income level. Reproduced from "Global status report on the public health response to dementia". Geneva: World Health Organization; 2021. Licence: CC BY-NC-SA 3.0 IGO.

"If hours of informal care are translated to full-time workers, it corresponds to about 67 million workers."

Even if care at home is of great value for persons with dementia, the fact that **nearly three-quarters of informal carers are women** – often preventing them from entering the labour market to pursue paid work or receive education – highlights the need to address equal opportunities for women.

Efforts to estimate global costs of dementia are seriously hampered by a lack of high-quality comprehensive data on epidemiology, resource use and costs for dementia from all countries in the world, but particularly from LMICs.

*Anders Wimo, MD, PhD, professor emeritus, Department of NVS, Centre of Alzheimer research, Department of Neurogeriatrics, Karolinska Institutet, Solna, Sweden*

<sup>1</sup> Global status report on the public health response to dementia. Geneva: World Health Organization; 2021. Licence: CC BY-NC-SA 3.0 IGO (pp 117–138)

## Political shifts and unexpected crises

Despite the hard work of advocates both at the local and global level, the development of national dementia plans is often at the behest of each country's geopolitical context. Conflict, economic crises, or simply a change in political leadership can put these efforts on hold, as highlighted by a number of ADI's member associations. While ADI acknowledges the struggles of prioritising long-term strategies in uncertain times, we urge states to remember those who are directly affected by dementia and who are not spared by these crises, all the while navigating their own situation.

The Russian invasion of Ukraine at the beginning of 2022 has been a stark reminder that people with dementia need additional support amid conflict or disaster. In March, ADI developed advice based on its report 'Forgotten in a Crisis: Dementia in humanitarian response' after it became distinctly clear that there was no practical advice or support for carers, people living with dementia, humanitarian agencies, communities and local agencies during times of crisis. This information was then further developed into advice cards, which are currently available in English, Ukrainian and Spanish. Additional translations are also in the works, reflecting a broader need for more awareness of the specific needs of people with dementia at times when they are so often forgotten.



**Examples of clear communication**

Instead of saying: "We need to leave because we are in danger if we stay here."

Try saying: "Name-of-person, we are going to leave name-of-place (e.g., bedroom, home, shelter). We are going to go to name-of-place. I am right here. You are safe."

The brief, mostly anonymous updates shared in this section clearly demonstrate that in times of turmoil, the issue of dementia – and the people affected – gets lost.

### Ukraine STAGE 2A

When we first created Nezabutni (meaning "unforgettable") from scratch in January 2021, we had high ambitions: to make Ukraine a dementia-friendly country.

With limited means, and despite the obstacles brought on by COVID-19, we were able to successfully launch several pilot projects in a short amount of time: a memory café bringing together people with dementia and carers in September; online and in-person support groups for relatives and carers of people with dementia; a website we hope will become a much-needed, in-depth reference on Alzheimer's and dementia in the Ukrainian language. We established partnerships with cultural organisations that committed to creating dementia-friendly spaces. We spoke to prominent local media to raise awareness of dementia and our work developing support systems for people affected by the condition.

Most importantly, we were in the crucial and promising early stages of reaching out to the

Ukrainian government to convince them to devise a national dementia plan.

Last year now feels like another life altogether. Since Russia invaded Ukraine in late February 2022, Nezabutni has had to adapt our efforts to meet the urgency of the moment, including helping families evacuate to safer areas and coordinating the dissemination of 800 kilogrammes of medication donated by Americares – all whilst dealing with personal displacement and uncertainty because of the war.

Nezabutni has been coordinating with the Ukrainian Ministry of Social Affairs and Doctors Without Borders (MSF) over how and where to evacuate elderly people – including those with dementia – from at-risk areas. The situation fluctuates daily, meaning that a care home in the suburbs of Kyiv partially damaged by fighting could later become a refuge for elderly Ukrainians evacuated from other regions now under fire.

We have heard heartbreaking stories about the terrible choices that families have been faced with in recent weeks. Some, having taken refuge abroad, struggle to find the proper support and medical care for their relatives with dementia; others, unsure of how they could safely escape with a parent with dementia, have stayed at home at the risk of ending up caught up in the violence. Some care workers, meanwhile, have told us of people who have escaped the country while leaving their relatives with dementia in their nursing homes.

The conflict has had an undeniable impact on the wellbeing of people with dementia in Ukraine. Some have died, while others have seen their memory worsen and agitation increase in response to the high levels of stress around them.

Dementia does not know borders nor geopolitics. The current situation in Ukraine has highlighted the importance of having resources to support people with dementia in times of crisis – such as the informational cards devised by ADI – as well as better awareness of the disease globally so people living with dementia, like many others with so-called “hidden disabilities”, are not left behind.

While much of the international support for Ukraine has, understandably, gone towards armed forces and emergency medical response, we urge the international community to remember Ukrainians living with dementia – they don't deserve any less support than the rest of us.

*Irina Shevchenko, founder, Nezabutni, Ukraine, April 2022*

### Lebanon – Stage 2B



Lebanon has been in survival mode for the past two years as the economy has crashed and the Lebanese pound lost 90% of its value. People can't find medications they need, and unfortunately, nothing is being done on the issue of dementia.

### Bosnia and Herzegovina – Stage 3D



The political situation in Bosnia and Herzegovina has been tense since October, with the Serbian representative in the country's tripartite presidency quitting state institutions put in place in the 1995 peace accords. We are waiting for better times to continue our efforts for a dementia plan.

### Venezuela – Stage 1



Our association had a great working relationship with the former Ministry of Health director with whom we had been discussing a dementia plan until 2018. Since the last ministry reshuffle, though, our efforts have fallen on deaf ears. The plan and letters have been sent countless times to the current officials, but so long as Venezuela does not change its government, we see no solution.

### Montenegro – Stage 1



The prime minister was ousted in a motion of no confidence in February 2022, and the formation of a new government may take a few months. As a result, dementia is not high on the list of priorities. We are very disappointed by this, and we feel like we are taking one step forward and two steps backwards.

## Case studies

A range of Alzheimer and dementia associations have shared how their efforts to develop and implement national plans in their respective countries have panned out in the past year, further reinforcing the need for urgent action to support these endeavours in order to achieve the WHO target.



### New Zealand STAGE 3C

"Stalled" is a good word to describe New Zealand's progress towards funding and implementing the Dementia Mate Wareware Action Plan, designed to better address the inequities experienced by Māori living with dementia – known as "mate wareware" in te reo, the Māori language.

The current government committed to support the plan in its 2020 election manifesto and the minister responsible for dementia policy has since indicated that her backing of the plan hasn't diminished.

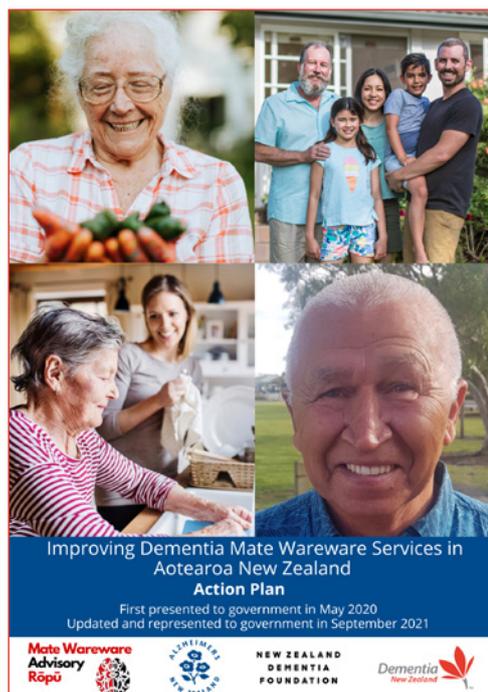
The original plan was refreshed during the year in collaboration with the Mate Wareware Advisory Rōpū. The role of the rōpū (organisation) is to advise Alzheimers NZ and our partner organisations on the experience, needs and expectations of whānau (families and communities) living with dementia mate wareware.

Aotearoa New Zealand has a higher estimated dementia risk than comparable countries, and that risk is likely to be even higher for Māori and Pasifika people, mainly due to the high prevalence of untreated hearing loss and obesity.

Our 2021 Dementia Economic Impact Report<sup>1</sup> notably highlighted that the prevalence of dementia among Māori, Pasifika and Asian communities is likely to triple by 2050.

That projection, in addition to other related factors such as the lack of culturally appropriate support services for the Māori, Pasifika and Asian communities in the country, makes the implementation of Dementia Mate Wareware Action Plan crucial.

In a bid to focus the government's mind on the plan, Alzheimers NZ launched our *Deliver for Dementia* campaign in late 2021, notably presenting an open



letter, signed by several thousand people, to relevant ministers urging them to act on dementia.

While we are still awaiting the government's response to this campaign and to the plan itself, we have continued to work closely with the cross-party Parliamentary Friends of Dementia group that continues to take an interest in dementia issues, despite all the challenges brought on by COVID-19.

If the government's manifesto pledge isn't turned into action in its 2022 budget, our advocacy work will focus on the budget for 2023!

*Catherine Hall, Chief Executive, Alzheimers New Zealand*

<sup>1</sup> Alzheimers New Zealand's Dementia Economic Impact Report 2020 can be accessed here: <https://cdn.alzheimers.org.nz/wp-content/uploads/2021/09/Dementia-Economic-Impact-Report-2020.pdf>

## Lithuania STAGE 2A

The Ministry of Health of the Republic of Lithuania has been working on the formation of the Dementia Working Group since September 2021. The aim of the group is to develop a continuous and cohesive dementia policy by including partners from different sectors: representatives of people living with dementia, as well as professionals from the fields of neurology, psychiatry, psychology, social services, humanities, education, public services, advocacy, etc.

The creation of Dementia Working Group is a significant step forward in advancing dementia policy in Lithuania. Since the group is multidisciplinary and includes professionals and people with a lived experience of dementia, it increases the likelihood that the complexity of dementia policy will be approached with sensitivity from a diversity of perspectives.

The further development of Lithuania's dementia policy was done with meaningful contribution from Dementia Lithuania, which was consulted during the formation of the working group. Since the founding of the association in 2021, its objective has been to create a community of people living with dementia and their carers and offer opportunities for people living with dementia to connect with each other, support each other, and to advocate for themselves and their rights – all in line with the association's motto of "nothing about us without us".



Brain Awareness Week event on 17 March 2022.

In the short time span since Dementia Lithuania's creation, the association has urged the government to address dementia through the creation of a national plan – including by advocating in front of the Lithuanian parliament during Brain Awareness Week in March 2022 – while also highlighting the importance of consulting and collaborating with people with experience of how these policies affect people's lives.

Even though Lithuania is in the initial stages of developing its dementia plan and the government still has a long way to go in raising awareness of dementia, recent events do feel hopeful. We must keep acting with hope and determination so that people living with dementia and their carers, now and in the future, can reduce risks starting today.

*Ieva Petkutė, artist researcher, lead of the association "Dementia Lithuania", senior fellow at the Global Brain Health Institute*

## Bonaire STAGE 5A

Analysing our progress in 2021, our national dementia policy plan has not yet met our expectations during its implementation process. The plan was written and approved in October 2019, with the Public Health Department tasked with putting it into action – but it has understandably encountered delays due to the COVID-19 pandemic.

In June 2021, a steering committee on dementia was installed by the local government to speed up the process; however there has yet to be concrete and visible progress. Fundashon Alzheimer Bonaire (FAB) insists on the right implementation of the plan and has already taken measures to take things to the next level.

We started 2022 on the right path, signing a research project on dementia in the Dutch Caribbean islands. We are hopeful that we will proceed with the implementation of our plan for dementia in an impactful way, on behalf of our people living with dementia with the aim of fostering a dementia-friendly community.

*Evert L. Piar, president of Fundashon Alzheimer Bonaire*



## Scotland STAGE 4A

As reported last year, Scotland would have been developing its fourth national dementia strategy if not for the pandemic. Instead, it has been replaced by an interim plan (Dementia and COVID-19 – National Action Plan to Continue to Support Recovery for People with Dementia and their Carers), which complements the existing 2017–2020 National Dementia Strategy. However, the Minister for Health and Wellbeing has confirmed that a national consultation to inform a fourth national dementia strategy will begin in 2022.

A key campaign priority for Alzheimer Scotland has been greater government accountability for the delivery of its national dementia strategy commitments, including funding. Following calls from Alzheimer Scotland, the Scottish Government announced a national investment of £3.5 million per year, notably to meet 100% of the national post-diagnosis delivery plan target. This ringfenced funding has now been made available to Scotland's Health and Social Care partnerships, and we are beginning to see plans for how that additional funding will increase capacity.

The Scottish government has also made additional investments in building community capacity to support people with dementia and carers. There are other commitments relating to the

transformation of specialist dementia care hospital environments, including plans to replace existing NHS specialist dementia care facilities with smaller, specially designed dementia care environments. While Scotland's strategy and action plan include commitments related to design, digital technologies and housing, they do not include specific guidance.

In its current Programme for Government, Scotland has committed to implementing the recommendations of the Independent Review of Adult Social Care, published in February 2021 in response to the impact of COVID-19 and gaps the pandemic has highlighted in Scotland's adult social care system.

Alzheimer Scotland has fully welcomed this report and the Scottish Government's commitment to establishing a new national care service, which Alzheimer Scotland believes presents a positive and transformative vision for adult social care in Scotland. However, establishing a new national care service will take several years – time that people with dementia and carers don't have. We will continue to campaign for action that can be taken now to deliver on existing commitments.

*Jim Pearson, director of Policy and Practice, Alzheimer Scotland*



## Trinidad and Tobago STAGE 3B

Notwithstanding the exigencies of the year past, COVID-19 has not succeeded in quenching the spirited purpose of Alzheimer's Association of Trinidad and Tobago (AzATT).

We are still in the sensitisation stage as far as efforts towards a national dementia plan go, since for many, Alzheimer's is seen as an ailment of the aged and infirm. However, through the phone calls we receive from carers of people living with the disease, we understand the urgent need for a national plan.

As part of the preparatory measure towards launching an appeal to our Ministry of Health, AzATT has highlighted the work we do and the urgency of the situation as it relates to the incidence of Alzheimer's in Trinidad and Tobago. Between 2021 and 2022, our association organised several webinars

and support groups, as well as made TV and radio appearances to raise awareness of our work.

The word is out, evidenced by the organisations who have reached out to us – chief among them the Ministry of Social Development and Family Services' Division of Ageing. We have also been collaborating with Professor Gershwin Davis from the University of the West Indies on a project to determine the effect of COVID-19 on people living with Alzheimer's and other forms of dementia, with the possibility of working together to help develop a national dementia plan.

Based on the above, AzATT is in a good place as we seek to engage our health ministry about a national health plan.

*Michèle Clavery, president of AzATT*



## Malaysia STAGE 3B

In partnership with ADI, Alzheimer's Disease Foundation Malaysia (ADFM) has continued its quest to secure a vital commitment from the Health Ministry of Malaysia. When COVID-19 arrived in Malaysia, ADFM was informed by the Ministry of Health in April 2020 that the preparation of the draft dementia action plan would be delayed. The plan has since been pending discussion by the ministry's high-level management and continues to be deferred amid the pandemic.

On 15 November 2021, ADI sent a congratulatory letter to the current Minister of Health, YB Khairy Jamaluddin, on his appointment as vice-president of the 75<sup>th</sup> World Health Assembly and sought an opportunity to meet with the minister to discuss on the implementation of the national dementia plan in Malaysia.

A little over a month later on December 21, ADFM's representatives met with representatives of the Ministry of Health. The ministry gave an update on the progress of the Malaysia National Action Plan 2020–2030 and the implementation plan, while ADFM gave a presentation of its activities supporting the dementia community. A discussion ensued on care plans for people living with dementia and their carers.

During the meeting, the deputy director of the Family Health Development Division expressed a desire to keep pushing for the plan to materialise by next year: "It will be wonderful if the Ministry of Health can finalise the National Dementia Plan and have it launched during World Alzheimer's Month celebrations in September 2023."

*Gan Chong Shyan, project director, Alzheimer's Disease Foundation Malaysia (ADFM)*

## France STAGE 4A

Since April 2021, France Alzheimer et maladies apparentées has continued to contribute to the elaboration of a neurodegenerative diseases roadmap for 2021–2022, following the expiration of the French neurodegenerative diseases plan 2014–2019. This roadmap was officially launched by the French Minister of Health Olivier Véran on 1 June 2021, with the perspective of an expansion until 2024 – which was anything but guaranteed before the presidential election in April 2022.

In July 2021, a group created with other stakeholder organisations tackling neurodegenerative conditions signed an open letter denouncing the lack of funding of this first version of the roadmap, which has barely gotten off the group nearly a year later. We did our best to get our voice heard during the hurried development of a second, expanded version of the roadmap rushed through only a few weeks before the election. Despite the Ministry of Health promising that this roadmap would be validated in February, nothing has changed. We are now waiting for it to become official, but we will stay attentive to whether

the plan receives adequate financing and political support during President Emmanuel Macron's second term, as we told his health advisor during the electoral campaign.

We can no longer accept half-measures to address the fight against dementia, which must be perceived as a political priority. People living with dementia and their families are in urgent need of concrete answers. That's why, amidst the presidential campaign, we called on candidates to commit to a fully developed and funded plan on our dedicated website, [alzheimeradisparu.fr](http://alzheimeradisparu.fr).

While Alzheimer's seems to have disappeared from political discourse, it remains in the lives of millions of people concerned in France. This the message we will defend during the campaign for upcoming parliamentary elections in June.

*Lorène Gilly, head of public policy monitoring for France Alzheimer et maladies apparentées*

## Armenia STAGES 3A and 3B

Alzheimer's disease is a public health priority in Armenia, which has a growing aging population. By 2030, 20% of the population in Armenia will be 60 years or older, which is likely to result in a rapid rise in the number of people affected by Alzheimer's disease and other types of dementia, with a forecast increase of 119% by 2050.

In the autumn of 2021, a work group was formed by Alzheimer's Care Armenia in cooperation with the Republic of Armenia Ministry of Health in order to develop a national dementia plan. The work group conducted a series of focus groups with healthcare professionals in Armenia who work with older adults, with the aim of identifying the main barriers to providing care for people living with dementia and their families. Stakeholders were also identified and participated in focus groups.

- The work group identified gaps in care and support, including:
- The need for dementia education and training primary care physicians, who often act as gatekeepers,
- Enhanced public awareness and visibility of Alzheimer's disease,
- Improvements in early diagnosis, treatment and care planning,
- Development of community-based care programmes,

- And the creation of standards of care, policy formation and guidelines for people with dementia and their carers.

The objectives of the national dementia plan are to enhance public awareness, visibility and reduce stigma; promote health and risk reduction through the development of country-wide educational training classes, support programs and services such as memory screening programmes, day care and residential care facilities, healthy aging memory clubs, and caregiver support groups; create dementia health policy initiatives and strategic planning of clinical guidelines and standards of care for healthcare providers; promote basic and clinical research on dementia; and initiate Alzheimer's disease trainings for primary care physicians, nurses and other healthcare professionals country wide.

By recognising that Alzheimer's disease is a public health priority, the National Dementia Plan Work Group is committed to cultivating a plan that includes the development of policy formation and care guidelines in diagnosis and treatment of people with Alzheimer's and their carers, with the aim of ensuring integrated services and programmes at the national, regional, and local level designed to meet the needs of the growing number of people with Alzheimer's disease and their families.

*Dr. Jane L. Mahakian, founder and chairman of Alzheimer's Care Armenia*

### Key points



**Five years on, member states are woefully lagging on the goals set for Action Area 1, with ADI positing only 39 national dementia plans and integrated plans in place out of a target of 146. While some countries face serious geopolitical or socioeconomic hurdles to prioritising dementia policy, it is imperative to accelerate efforts towards national plans while the momentum of the Global action plan is still there.**

## 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.**

**Alongside the fundamental challenge of awareness raising and challenging stigma, this section also provides an overview of dementia-friendly activities, including a focus on design as a facet of dementia friendliness, as laid out in the World Alzheimer Report 2020.<sup>1</sup> The range of case studies exemplifies the variety of ways in which civil society can engage in raising awareness of the condition in creative, collaborative ways.**

The notion of awareness also raises the issues of equity, discrimination, and human rights as it relates to the treatment of people with dementia, as explored by Tiffeny James (University College London) in her essay. Widespread inequality when it comes to access to care needs to be addressed, taking into consideration patient characteristics such as age, gender, sexuality, and cultural or religious backgrounds.

## World Alzheimer's Month

World Alzheimer's Month, the global campaign delivered by ADI every September to raise awareness and challenge the stigma surrounding dementia, is a time of activities and advocacy to support people affected by dementia and Alzheimer and dementia associations globally. ADI supports these associations by providing toolkits, creative materials, public relations support, and digital and social media classes in the run-up to World Alzheimer's Month.

The theme for World Alzheimer's Month 2021 was 'Know Dementia, Know Alzheimer's', focussing on the importance of a timely diagnosis, the 10 warning signs of dementia, and the continued need to break down the stigma that still surrounds Alzheimer's disease and dementia. The campaign also tied into the theme of that year's World Alzheimer Report, 'Journey through the diagnosis of dementia'. World Alzheimer's Month posters, toolkits, social media banners and infographics were produced for the campaign in 2021 and adapted by ADI member associations worldwide into their own languages and with their own logos. ADI also collected video testimonials of those living with dementia and carers on their experience of the diagnosis process.

Following on last year's campaign, World Alzheimer's Month 2022 will focus on the important topic of post-diagnostic support. In many parts of the world, support for those diagnosed with dementia is insufficient, difficult to access or not available at all. Through this year's World Alzheimer's Month campaign and associated World Alzheimer Report, ADI will aim to raise awareness of this issue and provide recommendations for how the system can and must improve.

### World Alzheimer's Month 2021 online



465,000  
'likes'



45 million  
hashtag  
impressions



700,000  
interactions



<sup>1</sup> Fleming, R., Zeisel, J. & 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.

## Equity and human-rights in dementia care

People living with dementia should have the same rights as everyone else, including the right to attain the highest standard of health,<sup>1</sup> free from discrimination based on characteristics including ethnicity, age, and sexual orientation. Yet care is sometimes inequitable; dementia diagnosis, which is the gateway to treatment and support, is often delayed in younger people, people from minority ethnicity groups,<sup>2,3</sup> while lesbian, gay, bisexual and trans older people are more likely to have their dementia needs unmet.<sup>4</sup>

To ensure everyone has a fair opportunity to achieve their full health potential, dementia policy should address specific needs related to patient characteristics. The WHO recognises this and has human-rights and equity as cross-cutting principles of its Global action plan. The plan proposes actions for member states to improve access to person-centred, gender sensitive, and culturally appropriate services. So how does current dementia policy enable this?

Clinical practice guidelines, which provide recommendations about the most effective approaches to diagnosis and management, help bridge the gap between policy and practice. In a systematic review, we searched for national dementia guidelines for all countries and assessed whether they consider patient characteristics in their recommendations.<sup>5</sup> The existence of approved guidelines, standards, or protocols is a key WHO GDO indicator of a country's dementia readiness, but we identified only 46 guidelines across 44 countries, all high- or middle-income.

Age was the most frequently referenced characteristic (in 31/46; 67% of guidelines) followed by ethnicity, culture, or language (25/46; 54%). Guidelines recommended specialist investigation and support for younger people affected by dementia, who are more likely to be misdiagnosed or undiagnosed altogether. Guidelines for general psychiatry or mental health and dementia plans can mitigate this by including information about young-onset dementia.

Guidelines in our review recommended consideration of culture when investigating dementia and providing person-centred care. Using culturally and linguistically appropriate and valid tools is crucial to achieving the WHO's target that 50% of people with dementia will receive the diagnosis in 50% of member states by 2025, and should be a goal for all countries.

The Global action plan calls for culturally appropriate services and care, but what does this look like in practice? Only three guidelines in our review gave examples. These included ensuring that people living with dementia have culturally appropriate food, opportunities to practice religion, and access to staff or interpreters who speak their language when conducting assessments and delivering information about diagnosis and treatment. To support the provision of culturally appropriate care, plans and guidelines should include specific examples of how this can be done.

Other recommendations in our review included considering religion when providing person-centred and end-of-life care; and intellectual disability and sensory impairment when investigating dementia. Most recommendations about sex were about not using sex hormones to treat cognitive impairment in men or women. Two mentioned a potentially higher care burden for women. Only one guideline referenced sexual orientation with a single recommendation, and none mentioned gender identity.

Different individuals' characteristics impact their experiences of dementia and engagement with services. Without acknowledging and addressing this, policy and guidelines may only improve care for the most advantaged populations. Dementia plans should specify how people's characteristics impact dementia experiences, and guidelines should provide detailed related recommendations across the course of dementia care from service access to assessment, treatment, and end of life to help reduce inequities in dementia care.

*Tiffany James, University College London, Division of Psychiatry*

- 1 Office of the United Nations High Commissioner for Human Rights, World Health Organization. The Right to Health; Fact Sheet No. 31. 2008.
- 2 Cooper C, Tandy AR, Balamurali TB, Livingston G. A systematic review and meta-analysis of ethnic differences in use of dementia treatment, care, and research. *The American Journal of Geriatric Psychiatry*. 2010;18(3):193–203.
- 3 Van Vliet D, De Vugt M, Bakker C, Pijnenburg Y, Vernooij-Dassen M, Koopmans R, et al. Time to diagnosis in young-onset dementia as compared with late-onset dementia. 2013;43(2):423–32.
- 4 Fredriksen-Goldsen KI, Jen S, Bryan AE, Goldsen J. Cognitive impairment, Alzheimer's disease, and other dementias in the lives of lesbian, gay, bisexual and transgender (LGBT) older adults and their caregivers: Needs and competencies. *Journal of Applied Gerontology*. 2018;37(5):545–69.
- 5 James T, Mukadam N, Sommerlad A, Pour HR, Knowles M, Azocar I, et al. Protection against discrimination in national dementia guideline recommendations: A systematic review. *PLoS medicine*. 2022;19(1):e1003860.

## Strength through partnership

Partnership is key to making the vision of a better quality of life for people with dementia and family carers a reality across the globe – and a value at play in efforts in southeast Asia.

In 2018, I had the chance to speak to all 10 member states of the Association of Southeast Asian Nations (ASEAN) during a Health Cluster Meeting in Vientiane, Lao PDR, on the importance of prioritising dementia in the region, where an estimated 3.5 million people live with the condition. Since 2020, ADI has officially partnered with ASEAN, working closely with two divisions: Health Cluster 1 (ministries of health) and Education Sports Youth Division (ministries of youth, sports and welfare) in the region.

Eight of the 10 ASEAN member states – Brunei, Indonesia, Malaysia, Myanmar, Philippines, Singapore, Thailand and Vietnam – have Alzheimer and dementia associations affiliated with ADI, either as fully fledged member associations or part of ADI's membership development programme. These existing ties have strengthened the ADI-ASEAN partnership in its efforts during World's Alzheimer Month, during which all 10 ASEAN countries developed programmes.

One of the facets of the work to increase dementia awareness in ASEAN member states has been to encourage more youth organisations to be active in dementia advocacy. ADI's very first Youth Engagement Programme (YEP) was kickstarted by Datin Jacqueline Wong, an honorary advisor for Demensia Brunei, in conjunction with the ADI Asia Pacific Regional Conference in KL Malaysia in August 2019, with the support of all ADI Asia Pacific Region members. The inspiring session involved 17 youth presenters from the region and was attended by approximately 300 participants from more than 20 countries.

Since then, YEP continues to inspire youth to become advocates for people with dementia, volunteer in dementia friendly initiatives and at the same time support their peers who are young carers in several countries including several initiatives that have been showcased at our recent 2020 ADI Conference from Indonesia, Brunei, Thailand and Malaysia. YEP's work garnered interest from ASEAN and led to a joint ADI-ASEAN webinar on intergenerational collaboration, which was successfully conducted in February 2020 involving 70 youth participants from more than 10 countries in the region.

Why is it important to involve youth? Young people who develop a good understanding of dementia as a public health issue – including the potential for prevention – and who are engaged in advocating for action on dementia can provide a strong support system for people with dementia and their carers. Youth participation and inclusion is critical for dementia communities, whether through volunteering, advocacy and awareness raising.

**“Youth participation and inclusion is critical for dementia communities, whether through volunteering, advocacy and awareness raising.”**

The successful showcase of intergenerational solidarity has also provided a platform for engagement opportunities beyond borders. The strengthening of regional and international partnerships has had a huge impact on the growth and success of programmes, which can undoubtedly contribute to progress on the WHO's Global dementia plan Action Area 2 targets.

*DY Suharya, regional director Asia Pacific, ADI*



## Australia STAGE 3B

Dementia Australia's Dementia-Friendly Communities program plays an important and unique role in empowering and supporting individuals and local communities to improve knowledge and awareness about dementia, reduce stigma and discrimination and promote social engagement.

In a dementia-friendly community:

- People have an understanding of dementia. They raise awareness of the needs of people living with dementia in the community.
- Local community groups, organisations and businesses make simple changes to enable people living with dementia to access their services.
- Organisations or communities make sure the built environment incorporates accessible signage, lighting and building design.
- People in the community come together as a dementia alliance to create a more inclusive and welcoming place for everyone to live.

The Dementia-Friendly Communities concept has been embraced and developed on a global scale over the last decade. Dementia Australia's award-winning program supports alliances, organisations and initiatives in every state and territory across the country in varying stages of

development. Across the country, there are currently almost 33,000 Dementia Friends, 56 alliances, 64 Dementia-Friendly Organisations, around 120 Dementia Friends hosts (and an additional 40 on the waiting list), and 25 community engagement programme projects.

**"A community that is dementia-friendly is simply a community that benefits everyone."**

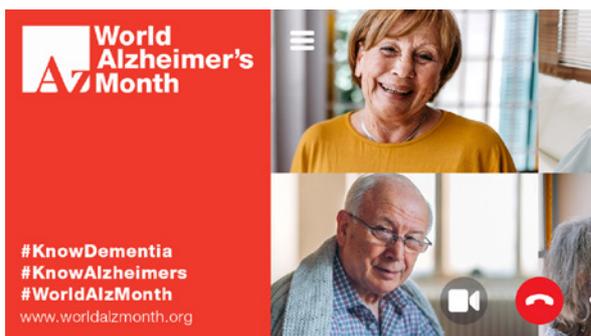
Given the demonstrable success of the Dementia-Friendly Communities program, Dementia Australia recently released a discussion paper<sup>1</sup> calling on all sides of Australia's parliament to commit to recurring funding to ensure the growth, development and sustainability of current and future Dementia-Friendly Communities initiatives.

The programme's success is based on the central role that people living with dementia play in all program tiers, from the establishment of alliances and development of action plans, through to awareness raising activities and implementation of grassroots dementia-friendly change initiatives.

The increasingly active dementia-friendly movement in Australia continues to be driven primarily by the rigorously developed and successfully implemented Dementia-Friendly Communities programme by Dementia Australia.

The Dementia-Friendly Communities programme team is committed to continue to work towards an inclusive community. A community that is dementia-friendly is simply a community that benefits everyone.

*Maree McCabe AM, CEO, Dementia Australia*



<sup>1</sup> The November 2021 discussion paper can be accessed here: <https://www.dementia.org.au/sites/default/files/2021-11/PFOD-Discussion-Paper-Nov-2021.pdf>



## Brunei STAGE 3D

Demensia Brunei (DB) had originally planned for roadshows in all four districts of Brunei to raise public awareness on dementia in September 2021. Unfortunately, after more than a year without COVID-19 infections in the country, an unexpected second wave began in August 2021. This caused a sudden change of plans for World Dementia Month, requiring an online approach using DB's Instagram account.

We had recruited seven team members from Universiti Brunei Darussalam to spend three months for their community outreach programme with DB. Instead of coordinating and running the roadshows, their roles switched to developing content, infographics and event programming for a social media calendar.

Instagram posts, stories and IGTV videos were shared throughout September, including weekly 'conversations' about dementia on Instagram Live videos. The Instagram analytics tool was used for impact measurement. DB's 48 posts, 114 stories, 13 IGTV videos and 5 live videos cumulated a total of nearly 20,000 views. Our Instagram account's reach increased by 315% compared to August 2021, with a tremendous 859% increase among users who did not previously follow DB's account.

The most popular content included informative posts on exercise and pain for people living with dementia, the role of family and caregivers, and how to manage negative emotions. Announcements about DB merchandise (face masks, cups, tote bags...) also garnered a lot of attention.

Additionally, two Zoom sessions were held in September with guest speakers Emily Ong, who spoke about rehabilitation and quality of life from the perspective of a person living with dementia, and Jacqueline Wong, who shared about dementia-friendly community initiatives and youth empowerment. Six newspaper articles, four radio interviews and a morning talk show also addressed dementia during the same time period.



On 21 September 2021, the Minister of Health mentioned World Alzheimer's Day during a daily COVID-19 press conference, acknowledging the theme "Know dementia, Know Alzheimer's", all while wearing a DB face mask.

Due to the success of the World Alzheimer's Month campaign, further weekly virtual talks were organised in October 2021 on Instagram Live and on the radio. An unexpected situation has opened up new possibilities for our outreach.

*Dr Shyh Poh Teo, president of Demensia Brunei, consultant geriatrician and physician, RIPAS hospital, Brunei Darussalam*



## Canada STAGE 5A

In January 2022, during Alzheimer's Awareness Month in Canada, the Public Health Agency of Canada (PHAC) launched its first national awareness campaign on reducing dementia stigma, as part of the efforts to implement the country's first national dementia.

The campaign draws on data from public opinion research conducted by PHAC and responds to objectives in 'A Dementia Strategy for Canada: Together We Aspire'. The PHAC campaign recruited high-profile English- and French-speaking ambassadors in Canada's two official languages, ran TV spots, and shared social media posts encouraging Canadians to learn more about dementia.

PHAC's national awareness campaign has a broad public education focus designed to reach as many Canadians as possible. However, public health awareness campaigns will need to become more targeted in their approach by focussing on often overlooked populations, such as young-onset dementia, which affects an estimated 28,000 Canadians according to research conducted by the Alzheimer Society of Canada.

Messaging should also promote access to early diagnosis and the availability of post-diagnostic support, in addition to stigma and risk reduction. Growing campaign approaches to incorporate more culturally appropriate messaging and supports for different communities are also important.

Overall, targeted awareness campaigns do offer the opportunity for partnership between government and external stakeholder organisations that can take on the role of executional lead and leverage their existing networks. Innovative campaigns that create greater awareness and a sense of urgency are an essential support to the implementation of dementia strategies.

The Canadian campaign launched in January is a good start – and we hope it grows, networks, expands and adapts in the future.

*Randy Steffan, director of public policy and government, Alzheimer Society of Canada*



## Malaysia

As part of Alzheimer's Disease Foundation Malaysia's (ADFM) commitment to look at the continuum of care for people living with dementia, we have looked at how to enhance quality of life for those using our daycare centre. The idea for a sensory garden came as we asked ourselves how to provide a soothing environment while stimulating the senses.

A team of dedicated volunteers – including people from Kebun Kebun Universiti Bangsar Teknologi Puncak Alam Mara faculty of business and management, the Urban Biodiversity Initiative, UCSI university vocational interns, and refugees and asylum seekers from Myanmar, Yemen and Pakistan – came together with ADFM to bring this project to fruition.

Flowers, fruits, herbs and vegetables intended to rouse the senses of sight, hearing, smell, touch and taste provide an ideal space for people with dementia to take a stroll and stimulate reminiscence. The fragrant smell of flowers, chirping birds, and colourful butterflies are all part of the therapeutic effects of nature that bring a sense of calm and respite to both people with dementia and their caregivers.



ADFM appreciates each and every one for coming together to assist in this project for the benefit of the dementia community.

*Gan Chong Shyan, project director, Alzheimer's Disease Foundation Malaysia (ADFM)*



## Hong Kong STAGE 3C

Echoing the "Dementia Friends" started by Alzheimer's Society UK, Hong Kong Alzheimer's Disease Association (HKADA) has been a part of this global movement since 2017 to encourage people from all walks of life in Hong Kong to become Dementia Friends, aiming to raise public awareness of dementia, address people's misconceptions of the disease, and tackle the stigma associated with it.

As of March 2022, around 18,000 people have become Dementia Friends – whether public utilities staff, bank and property management employees, social services, or school students. Meanwhile, trained Dementia Friends ambassadors continue to disseminate dementia-friendly messages to the public.

HKADA has been continuously advocating for policies, services, and support for people with dementia and their families in its interactions with the Social Welfare Department (SWD) of the Hong Kong Government. The SWD has commissioned HKADA to conduct "Dementia Friends" information session and Dementia Friends ambassador training throughout all districts of Hong Kong since 2018. A more recent collaborative project is the building of a dementia-friendly community in Hong Kong.

*Maggie Lee, Executive Director, Hong Kong Alzheimer's Disease Association*



Dementia Friends information session for residents of the Tsuen Wan District of Hong Kong.

## Design and dementia

As evidenced in the 2020 World Alzheimer Report, planning, designing and making residential, long terms care and public spaces accessible to people with dementia is an essential part of fostering dementia-friendly societies. Integrating these values in design is crucial to ensure that people with dementia are not an afterthought in their own communities.



### Singapore – STAGE 5A

A safe, inclusive, and accessible public transport system is an indispensable component of dementia-inclusive communities. People with cognitive disabilities like dementia usually have difficulties in navigation and orientation. As a result, it affects their independence and limits their autonomous mobility, causing many to choose to live an immobile lifestyle.<sup>1</sup>

Singapore launched its national dementia-friendly initiative in March 2016 to prepare society for an expected increase in the number of older people with dementia. In 2017, the Public Transport Council (PTC), Land and Transport Authority (LTA), and public transport operators launched the "Heart Zone" initiative to promote a caring culture in Singapore's public transport system. Public transport users are encouraged to step up and show care and assistance to others in need during their daily commute.

With increasing awareness of dementia also comes more recognition of invisible disabilities. "May I have a seat please" lanyards and cards aim to make rides

more comfortable for those with invisible medical conditions, including those with chronic pain like arthritis or recovering from surgery.

One recent area of focus has been wayfinding measures to help older people and those with cognitive impairments feel confident using public transportation. The latest Thomson-East Coast Line (TEL) has prominently positioned navigation and wayfinding signage, lettering large enough to read from a distance, and colour-contrasted signages and platform seats.

The "Find Your Way"<sup>2</sup> initiative is the first of its kind, in which people living with dementia are involved in co-designing public transportation as dementia and accessibility advisors.

The following recommendations were implemented based on the lived experiences and insights of the dementia advisors:

- Colour-coded nostalgic murals to help with destination recognition, tactically positioned to help check if the commuter is headed in the right direction.
- Directional floor stickers to guide to the respective boarding areas.
- Segmentation of the interchange into distinct zones to eliminate or reduce errors and confusion.

While these initiatives help make public transport more accessible and inclusive, there is still more to do to create a user-driven public transport system that incorporate a co-design approach to mobility solutions. Disabled people must be part of the team leading the design of safe, inclusive, accessible transport systems for all.

*Emily Ong, DAI Environmental Design Special Interest Group (ED-SiG)*



<sup>1</sup> Gomez, Javier et al. 2015. An Adapted Wayfinding System for Pedestrians with Cognitive Disabilities. Hindawi Publishing Corporation. Available from: <http://dx.doi.org/10.1155/2015/520572>



## Australia STAGE 3B

Small-home, person-centred environments have been shown to increase engagement, reduce distress, decrease mortality rates<sup>1</sup> and improve both quality of care and quality of life for those with dementia.<sup>2</sup> This model has recently been endorsed by the Australian Royal Commission into Aged Care Quality and Safety and recommendations have been made to encourage its implementation.<sup>3</sup>

Research involving HammondCare of a group of 55 residents living with dementia who moved from an old, traditional nursing home to a purpose-built, cottage-based service, showed increased engagement, health and wellbeing through reduced weight loss and dependence of others at mealtimes, all because the space made more sense and empowered the person.

An important element of HammondCare's approach is the food and meal preparation for those in our care. The small cottages in our dementia care homes each come with their own kitchen, where staff prepare wholesome and tasty meals. While many people living with dementia struggle with loss of appetite or interest in food, the smells, sounds and sights of cooking tempt even the most reluctant diner.

Large kitchens were introduced in nursing homes in the 1980s and 1990s, with the promise that they would be more efficient and provide better quality control through a more standardised "product". However, this approach has resulted on many occasions in "cattle-class" airline food, favoured by so many aged care providers.

In contrast to large, centralised kitchens, HammondCare's approach is to have freshly cooked meals, ideally prepared in small houses with their own fully functioning kitchens. Food and its preparation are important cues to the rhythms of life and having such a localised activity allows that.

Good design is complemented by a model that supports staff to build relationships of trust with those in care and to understand who they are as a person. This is essential to maintaining resident choice and



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autonomy, particularly when a person's priorities may conflict with "best" or "usual" practice. For example, in an organisation that focusses only on safety, "high-risk" foods (e.g., soft cheeses and rockmelons) will be prohibited; in an organisation that balances safety with resident dignity and choice, such risks are managed.

Yes, there is a higher upfront capital investment if you decide to build kitchens in every house or apartment. But this is offset by lower transport and staffing costs and savings on "cook-chill" equipment. When all factors are considered, the small-house model has been demonstrated to provide freshly cooked meals at a lower cost – all with the added benefit of increased flexibility which benefits the person with dementia.<sup>4</sup>

Giving people meaningful places to go and things to do elevates a design above being functional, for example, enabling someone to get involved in cooking dinner. When design looks at empowering people, being able to share in the daily rituals of food preparation, or even making a cup of tea, are vital. Embracing a commitment to putting fresh-cook kitchens at the heart of each cottage for dementia care requires a functional kitchen that people can see or sense; it also needs to support a culture that the kitchen can be untidy at times and that set-up and clean-up can be important to those who wish to continue to be engaged in these activities.

*Professor Colm Cunningham, executive director of research, international and dementia design for HammondCare Dementia Centre*

- 1 Smith, Mathews, Gresham, 'Pre- and post-occupancy evaluation of dementia care cottage.' *American Journal of Alzheimer's Disease and Other Dementias*, 25: 265 (2010)
- 2 Dyer SM et al, 'Clustered domestic residential aged care in Australia: few hospitalisation and better quality of life'. *The Medical Journal of Australia*, 208, 10 (2018): Access: <https://doi.org/10.5694/mja17.00861>
- 3 Royal Commission into Aged Care Quality and Safety (February 2021) Final Report – Recommendation 45, 46 and 142. Accessible via: <https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-recommendations.pdf>
- 4 J. Cohen-Mansfield & A. Bester, 'Flexibility as a Management Principle in Dementia Care: The Adards Example', *The Gerontologist*, vol.46, issue 4, 2006, pp. 540–544.



## Norway STAGE 4A

In 2021, the Norwegian government adopted the fourth consecutive national action plan on universal design standards. The aim of the plan, which involves eight ministries, is to ensure the Norwegian society is accessible to all.

The action plan is linked to Agenda 2030 and the 17 Sustainable Development Goals, especially Sustainable Development Goal 11, "making cities and human settlements inclusive, safe, resilient and sustainable". It also corresponds to country-level initiatives, e.g. the national quality reform for older persons called "A full life – all your life", approved in 2018.

and site development; and digitalisation. The aim is to give people with dementia the opportunity to live as long as possible in their own homes. This requires, amongst many things, facilitation of residential facilities, both existing and new.

As our society becomes more digital, the Ministry of Health and Care Services will implement an information campaign to raise awareness about dementia and the importance of tearing down physical and digital barriers in society, in order to reduce the risk of people with dementia being excluded from participation in society.

"As our society becomes more digital, the Ministry of Health and Care Services will implement an information campaign to raise awareness about dementia and the importance of tearing down physical and digital barriers in society."

Norwegian law requires that challenges with vision, hearing and cognition are taken into consideration when developing new webpages, applications and other digital tools. As a result, both private and public organisations and businesses must follow the regulations to ensure digital accessibility for all through universal design.

It is worth noting that guidelines regarding how to accomplish universal design for people with dementia are yet to be fully implemented.

In the action plan, dementia-friendly measures and requirements are promoted in three areas: residential facilities for people in need of 24-hour health and care services, as well as housing collectives; housing

*Mirjeta Emini, advisor, Nasjonalforeningen for folkehelsen*

### Key points



**Awareness is the essential first step to effective advocacy and dementia policy development, throughout the year. Raising awareness and challenging stigma through a variety of means are key to shifting the discourse surrounding dementia to one based on the values of equity and human rights. National associations and relevant health and care organisations are important actors in these campaigns and inclusion of the voice of people living with dementia and their carers is fundamental. States looking to raise awareness of dementia would do well to include grassroots organisations in these efforts, as well as seek out opportunities for regional or international cooperation.**

# 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 absence of a disease-modifying drug for dementia that is available globally, risk reduction strategies present the most tangible way for individuals to decrease their own personal risk of dementia and for governments to provide clear public health guidance, raise awareness, and promote healthy ageing within their dementia plans.**

The 2020 Lancet report on dementia prevention outlined for the first time how taking steps throughout the life course could reduce an individual's risk of developing dementia by up to 40%.<sup>1</sup> Not only did the report clarify specific factors and behaviours that could increase risk, it also described protective factors that could help guard against cognitive decline. This "life course roadmap" provides clear guidance to individuals and governments; encouraging individuals to take advantage of protective factors and make healthy life choices, whilst calling on governments to develop policies that promote and support healthy lifestyles and to invest in infrastructures that enable people to act upon their healthy choices.

As many countries emerge into a "post-COVID" world, there is a renewed focus on the importance of brain health and healthy ageing. Good brain health requires a life course approach that starts at a young age, with ongoing access to education. Access to information on risk reduction and healthy life choices is important and this requires a health workforce that is trained and able to provide timely and up-to-date advice and support. Public health awareness campaigns are key to success too; as dementia risk reduction is closely linked with risk factors for other non-communicable diseases (NCDs) and campaigns can be aligned to reinforce messaging and increase impact.

"Good brain health requires a life course approach that starts at a young age, with ongoing access to education."

Effective risk reduction strategies require a multi-pronged approach, and this chapter provides some excellent examples of initiatives and research from around the world. Here we will explore new insights into individual risk reduction combination therapies, the importance of population-based risk strategies, new proactive policies in the US to tackle risk, the significance of social interaction and well-being, – and how this can increase engagement and well-being.

<sup>1</sup> 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)

## The importance of population-based risk reduction

"Reducing the level of exposure of individuals and populations to [dementia's] potentially modifiable risk factors, beginning in childhood and extending throughout life, can strengthen the capacity of individuals and populations to make healthier choices and follow lifestyle patterns that foster good health": This key passage from Chapter 3 of the Global action plan emphasises the need for both individual and population approaches to dementia risk reduction.

Much energy has been put into supporting or encouraging individuals, particularly those identified as high-risk for the development of dementia, to reduce their risk. We will learn much from the study of the individual-based WW-FINGERS intervention around the world. However, we've known for many decades that individual-based solutions can only ever be a small part of population health improvement, because:

- The relatively small number of people at "high-risk" of disease will contribute many fewer cases of dementia than the very large group of people at "normal-" or "slightly elevated-" risk.<sup>1</sup> To achieve the scale of reduction in dementia that we all want, and has been shown to be possible,<sup>2</sup> we need population approaches to shift everyone towards healthier lifestyles.<sup>3</sup>

- Making and sustaining healthier choices is difficult for individuals, and requires resources (material, social or cognitive) that are not evenly distributed across society.<sup>4</sup> Interventions placing the onus on individuals to change their lifestyle are known to exacerbate socioeconomic inequalities, and are likely to do so in the incidence of dementia. This is particularly important given the increasing majority of new dementia cases occurring in low- and middle-income countries. We need population approaches to influence the upstream socioeconomic, cultural, and commercial determinants of health so that the environments in which people make lifestyle choices are geared up to help them succeed.

But what exactly do population-level approaches to dementia risk reduction look like? Building on the work of others,<sup>5</sup> we propose the following working definition: "Interventions that influence the social, physical, economic and/or legislative environments, to make them less conducive to the development or maintenance of risk factors for dementia, and more conducive to neuroprotective and cognitively enhancing lifestyles." Examples of population-level prevention policies to address risk factors for dementia are compared to individual-level policies (see table).

Finally, it makes no sense to see risk factors like physical inactivity, obesity, hypertension, smoking, and excess alcohol consumption as risk factors for dementia in isolation (either from each other, or from other conditions associated with healthy ageing). As the Global action plan instructs us, dementia risk reduction must be embedded within countries' broader population health agenda.

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"We've known for many decades that individual-based solutions can only ever be a small part of population health improvement."

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Table: Examples of prevention policies against risk factors for dementia, according to individual or population approach. Reused from Walsh et al. under a CC BY 4.0 copyright agreement

	High-risk individual prevention (Conscious behaviour change)	Whole population prevention (Unconscious behaviour change)
<b>Obesity and physical inactivity</b>	<ul style="list-style-type: none"> <li>● Identification of individuals at high risk by primary care-based routine health check-up of all late middle-aged individuals and referral of obese individuals to weight management clinics/exercise clinics</li> </ul>	<ul style="list-style-type: none"> <li>● Investment in walking/cycling infrastructure that makes active travel easier and safer</li> <li>● Subsidised cycling equipment</li> <li>● Investment in better quality green spaces</li> <li>● Designing buildings so that staircases are more prominent than escalators</li> </ul>
<b>Poor diet</b>	<ul style="list-style-type: none"> <li>● Partial replacement of welfare benefits with fruit and vegetable vouchers</li> <li>● Individual dietary interventions and advice</li> </ul>	<ul style="list-style-type: none"> <li>● Sugar levy</li> <li>● Changes to licensing law to influence the food environment</li> <li>● Adding nutrition and culinary skills to the school curriculum</li> </ul>
<b>High blood pressure</b>	<ul style="list-style-type: none"> <li>● Identification of those with high blood pressure by primary care-based routine health check-up of all late middle-aged individuals and offering intensive pharmacological blood pressure management</li> </ul>	<ul style="list-style-type: none"> <li>● Legislation and work with industry to reduce salt content of food</li> </ul>
<b>Smoking</b>	<ul style="list-style-type: none"> <li>● Identification of smokers by primary care-based routine health check-up of all late middle-aged individuals and offering smoking cessation advice and support</li> </ul>	<ul style="list-style-type: none"> <li>● Banning the advertisement of cigarettes, and mandating plain packaging</li> <li>● Legislating smoke-free indoor public spaces</li> </ul>
<b>Low education and lack of cognitive stimulation</b>	<ul style="list-style-type: none"> <li>● Mobile phone application designed to encourage recently retired people, worried about losing their memory, to engage in cognitive training each day</li> </ul>	<ul style="list-style-type: none"> <li>● Legislation and cultural work to raise the average age that boys and girls remain in formal education for</li> <li>● Subsidies for higher education</li> <li>● Improving the quality of work available, and supporting in-work training</li> </ul>
<b>Social isolation and loneliness</b>	<ul style="list-style-type: none"> <li>● Social prescribing for those reporting feeling isolated or lonely into community activities or voluntary groups</li> </ul>	<ul style="list-style-type: none"> <li>● Cross-government work to improve social cohesion and integration</li> <li>● Age-friendly town planning</li> <li>● Improving internet access to rural areas</li> <li>● Investment in public transport in rural areas</li> </ul>

Examples of prevention policies against risk factors for dementia, according to individual or population approach. Reused from Walsh et al. under a CC BY 4.0 copyright agreement.

## Social health and prevention of dementia

There is a discordance between neuropathology and clinical symptoms<sup>1</sup> – meaning that biological factors are not the only ones that might influence cognitive processes and dementia. One of the potential influential factors is social health, being the relational domain of health as defined by the WHO in 1946, alongside physical and psychological health.<sup>2</sup>

Social health markers, such as social network and frequency of contacts, may contribute to cognitive reserve<sup>3</sup> and delay of dementia symptoms.<sup>4</sup> Conversely, markers of poor social health, such as poor social engagement, were associated with a higher incidence of dementia.<sup>5</sup> The marker social isolation is now acknowledged as one of the modifiable risk factors for dementia.<sup>6</sup>

Recently, we found that social health was associated with brain structure, where better perceived social support at baseline was associated with better brain structure over time.<sup>7</sup> Social health is not only relevant in relation to the onset of dementia, but also to its course. It is one of the key elements in psychosocial interventions. However, in epidemiological research other important social health markers are understudied, such as dignity and reciprocity. In psychosocial interventions, social elements are included but often taken for granted and its potential is not fully explored.

A major barrier to fully explore the potential of social health is the lack of conceptual clarity. INTERDEM, a Pan-European network for psychosocial research in

dementia, engaged in making the case of social health in dementia research by defining the overarching concept and making efforts to bridge the gap between biological and social sciences. This includes the development of the social health hypothesis, in which social health can act as the driver for accessing cognitive reserve.<sup>8</sup>

Several interdisciplinary research projects were initiated by INTERDEM. In one of them, the Social Health And REserve in the Dementia patient journey (SHARED) project, a conceptual framework has been developed providing knowledge on what social health is and on how to recognise its markers. This has been used to identify social health markers in large epidemiological databases and consequently to study the associations between these social health marker and cognition. Reviews and qualitative studies of SHARED identify additional social health markers that can be used in future studies.

Scientific knowledge bridging biological and social sciences adds to our knowledge that better use of our social health potential might protect our cognitive potential. Given the huge impact of dementia worldwide, and the absence to date of a significant breakthrough, a novel approach is needed. We suggest it is timely to better explore the potential of social health and its mechanisms both to prevent dementia and to strengthen living well with dementia for persons with dementia and their carers.

*Professor Myrra Vernooij-Dassen, chair of INTERDEM*

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## The World-Wide FINGERS network: a joint global effort of multidomain interventions to reduce dementia risk

World-Wide Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (WW-FINGERS) is a global network of multidomain clinical trials based around lifestyle intervention for modifiable risk factors – such as obesity, diabetes, and physical inactivity – that account for approximately 40% of all dementia cases.<sup>1</sup> WW-FINGERS aims to enable the sharing of knowledge between existing lifestyle interventions, create new multidomain trials following a common methodology, and facilitate joint analyses, in a bid to combat cognitive impairment and dementia.

As dementia is a global challenge, the solution must utilise a global approach. To this end, the WW-FINGERS network is continually expanding and incorporating new members. The network is now formed of research teams from over 45 countries and across six continents, with the most recent additions including Mauritius, the Philippines, Norway, Denmark, Portugal, and Greece. As low- and middle-income countries (LMICs) will experience the greatest burden from growing dementia prevalence and are often underrepresented in randomised dementia prevention trials, there is a particular drive to include and support research groups from such areas.

WW-FINGERS understands that the most effective dementia prevention solutions must be tailored to the individual needs of each country or culture. Therefore, while all the multidomain trials included in the network will share a common methodology, there is an emphasis on regional adaptations based on specific cultural and economic factors. The harmonised aspects of the study methodology will also give a unique opportunity to compare results from different cultural and economic settings, furthering our understanding of dementia risk and response across the globe.

Over two years have passed since the COVID-19 pandemic began and the WW-FINGERS network has responded to the challenges presented, including by exploring novel ways of reaching participants, such as piloting transitions to virtual activities/interventions, and researching the development of e-health tools. While the pandemic has slowed ongoing studies, it has allowed for WW-FINGERS to focus on the planning stage of newly joined members, such as securing funding and finalising methodology. This creates a solid foundation which will support future studies to progress quickly once public health restrictions allow.



Courtesy of WW-Fingers.

<sup>1</sup> Livingston, Gill, et al. "Dementia prevention, intervention, and care: 2020 report of the Lancet Commission." *The Lancet* 396.10248 (2020): 413–446.

The WW-FINGERS-SARS-CoV-2 Initiative was created to examine the impact of the COVID-19 pandemic on those at risk of cognitive impairment and dementia, with results already available from Finland showing a clear negative impact on several risk factors for brain health, including reduced physical activity, as well as increased sleep disturbances, feelings of loneliness, and subjective memory problems.<sup>2</sup> Once completed, data from thousands of participants responding to surveys in a number of countries will be harmonised to create a comprehensive visualisation of how the COVID-19 pandemic and related public health restrictions have affected older people around the world. Considering the initial findings of negative effects of the COVID-19 pandemic on risk factors for dementia, it is now more important than ever to focus on risk reduction through innovative approaches and broad collaborations.

Building upon a wealth of experience from current multidomain models, WW-FINGERS aims to expand into a new generation of clinical trials. Studies such as MET-FINGER, which combines the original FINGER study<sup>3</sup> and the diabetes medication metformin, will spearhead research into the effects of combining lifestyle and pharmacological interventions in a clinical setting to reduce dementia risk. This is a major step towards a precision prevention approach, where the right interventions are targeted to the right people at the right time.

WW-FINGERS also supports implementation and rapid translation of results into clinical practice. Initiatives such as EURO-FINGERS are currently identifying the best ways to communicate about dementia risk reduction and how to better motivate people to adhere to lifestyle changes. As patient and user involvement are so important to both research programmes and policy development, initiatives such as this will provide the understanding needed to apply research to real-world settings with the greatest impact.

Finally, WW-FINGERS is exploring new technologies and digital solutions to combat dementia risk. The 'E-FINGERS' project is investigating the ability of e-health tools to help implement interventions and monitor outcomes. In addition, a federated database system for large-scale data sharing and joint analyses, which are essential for gaining optimal information about effective and feasible interventions in diverse populations, is currently being created.

All the work at WW-FINGERS, from its utilisation of a global perspective, to focus on multidomain methodological approaches, and active inclusion of LMICs, is in line with the WHO's risk reduction guidelines and is filling identified gaps in the current evidence.<sup>4</sup> In collaboration with Alzheimer's Disease International, WW-FINGERS is forging ahead, using the highest quality research, with the aim to reduce dementia risk.

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“Initiatives such as this will provide the understanding needed to apply research to real-world settings with the greatest impact.”

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## USA STAGE 5B

In December 2021, the U.S. National Plan to Address Alzheimer's Disease was updated to include a sixth overarching goal: accelerate action to promote healthy aging and reduce risk factors for Alzheimer's Disease and related dementias. This sixth goal complements existing goals on research, quality care, support for individuals and families, public awareness, and improving data – and it is the first plan goal to exclusively focus on the pre-symptomatic phase of Alzheimer's disease.

Nearly two-thirds of American adults have at least one of five major risk factors for dementia – and the numbers are even higher for Black, Hispanic, and Native Americans. The healthy aging/risk reduction goal – the first goal added since the initial release of the plan in 2012 – was in response to a growing body of evidence indicating that addressing risk factors could reduce the risk of cognitive decline and possibly dementia.

The inclusion of the goal on healthy aging and risk reduction comes after a call to action from the National Plan Advisory Council – a group that

includes 13 members of the general public who advise the government on the National Alzheimer's Plan. The council noted that an aggressive public health effort to address risk factors for Alzheimer's could result in as many as one million fewer Americans living with Alzheimer's in 2050. They urged a focus on 10 specific risk factors: midlife hypertension, physical inactivity, smoking, diabetes, traumatic brain injury, poor diet and obesity, poor sleep, alcohol abuse, depression, and hearing loss.

In order to achieve the new goal, the national plan outlines a multi-pronged strategy that involves public health, the aging community network, clinical practice, expanded research, and public engagement on ways to reduce risks. In addition, it specifically calls out the need to address inequities in dementia risk factors among marginalised populations. Within this multi-pronged strategy, the plan lists 26 specific action steps being undertaken by the U.S. federal government.

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### Key points



**In the absence of disease-modifying treatment that is accessible to all, dementia risk reduction deserves more attention and investment from governments. While individuals can take steps to decrease their personal risks, large-scale, holistic initiatives are crucial to achieve a broader impact. The pandemic has highlighted the ties between social health and dementia, further emphasising that risk reduction should be approached from a societal rather than individualistic perspective. While the long-term effects of COVID-19 on cognition will take time to be more fully understood, states should see risk reduction as an essential and cost-saving tool to integrate in their national dementia plans.**

# Chapter 4

## Diagnosis, treatment, care and support



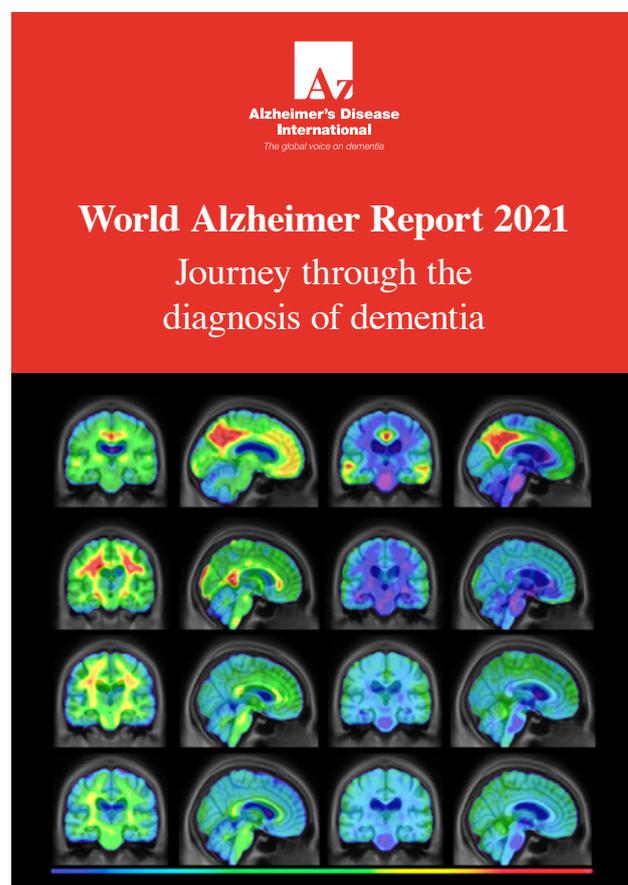
**WHO target: In at least 50% of countries, as a minimum, 50% of the estimated number of people with dementia are diagnosed by 2025.**

**Action area 4 of the Global action plan is arguably the broadest of all, encompassing the wide spectrum of needs during and after a diagnosis of dementia. As such, its aims are ambitious and cut across a variety of sectors.**

Access to diagnosis is still a huge hurdle in much of the world, as explored in the World Alzheimer Report 2021, entitled "Journey through the diagnosis of dementia". ADI estimates that three quarters of people with dementia are undiagnosed globally, complicating access to support and care. Diagnosis rates vary dramatically between high- and low-income countries, further compounding inequities. Fewer than 50% of Global Dementia Observatory reporting countries (under 30 countries) are able to report on their diagnosis rates – which has a trickle-down effect on accurately gauging the scope of the issue and investing adequately in post-diagnosis support.

Treatment, as part of post-diagnosis support models, will become ever more crucial as emerging disease-modifying treatments (DMT) and symptomatic treatments continue to be developed. The world's attention has been focussed on the difficult emergence of a first disease-modifying treatment, currently available with clinical trial restrictions in the United States and in the United Arab Emirates. Multiple additional candidates are starting the approval process, but even in these early stages it is clear that many health systems are not sufficiently prepared for DMTs in terms of cost, availability, equity of access and in terms of training and monitoring. In addition, the dementia sector still lags far behind other conditions in terms of symptomatic treatments.

Dementia care remains an underinvested field – but one where civil society often leads the way with innovative and tailored approaches, as shown in this chapter's case studies. The 2022 World Alzheimer Report, to be published in September during World Alzheimer's Month, will further delve into this complex topic.



Two years on, COVID-19 still looms large in the dementia community. As detailed by this chapter's contributors, including member associations across the world, the pandemic continues to impact diagnosis, post-diagnosis support and wellbeing for people with dementia. As many countries seem to move past the sense of urgency of pandemic crisis management, it is imperative that dementia be reprioritised.

## Impact of COVID-19 on the long-term care sector, two years into the pandemic

It would be difficult to overstate the magnitude of the impact of the pandemic on people who rely on care from others, and those who provide long-term care. The WHO defines long-term care as: "The activities carried out by others to ensure that people with, or at risk, of a significant ongoing loss of intrinsic capacity can maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity".<sup>1</sup> Some long-term care is provided in nursing homes and other group settings (care homes), but in practice the majority of long-term care is provided in people's own homes and in community settings, and most carers are family members, usually women. People living with the more advanced stages of dementia are a large proportion of those who use long-term care.

While most countries have well organised systems for medical and acute healthcare, there are very few countries that have established long-term care systems, even among high-income countries. When the pandemic started, the implications of not having robust long-term care systems became rapidly and tragically apparent, as large numbers of people died from COVID-19 in care homes all over the world, while people relying on care in their own homes or in community settings had to try to manage without essential care services. In the first months of the pandemic, many countries saw about half of all deaths from COVID-19 affecting people living in care homes and other group care settings.

The early research on the major impacts of the pandemic is showing that structural weaknesses of long-term care systems and the lack of public and political visibility of the sector made the situation worse, as documented in the LTCcovid International Living Report on COVID-19 and Long-Term Care.<sup>2</sup> Despite the inherent danger that this virus posed to people who rely on care from others – due to their higher frailty, underlying health conditions, and the close proximity in which care is given – those populations were not initially prioritised for access to Personal Protection Equipment and testing in most countries, and were sometimes denied essential healthcare from which they could have benefited.

The research also shows that poor pay and working conditions experienced by staff in the long-term care sector contributed to the spread of the virus, particularly in care homes, as many staff worked in multiple settings to obtain sufficient pay, and the lack of sick pay created a dilemma between economic hardship or risking

spreading the virus. Staff in the long-term care sector experienced the highest rates of mortality compared to other occupations and, due to their exposure to the virus and the need to isolate, existing workforce shortages were aggravated to the point that care had to be rationed and the army and other untrained personnel had to be deployed to try to maintain safety. In some countries, the working conditions of migrant live-in workers became untenable.

Many staff also experienced moral distress and trauma due to having to impose measures that they knew were harmful and distressing on care home residents, or due to not being able to adhere to COVID-19 measures because of the impossibility of doing so in a humane manner. Restrictions to the presence of family, friends and volunteers in care homes had major impacts on the mental health and wellbeing of people living in care homes, their relatives and staff, and exposed the lack of mechanisms to monitor violations of the human rights of people who live in care homes.

There is growing evidence of the enormous impact of the pandemic on unpaid carers, who experienced higher care loads due to lack of support from formal services and from other family members, sometimes as a result of measures adopted to curb the spread of the virus. In most countries, support for carers was largely missing from the pandemic responses.

There have been some positives, though: very important advances in the use of technology for telemedicine and social interaction support in care settings, and enormous research efforts may lead to improvements in the provision of care. For example, one study<sup>3</sup> found that the reason why some people with advanced dementia living in care homes seemed to show fewer signs of distress during the lockdowns may have been due to a reduction in noise and other unplanned stimuli. This – and other research showing that smaller, more modern and home-like types of care homes did better in the pandemic – can potentially lead to improvements in care homes. Perhaps the increased awareness of the structural deficiencies of long-term care systems may encourage more countries to develop well-governed and funded systems.

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## Evolution of post-diagnosis landscape

As we have passed the halfway mark in the WHO Global action plan, we can see important changes in the landscape of diagnosis, treatment, care and support.

The COVID-19 pandemic has accelerated the use of remote cognitive and behavioural assessments<sup>1</sup> and a combination of cognitive, functional and mood/behavioural scales validated for online use which may speed up referrals to primary care services and speciality consultations.<sup>2</sup> The dramatic loss of life due to the pandemic in long-term care facilities is leading to a rethinking of where persons living with dementia (PLWD) should live across their journey, as well as shedding light on the preparedness of the healthcare professionals within these facilities to care for them.<sup>3</sup>

New drugs with the potential to delay disease progression are emerging from phase 3 randomised clinical trials. Their use will require earlier diagnosis into the prodromal or pre-dementia stage of Alzheimer's disease (AD), and biological tests to confirm the presence of amyloid- $\beta$  pathology in the brain.<sup>4</sup> These tests include brain imaging with Positron Emission Tomography, cerebrospinal fluid and blood measurements of key proteins associated with AD pathology.<sup>5</sup> In addition, ApoE genotyping will likely be recommended for screening among persons with concerns about their cognition and will be required for safety reasons if they start anti-amyloid therapies. This will require ethical reassessments of use of genetic testing systematically in early stages of diagnosis.

Another even larger ethical issue will be who can have access to these new drugs, considering their costs and

complexity of administration and safety monitoring. The arrival of this new generation of drugs presents both a challenge and an opportunity to rethink our approach to early and accurate diagnosis of dementia conditions in their early symptomatic stages and streamline referrals to specialty services that can initiate the new treatments.

Whilst the World Alzheimer Report 2021<sup>6</sup> gives insights into the earlier and biological diagnosis of dementia, the World Alzheimer Report 2022, set to be published in September, will focus on post-diagnostic care of dementia. Apart from describing the natural progression of dementia and indicating how to manage symptoms as they emerge over time, the 2022 report will also highlight the impact of diagnosis on persons living with dementia, family and informal carers, as well as clinicians. Furthermore, the 2022 report will also review the current non-pharmacological interventions, models of care around the world, and emphasise the need and ways to increase educational opportunities for healthcare professionals, persons living with dementia and their carers. Finally, the report will explore strategies for best use of the new drugs.

We are thus cautiously optimistic that components of the WHO Action area 4 will be met, but we already foresee new challenges and opportunities for global care of dementia.

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## People with dementia paying a high price in the pandemic

The COVID-19 pandemic has acted as an extreme stress test for health and social care systems, with people with dementia and their carers paying a very high price. The pandemic has made it clear that the pro-dementia policy and practice advances of the past ten years have very shallow roots. Despite good intentions, little has truly changed in the fundamental values, attitudes, and beliefs of the health system, of politicians, and even of well-meaning and hard-pressed practitioners on the front lines faced with difficult decisions.

People with dementia both living in care homes and at home have had the highest mortality of any group, partly because of the frailty inherent in many with dementia.<sup>1</sup> However, it is also driven by the lives of people with dementia being accorded a lower value than the lives of those without dementia.<sup>2</sup> The Elizabethan Poor Law created the concept of the "deserving poor", whose needs should be met, and the "undeserving poor", whose needs could be ignored. When presented with the COVID-19 crisis the system reverted reflexively to a mindset of, often unconscious, discrimination against older adults and people with dementia, creating a class of the "undeserving ill". In this time of crisis, they could be deprioritised from treatment, not only for COVID-19 but for other conditions requiring hospital care.

The dementia diagnostic rate in England has dropped below target since April 2020, hitting a five-year low in January 2022.<sup>3</sup> Another mark of quality, the rate of prescription of potentially harmful antipsychotic medication, is conversely at a five-year high, with prescription rates in March, April, and May 2020 substantially higher than in the same months in 2018.<sup>4</sup>

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**"The pandemic has made it clear that the pro-dementia policy and practice advances of the past ten years have very shallow roots."**

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Half a decade of hard-won improvement in dementia care has been swept away by the pandemic. There is need to remake the case for dementia and ensure that as we rebuild, we build in dementia as a priority and ensure that there is equity in service provision for young and old, for those who have cognitive impairment and those who do not.

*Sube Banerjee, executive dean and professor of dementia, Faculty of Health, University of Plymouth, United Kingdom*

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<sup>1</sup> Burns, A. and Howard, R. (2021), COVID-19 and dementia: A deadly combination. *Int J Geriatr Psychiatry*, 36: 1120-1121. <https://doi.org/10.1002/gps.5551>.

<sup>2</sup> <https://www.cbc.ca/news/opinion/opinion-dementia-long-term-care-homes-1.5871981>

<sup>3</sup> <https://digital.nhs.uk/data-and-information/publications/statistical/recorded-dementia-diagnoses/january-2022>

<sup>4</sup> Howard R, Burns A, Schneider L (2020). Antipsychotic prescribing to people with dementia during COVID-19. *The Lancet Neurology*, 19, 11, 892



## TADA Chinese Taipei STAGE 5A

Over 300,000 people are estimated to be living with dementia and this number is expected to increase in the future. It is worth noting that more than 70% of them have been diagnosed with very mild dementia or mild dementia, and as such the majority continue to live in their communities with informal caregivers at home. In order to meet the needs of people with dementia and their families, the government has included dementia care service in its "Dementia Prevention and Care policy and Action Plan 2.0" plan.

Integrated Dementia Care Centres (IDCC) and Support Centres for People with Dementia and their Families (SPDF) are two important resources in the plan, established to provide post-diagnosis support for people with dementia and their caregivers. More research should be done to evaluate the effect of IDCCs and SPDFs.

people with dementia through different phases of illness, give care advice and caregiver consultations – albeit only for the span of one year. If patients and their families need further support, they must apply once again to receive these services.

In parallel with these governmental programmes, TADA has been running a dementia advisory group (TDAG) since April 2019, with the purpose of empowering people living with dementia. Currently, this group is composed of five people with dementia and three caregivers, but has already become a strong source of support for its members, and will hopefully expand in time. Members of TDAG share their experiences, raise awareness, and advocate for themselves, by themselves.

Through the discussions held in TDAG's monthly meetings, TADA has been better able to include the voices of people living with dementia in its interactions with the government. Furthermore, TDAG's involvement in activities to eliminate stigma and improve the public's understanding of the disease has led its members to speak at events in libraries, district public health centres and regional dementia associations in sixteen cities. Over the past two years, more and more people with dementia have begun participating in these activities.

**"By practicing meaningful engagement and self-advocacy, TDAG reminds people with dementia that they are still capable of representing themselves, interacting with others and contributing to society."**

There are now more than 500 SPDFs accessible to people with dementia and their caregivers, providing family support services, caregiver education, and diversified cognitive interventions for people with dementia. Meanwhile, IDCCs not only dispense medical care, but accompany

By practicing meaningful engagement and self-advocacy, TDAG reminds people with dementia that they are still capable of representing themselves, interacting with others and contributing to society. Moreover, they encourage more people living with dementia to stand up and speak out for themselves.

TADA



## Sweden STAGE 5A

"Our opportunity to live longer than ever is a privilege made possible by science, knowledge and information. However, ensuring high-quality elderly and dementia care for all in our ageing communities is going to require even more research, as well as new ideas and innovative solutions such as yours."

Those were the words of Her Majesty Queen Silvia of Sweden, during the Queen Silvia Nursing Award 2021 grand ceremony in the royal palace in Stockholm on 21 September 2021.

The Queen Silvia Nursing Award is an annual award established by Swedish Care International (SCI) and the Forum for Elderly Care in 2012, with the expressed mission to motivate talent to explore a career within nursing, particularly in older person and dementia care. The award addresses rapid population ageing and the lack of skilled nurses to care for older patients – many of whom are living with multiple health conditions including dementia, which causes enormous distress, cost and pain for patients, families and loved ones alike.

This proportion of older people is projected to exceed that of children for the very first time in 2047. If the 20<sup>th</sup> century was a period known for global population growth, then this century will be known for population ageing. The Queen Silvia Nursing Award is dedicated to addressing the impact and needs of the world's elderly population, including people living with dementia, by highlighting the opportunities for nursing talent in this area.

This year marks a decade of the Queen Silvia Nursing Award, and the prize is currently available in seven countries. In the past ten years, applicants for the award have submitted a wide range of ideas or innovations to improve outcomes for older patients and people with dementia. Regardless of their whereabouts, applicants focus on leveraging their learnings from nursing school or best practice from healthcare environments to contribute to this specific patient profile – a profile that is only set to become more recurrent worldwide.

*Sophie Lu-Axelsson, CEO, Swedish Care International*



Her Majesty Queen Silvia of Sweden with the 2020 winners of the Queen Silvia Nursing Award (Swedish Care International).



## Germany STAGE 5B

A diagnosis of dementia usually comes as a shock to the 1.6 million people affected in Germany and their families, whether it is expected or not. In addition to reducing the risk of dementia, sport can have a positive effect on the course of the disease in its early stages – and for people with dementia, it can also mean an increase in their quality of life.

In October 2020, the German Olympic Sports Confederation (DOSB) started the project "Sport moves people with dementia" in cooperation with the German Alzheimer Association. Amid delays due to COVID-19, four DOSB member organisations have started practical field work for people with dementia. DOSB and DALzG have used the pandemic as an opportunity to hold four online courses for more than 250 trainers, designed to inform them about dementia, how to communicate with people with dementia in a proper way, and how to organise sport activities for them.

The German Alzheimer Association advises on all aspects of the issue and is involved in the creation of a material box provided to trainers and in the development of courses. The project is funded by the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth.

In the federal state of Nordrhein-Westfalen, some clubs have adopted a cognitive sport model designed by the German Sport University Cologne. The German Gymnastics Federation will meanwhile address clubs in Frankfurt to raise awareness of dementia and support people with dementia's continued engagement in sports clubs. The German centre for neurodegenerative diseases (DZNE) Greifswald has also joined the project for scientific evaluation.

Not all of these ideas are easy to perform. For example, the situation of sport clubs in rural areas is different from city clubs. But this cooperation shows that sport is an important tool within the implementation of the national dementia strategy. To conclude: A wonderful project where volunteers of the sport and the dementia movement have come together to improve participation, quality of life, and prevention through movement and enjoyable activities for people with dementia and their caregivers.

*Sabine Jansen, former managing director, Deutsche Alzheimer Gesellschaft, and Anna Gausmann, coordinator, Initiative Demenz Partner*



Table tennis for people with dementia at VfL Fortuna Marzahn sports club (Courtesy of Eleonore Pietereck).

## Impact of COVID-19 continues

While vaccines have brought some hope and relief, the pandemic continues to have an impact on people with dementia two years on – whether on diagnosis or the implementation of programmes. A global survey of Alzheimer and dementia associations in February 2022 highlights how COVID-19 is currently affecting the situation in their respective countries – and sheds a light on continuing disparities regarding the impact of the pandemic, particularly between high-, middle- and low-income countries.

### New Zealand – Stage 3C



The strain is definitely showing two years into this pandemic, with carers in particular tired after having few if any breaks – partly due to services been withdrawn during lockdowns and partly due to growing nervousness about using services and leaving the house. Another significant impact has been on funding for local Alzheimer's organisations, many of which are now struggling and forced to limit services to fit within the available funding.

### Macau – Stage 5A



The Macau Special Administrative Region is a tourist city, meaning government revenue has dropped sharply because of COVID-19, which has affected the funding for Macau Alzheimer's Disease Association (MADA).

### Seychelles – Stages 2A and 2E



Post-COVID-19 care, and residual symptoms after catching the virus are more difficult to identify and manage among dementia patients. Vaccination for patients living with dementia has been warranted by the government, with a fast track for those patients at vaccination centres.

### Kenya – Stages 3A, 3B, 3D



In 2021 the focus was on initially on COVID-19, but this changed towards the end of 2021, and we have started seeing the issue of dementia being addressed.

### Germany – Stage 5B



Topics related to the pandemic are increasingly playing a role in the consultations- in particular contact restrictions and thus loneliness, limited support offers and thus excessive demand, as well as questions about vaccination. The need for advice is very great.

### Jordan – Stage 2D



The Ministry of Health is facing too many challenges, and unfortunately dementia still isn't a priority in Jordan – neither before nor during the pandemic.

### Yemen – Stage 2B



Vaccination for COVID-19 is still not available for the public in the capital Sana'a and in northern Yemen as yet.

### Greece – Stage 5B



During 2021 the majority of services provided in people living with dementia, as well as their caregivers, were digitalised and therefore, they received relevant support according to their needs.

### Japan – Stage 5B



Due to the shortage of hospital beds and medical staff, it is more difficult than usual for people living with dementia to be admitted into healthcare facilities. Medical home visits have started, but don't meet the high demand.

### Zimbabwe – Stage 2A



COVID-19 has and continues to hamper development in other fields of health in a struggling economy where the health sector is very seriously underfunded. There has been no further progress with the government in the past year regarding a dementia plan, as COVID-19 restrictions and changes of personnel in the department of Mental Health have stalled all previous communications.

### Belgium – Stage 2B



Passing on information about the virus to people with dementia is difficult, as it has to be repeated, and it is also the cause of anxiety.

### Malta – Stage 4A



With respect to individuals with dementia, the situation has returned to pre-COVID-19 times with service provision back to normality. At time of writing, the extra majority of old adults (including individuals living with dementia) received the vaccine booster dose.

### Morocco – Stage 1



Delays in diagnosis of the disease are significant and patient care is less consistent.

### Sri Lanka – Stage 2E



Misinformation on vaccinating people living with dementia is minimal and almost all senior citizens are fully vaccinated. Older adults have started to move around freely and enjoy more social contact with family and friends.

### Argentina – Stage 2B



The pandemic has resulted in a novel and technology-dependent healthcare system transition that is not without its difficulties for some of our elderly patients, many of whom are who are alone in their homes without adequate access to the system.

### Brazil – Stage 3B



The closure of offices in 2021 reduced face-to-face support available to people living with dementia and their carers. Inequities in Brazil limited access to remote and online tools to those with access to technology.

### Uganda – Stage 2B



In the absence of awareness campaigns and other measures specifically targeting the elderly, vaccination uptake amongst the older population has been very poor, with only 5.2% having received a first dose as of June 2021.

### Cuba – Stages 4F and 5A



COVID-19 has meant a delay in the implementation of the national dementia plan, given the need to prioritise vaccination and other measures to mitigate the pandemic.

## Key points



The effects of COVID-19 continue to reverberate across the fields of dementia diagnosis and post-diagnosis support, although opportunities for more online or virtual services have emerged from the pandemic. Navigating the complexities of life after a dementia diagnosis can be a deeply challenging task requiring extensive networks of person-centred support based on a thorough understanding of dementia itself and the individuals affected by the condition. Post-diagnosis models will be explored in the World Alzheimer Report 2022, including treatment, care and support.

# 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.**

**The wellbeing of people living with dementia continues to rely overwhelmingly on informal carers – 70% of whom are women – who are forecast to provide unpaid care equivalent to 65 million full-time jobs by 2030.<sup>1</sup> Far too often, informal carers lack access to the right resources to provide better support to people with dementia and to receive support for themselves. According to Global Dementia Observatory (GDO) data, most support for carers programmes occur in high-income countries, despite a majority of informal carers living in low- and middle-income countries. Even within high-income countries, access to these services can vary based on social or geographical circumstances, as noted by Professor Dame Louise Robinson in her essay in this chapter. Care professionals, meanwhile, do not always receive specialised dementia training or guidance, affecting their ability to carry out their duties in an informed and considerate way.**

As seen in this chapter's case studies, efforts are being made to palliate these gaps, including through online resources and collaborative cross-border initiatives. However, these disparities will persist as long as the issue does not receive a sustained, committed response from governments. ADI urges states to rectify this situation through robust national dementia plans that account for dementia's effects, not only on the people living with the condition, but on their families and the communities in which they live.

### iSupport

Caring for someone living with dementia can have a significant emotional and psychological impact on carers, friends and family. As a consequence, WHO developed the iSupport training programme to help improve the physical and mental wellbeing of carers to those living with dementia. iSupport is a self-help training programme for carers of people with dementia, providing practical support messages and tips through a virtual course, posters, videos and Q&As. iSupport Lite complements the generic version of iSupport (available as a hardcopy manual and e-training).

As of August 2021, iSupport has been adapted to 31 countries and 27 languages, with a number of ADI member associations partaking in this work, such as the Alzheimer's Disease Association of the Philippines (ADAP). If you want to adapt iSupport for your country, please contact [whodementia@who.int](mailto:whodementia@who.int).



<sup>1</sup> Alzheimer's Disease International, World Alzheimer Report 2018. The state of the art of dementia research: New frontiers. 2018, Alzheimer's Disease International: London.

# ADI Accreditation Programme

The ADI Accreditation programme<sup>1</sup> was launched in December 2020, aiming to support the improvement of care for people with dementia and reduce the variation in the quality of care provided. Our approach is to achieve the global standards of programmes and apply culturally appropriate context to improve global dementia care quality.

We establish standards in knowledge and skills that the participants – whether carers, their trainers, and providers of training programmes – would need to adhere to while providing care services to people with dementia in order to be accredited by ADI. Accreditation means that their programmes, training, and learning activities have reached the required ADI global standards.

The uniqueness of ADI Accreditation comes from the fact that we make sure our accreditees are not only academically educated through comprehensive theory modules and programmes, but also practically involved with people living with dementia, person-centred care, civil society, communities and local organisations.

The Kiang Wu Nursing College of Macau was the first organisation to receive an ADI certificate of accreditation in January 2022. Since then, Qatar's Hamad International Training Centre (HITC) and Silverado, San Diego in the United States have begun the accreditation process.

ADI is proud to provide a programme that ensures high-quality carer training around the world, which supports Action areas 4 and 5 of the WHO Global action plan on dementia.



<sup>1</sup> <https://www.alzint.org/what-we-do/accreditation/>

## Primary care-based post-diagnostic dementia care and support for families in England and Wales: The PriDem programme

Following the WHO's recognition of dementia as a global public health issue, an increasing number of countries have developed or rejuvenated their national dementia policies and plans.<sup>1</sup> England has shown an impressive policy commitment to improving the lives of families living with dementia, starting in 2009 with a National Dementia Strategy,<sup>2</sup> followed by a unique Prime Minister's National Dementia Challenge, "an unprecedented programme of action to deliver sustained improvements in health and care, create dementia friendly communities and boost dementia research".<sup>3,4</sup>

The prime minister at the time, David Cameron, stated that he wanted England to be "the best in the world for dementia care and support... and to undertake research into dementia and other neurodegenerative diseases" by 2020. Reports have shown that England had indeed achieved success by 2020, topping a "European league table" in terms of commitment to dementia policy and research (assessed by the number of open clinical research trials).

Unfortunately, this is not the case regarding the availability of care and support services for people with dementia and their families.<sup>5</sup> Why is that so, in a country with a strong policy track record, evidence-based clinical guidance on dementia care<sup>6,7</sup> and a national Dementia Well Pathway to inform service provision for dementia prevention, diagnosis, and care?<sup>8</sup>

In 2018, the Alzheimer Society in England funded a programme of research aimed at mapping, critically reviewing, then improving the quantity and quality

of dementia care and support available to families living with dementia. We found that there were varied interpretation of the meaning and content of post-diagnostic support. In 2016, ADI defined post-diagnostic dementia support as "a system of holistic, integrated continuing care in the context of declining function and increasing needs of family carers".<sup>9</sup> While some professionals utilised the ADI definition, others considered it to comprise one or two meetings within the first year from diagnosis.<sup>10</sup>

Our e-survey to service commissioners in England also found considerable geographical inequalities in services, with support often concentrated at the point of diagnosis and heavily focussed on information provision.<sup>11</sup> Sustainability was a key challenge; lack of long-term funding led to an unacceptable fragility of care provision, with half of the respondents forced to review their services within the next year. Follow-up interviews with service providers a year after the COVID-19 pandemic began unsurprisingly revealed a negative impact on the provision of post-diagnostic support, leading to reduced access to services for many people with dementia and their families, thus potentially widening existing inequalities.<sup>12</sup> In primary care, general practitioners are financially rewarded for undertaking an annual care review of people with dementia on their practice list, but there is little guidance as to the nature and content of this service, nor what people with dementia and their families want from such a review.

Within this system of inequality and fragility, we nonetheless also found a range of good quality, sustainable services (primary and specialist care-led)

- 1 Alzheimer Europe. *National Dementia Strategies. A snapshot of the status of National Dementia Strategies around Europe*. 2021 14;7.2021; Available from: <https://www.alzheimer-europe.org/Policy/National-Dementia-Strategies>.
- 2 Department of Health. *Living Well with Dementia: A National Strategy*. 2009, Department of Health: London.
- 3 Department of Health. *The prime minister's challenge on dementia. Delivering major improvements in dementia care and research by 2015*. 2012, Department of Health: London.
- 4 Department of Health. *Prime Minister's challenge on dementia 2020*. 2015.
- 5 Alzheimer Europe. *European Dementia Monitor 2020. Comparing and benchmarking national dementia strategies and policies*. 2020, Alzheimer Europe: Luxembourg.
- 6 NICE. *Dementia: assessment, management and support for people living with dementia and their carers*. NICE guideline NG97. 2018.
- 7 NICE. *Dementia: Supporting people with dementia and their carers in health and social care*. 2006.
- 8 NHS England. *The Well Pathway for Dementia*. 2016.
- 9 Alzheimer's Disease International. *World Alzheimer Report 2016. Improving healthcare for people with dementia*. 2016, Alzheimer's Disease International: London.
- 10 Wheatley, A., et al. *Task-shifted approaches to post diagnostic dementia support: a qualitative study exploring professional views and experiences*. *BMJ Open*, 2020. 10: p. e3040348.
- 11 Frost, R., et al. *Mapping post diagnostic dementia care in England: an e-survey*. *Journal of Integrated Care*, 2020.
- 12 Wheatley, A., M. Poole, and L. Robinson. *Changes to postdiagnostic dementia support in England and Wales during the COVID-19 pandemic: a qualitative study*. *BMJ Open*, 2022. 12(2): p. e059437.

delivering integrated care to people living with dementia and their families. There was no one perfect model, but in-depth analysis of data from six of these sites revealed a set of "core components of post diagnostic care".<sup>13</sup> These components included evidence-based specific interventions but also key processes, such as having a named point of contact and providing ongoing, integrated support from diagnosis through to end of life.

dementia care and support which is now being implemented and evaluated in usual care. Our intervention follows global recommendations to move dementia care to a task shifted, task-shared approach akin to that used in the management of other long-term conditions such as cancer and diabetes. Importantly, we co-developed our intervention with both people with dementia and their families and with the health and social care professionals responsible for delivering dementia care.<sup>17</sup>

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"In order to now move From Plan to Impact, we need to urgently focus on service implementation to ensure consistent, high-quality care and support for all families living with dementia regardless of personal, social or geographical circumstances."

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Our research programme has shown that despite considerable national effort in the areas of dementia policy and research in England, in order to now move From Plan to Impact, we need to urgently focus on service implementation to ensure consistent, high-quality care and support for all families living with dementia regardless of personal, social or geographical circumstances. We hope our research might also offer insights on a wider scale to address the global challenge of providing affordable and sustainable approaches to enable people and their families to live as well as possible with dementia.

We have combined this data, along with key findings from our systematic reviews<sup>14,15,16</sup> to develop a primary care-based model of post-diagnostic

*Professor Dame Louise Robinson, on behalf of the PriDem team*

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- <sup>13</sup> Bamford, C., et al., *Key components of post-diagnostic support for people with dementia and their carers: A qualitative study*. PLOS One, 2021. 16(12): p. e0260506.
  - <sup>14</sup> Frost, R., et al., *Effectiveness of different post-diagnostic dementia care models delivered by primary care: a systematic review*. British Journal of General Practice, 2020. 70(695): p. e434.
  - <sup>15</sup> Frost, R., et al., *What works in managing complex conditions in older people in primary and community care? A state-of-the-art review*. Health and Social Care in the Community, 2020. 28: p. 1915–1927.
  - <sup>16</sup> Frost, R., et al., *Implementing post diagnostic dementia care in primary care: a mixed-methods systematic review*. Aging & Mental Health, 2020: p. 1–14.
  - <sup>17</sup> Brunskill, G., et al., *How do we meaningfully engage stakeholders in developing a best practice approach to post-diagnostic dementia support?*. Journal of Dementia Care, 2022. 30(2): p. 24–27.



## Slovenia STAGES 3A and 3C

Spominčica participated in the Erasmus+ KA2/ SINCALA II project, which is developing and piloting a model of pedagogical interventions based on a family-focussed approach to dementia. The project aims to identify the strengths and vulnerabilities of all family members, address the challenges that might arise, and build individual and family resilience.

The educational tool "Listen to my story" – a narrative-based workshop – was tested in 2021 with informal carers of people with dementia in Estonia, Greece, Italy, Portugal and Slovenia. A functional relationship between carers and people with dementia is the key for a successful change in roles as the whole family adjusts to life after someone has been diagnosed.

People belonging to different age groups and with different kinship ties to the person with dementia can have varying experiences and perspective on care,

so it is necessary to take all of them into account to be able to provide comprehensive and effective support. It therefore made sense for us to include all kinds of informal caregivers – whether spouses, children or grandchildren – to participate.

The workshops in Slovenia were very well received, and some of the participants wanted to continue to hold meetings to exchange their views, experiences and stories. Spominčica is now organising weekly online meetings and facilitating these group discussion on relevant topics. We provide space to express emotions and thoughts, but also provide guidance, recommendations and best practices – all in order to build resilience, acceptance of change, and supporting personal growth for each individual carer.

*Dr. Špela Glušović Krivec, senior consultant, Spominčica, Slovenia*



## Yemen STAGE 2B

Under the slogan "Khadeega initiative for Awareness against Alzheimer", the nursing section students at the High Institute for Health Science in Sana'a, Yemen enthusiastically responded to a training on dementia care in March 2021, which was a resounding success. Thirty students participated in the three-day training, with others also expressing interest despite the course being at capacity.

Students learned that Alzheimer's disease is rapidly increasing worldwide, and that Yemen is not an exception. Many cases go unreported in the country due to lack of awareness and stigma, and students participated in a brainstorming exercise to come up with ways to mitigate misconceptions. The training, led by myself and a researcher in neurology, involved a preliminary assessment and final examination. Nineteen of the 30 students received a training course certificate after passing the final evaluation.

The High Institute for Health Science receives students from all over the country who come to study different health science sectors – however, it does not cover Alzheimer's disease and dementia in its health science syllabi. This educational project has highlighted the urgent need to advocate for the development of an Alzheimer syllabus in Yemen's healthcare institutes and medical schools.



Participants in the Khadeega initiative in March 2021 (Courtesy of YFAAD).

Equipping students with knowledge of Alzheimer and dementia care is crucial so they can themselves become educators in their own governorates and remote villages. Doing so will enable the creation of a professional Alzheimer workforce to serve the community as social workers and Admiral Nurses (dementia specialist nurses) who can raise awareness and reduce the burden on family caregivers.

The absence of a national dementia action plan also contributes to a dearth in guidance, support and care for people living with dementia and their families in Yemen.

*Amal Saif, founder, Yemen Foundation against Alzheimer Dementia (YFAAD)*

## Ireland STAGE 4A

## Kenya STAGES 3A and 3B

Dementia organisations in Ireland and Kenya worked together to develop and deliver a much-needed e-learning course for family carers of people living with dementia in Kenya. The four-week course *Insights into Dementia* was planned to be delivered between December 2020 and January 2021. However, participants requested extra time to further engage with materials so the course was extended to last seven weeks in total.

With seed funding from The Atlantic Institute, staff from The Alzheimer Society of Ireland (ASI) and Alzheimer's Disease Organisation Kenya (ADOK) worked together to adapt materials already used by ASI in their family carer training courses. These materials were happily shared with ADOK, ASI recognising that the needs of family carers of people with dementia are very similar around the world.

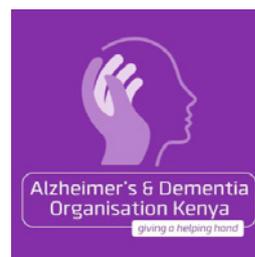
The Insights into Dementia e-learning course was delivered via weekly Zoom sessions to family carers of people living with dementia across Kenya. We also used WhatsApp to facilitate real-time discussion and questions. Post-course feedback from participants was very positive, with family carers enjoying hearing from other carers and gaining new understandings of various aspects of dementia. This was at least partly because course delivery was tailored to meet the expressed needs of Kenyan family carers.

We feel that this was an important initiative as our work aligned perfectly with Action Area 5 of the World Health Organization Global action plan on dementia. It's also consistent with three objectives from the United Nations Sustainable Development Goals: Goal 3 – Good Health and Wellbeing; Goal 4 – Quality Education; and Goal 17 – Partnerships for the Goals.

However, the project faced some challenges, including staff illness – which affected the number of staff working on the ground in Kenya – and unreliable



THE Alzheimer  
SOCIETY OF IRELAND



computer equipment, which caused some delays to the beginning of the project. These highlight the lack of resources and funding, especially for dementia care organisations in low- and middle-income countries.

This partnership had the potential to develop further, but sadly as yet no further funding has been accessed to prolong, deepen and extend our work. This is despite initial financial support from Atlantic Institute, strong interest from within Alzheimer's Disease International's Twinning Programme, and a very encouraging attendance at our launch event in September 2020. It begs the question to international funders; how can we make these types of partnerships sustainable in the future? Surely family carers right across the world deserve to join appropriate and user-tested e-learning courses that support them in their care tasks.

*Fergus Timmons, The Alzheimer Society of Ireland (ASI), Wambui Karanja, Senior Atlantic Fellow for Equity in Brain Health and Volunteer at Alzheimer's Disease Organisation Kenya (ADOK), and Elizabeth Mutunga, CEO, Alzheimer's Disease Organisation Kenya (ADOK)*

Key points



Informal carers bear the brunt of the responsibilities associated with dementia care, the impact of which is felt most acutely by women and those living in low- and middle-income countries. Care professionals by and large could also benefit from more specialised training when working with people with dementia, especially in areas where stigma remains high. Care needs to be coordinated with care pathways that are clear and accessible to all, regardless of their income or where they live.

Efforts to provide support and resources to carers continue to be led by Alzheimer's and dementia associations globally, especially in countries where national dementia plans are not yet implemented.

# 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.**

**Information systems, including systematic monitoring and evaluation of the respective data, are a core component of a national dementia plan or strategy, improving the accessibility and coordination of care and support for those living with dementia. Monitoring is also important for determining the effectiveness of current risk reduction policy or adapting current policy to benefit the needs of a population.**

Despite the importance of information systems for dementia, the recent WHO Global status report found that fewer than 31% of member states who contribute to the Global dementia observatory, monitor the numbers of those living with dementia, equating to just 19 member states. A sharper focus and willingness to invest in these information systems must occur if we are to stand a chance of reaching the target of 94 member states routinely collecting a core set of dementia indicators through their national health and social information systems every two years by 2025. The Global Dementia observatory is an important mechanism for monitoring holding member states accountable across all action areas of the Global action plan on the public response to dementia 2017–2025, with the next round of GDO data collection planned to commence before the end of the year.

ADI CEO Paola Barbarino says: *"We must never underestimate the importance of sharing information on dementia at all levels. From knowing how many individuals with dementia live in a country, to understanding the distribution of services and care on the territory, to making research data widely available to avoid duplication and make funding go further – data is critical to all we do. There have been promising steps forward in this area, but a lot still needs to be done."*

Despite the challenges, there are a number of highly successful information systems for dementia already in operation. For instance, Swedish registry system

Sydem has been operating since 2007, with all memory clinics in Sweden contributing data to the registry. NorCog, the Norwegian registry, has been successfully in place since 2013. More recently, the Australian Dementia network registry (ADneT) has been trialled, aiming to collect data on people living with dementia or mild cognitive impairment across the country. We have also seen some bold attempts at implementing registries in Latin America, such as the Puerto Rico Alzheimer's Registry (PRAR), which unfortunately has faced hurdles due to insufficient funding and governmental changes.

Knowledge sharing is also a key component of this action area as we move forward, and several organisations seem to be rising to the challenge, not least of all the WHO. In May 2021, the WHO launched its new Global Dementia Observatory Knowledge Exchange (GDO KE) platform. The ethos of the initiative centres around acting as a free shared repository for policies, guidelines and best practices to support the implementation of the WHO global action plan.

The importance of effective information systems for dementia has been championed by civil society and research institutions alike. The Alzheimer's Disease Data Initiative (ADDI) has striven to support bold and innovate research through its cloud-based platform, which has already been utilised by 2,400 researchers despite only being launched a year and a half ago. The community spirit that surrounds their platform centres on the belief that we cannot solve problems by working in silos. The Davos Alzheimer's Collaborative (DAC) has meanwhile collaborated on a number of projects to expedite progress in treatment breakthroughs, screening and health system preparedness, with an important focus on those living with dementia in low- and middle-income countries.

## Supporting mutual learning and knowledge sharing at global level: The Global Dementia Observatory Knowledge Exchange Platform

In May 2021, the World Health Organization (WHO) launched its new Global Dementia Observatory Knowledge Exchange (GDO KE) Platform in order to support the implementation of the global dementia action plan and enhances countries' responses to dementia by providing a space for stakeholders to share resources (e.g., policies, guidelines and examples of good practice) available at no cost. It supplements the GDO data portal, which collates and disseminates data from member states on 35 key dementia indicators to support evidence-based service planning and strengthening of policies as well as health and social care systems.

All resources are submitted by users of the platform or members of the general public. A comprehensive review process consisting of a panel of peer reviewers, focus groups of people with lived experience of dementia and the WHO secretariat ensure that selected resources meet quality and good practice criteria.

The peer-review network is a voluntary global group consisting of 79 dementia experts from 34 countries across all WHO regions, including academics, clinicians, policy makers and carers. Peer-reviewers share a broad range of expertise covering the seven action areas of the global dementia action plan.

Eight people with lived experience of dementia are actively involved in the review process through the GDO KE focus groups to ensure that shared resources would

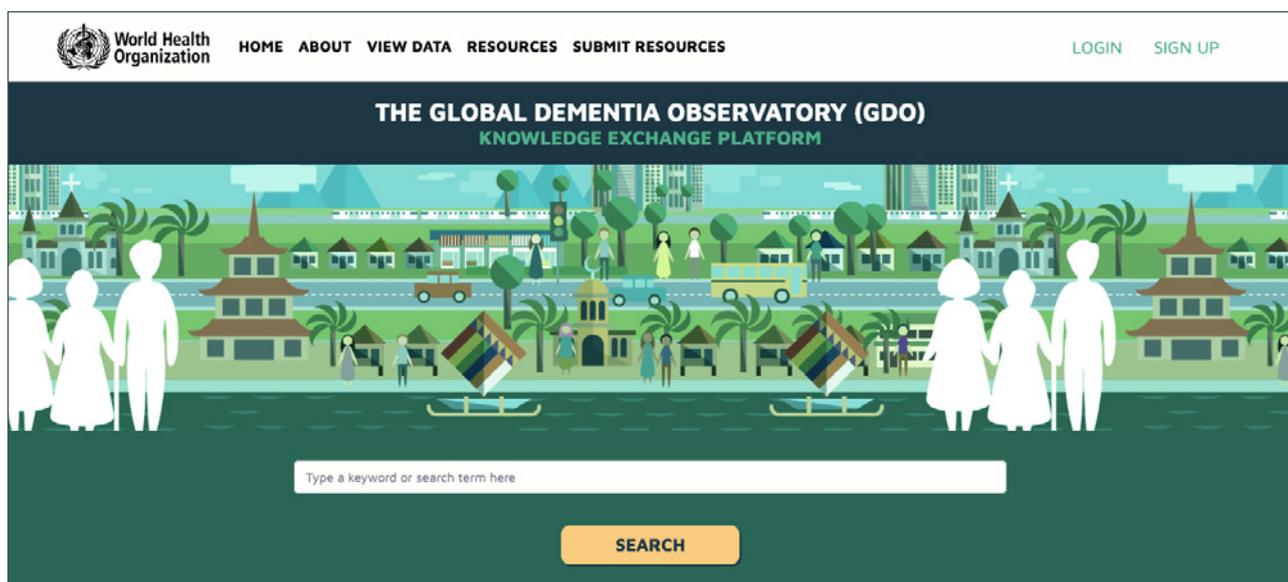
likely make a difference to the lives of people with dementia and their carers if implemented. Current focus group members come from Canada, Germany, Ireland, New Zealand, Singapore and the United Kingdom.

To promote active exchange about resources, the feedback provided by peer-reviewers and the focus groups is publicly available on the platform. Users of the platform are also invited to leave comments and rate resources.<sup>1</sup>

Resources in all languages are submitted to the platform. To support the review process, we need more language diversity among peer-reviewers and focus groups. We encourage anyone who is interested in joining the peer-review network to express their interest by completing a registration form.<sup>2</sup> If you are interested in joining one of the GDO KE focus groups, please email [whodementia@who.int](mailto:whodementia@who.int).

Sixty-seven good practice examples from 16 countries, covering all seven action areas of the global dementia action plan, are currently featured on the platform. WHO is calling for more submissions of resources for the platform. We are looking for a wide range of geographical, language, cultural, and contextual diversity. We encourage all stakeholders to share resources by completing a submission form.<sup>3</sup>

*Brain Health Unit, World Health Organization*



- 1 Become a user of the Platform: <https://globaldementia.org/en/register>
- 2 Peer-review network registration form: <https://extranet.who.int/dataformv3/456967?lang=en>
- 3 Resource submission form: <https://extranet.who.int/dataformv3/895286?lang=en>

## Helping support a global, open data community

Before the Alzheimer's Disease Data Initiative (ADDI) launched a year and a half ago, we heard from the dementia community that to make meaningful progress in finding new diagnostics, therapies, and cures, we must remove silos and fully commit to a global approach. This certainly includes the silos and approach related to data sharing. We know that we cannot rid the world of this dark disease if the brightest minds are working alone.

This is ADDI's aim – to help support bold and innovative efforts of researchers across disciplines, institutions, countries, and cultures.

More than 2,400 researchers worldwide have used ADDI's cloud-based platform, the AD Workbench, to discover, access, and analyse the more than 35 (and growing) available datasets from academic institutions and industry organisations committed to open data. Many of these have come from existing data sharing platforms that have agreed to make datasets interoperable with the AD Workbench. This allows more users to get seamless access to more data.

To support those who will contribute or use data, ADDI continues to add new resources. This includes supporting the development of and providing access to data harmonisation and curation tools. After all, datasets from various sources are only as good as the ability of various users to combine and analyse them. For those who may have concerns about the security of their data, ADDI offers federated access so that contributed data can still reside on their premises, as well as centralised data sharing for those who are more comfortable with that option. By securely bringing together harmonised and curated

datasets from all over the world, we hope to create opportunities that facilitate innovative secondary analysis.

Offering data that is easy to use is only part of what we need to do to enable the creative use of existing data. Researchers with limited computing resources may need further support. ADDI's offerings range from providing free and secure computing space to federated data sharing appliance tools. We also look to the data community to identify resources that they need. Recently, an open request resulted in ADDI supporting and ultimately making available a data exploration platform and a genome-wide association study (GWAS) analysis tool. ADDI looks forward to promoting and facilitating more "bottom-up" solutions.

The dementia community recognises that this is a complex disease that requires novel approaches. ADDI encourages endeavours that go beyond traditional perspectives. Studies that look at digital and voice-recording data as a diagnostic tool for dementia may not have seemed viable 20 years ago, but might yield some intriguing insights today. Unlike traditional clinical data, digital and voice-recording data is easier and less expensive to collect, which could become a key means to understanding and diagnosing dementia, especially in low- and middle-income countries.

This effort and the work by thousands of others around the globe cannot be done alone. ADDI's goal is to help support the dementia community, so together we can fundamentally transform this research and move the world closer to meaningful diagnostics, treatments, and cures.

*By Tetsuyuki Maruyama, Ph.D., executive director, Alzheimer's Disease Data Initiative*

## Davos Alzheimer's Collaborative

As the global population ages, the battle to defeat Alzheimer takes on greater urgency. There is broad agreement on how to make measurable progress: We need breakthrough therapies that can slow or reverse the disease's progression, and we need healthcare systems that can screen people at risk, diagnose the disease, and deliver treatments on a massive scale.

The Davos Alzheimer's Collaborative (DAC) was created to address these challenges. We are uniting leading organisations worldwide to build an innovation ecosystem that will accelerate treatment breakthroughs, develop, and scale promising solutions, and equip healthcare systems to bring an end to this terrible disease. To achieve these goals, we have

launched three global initiatives backed by a planned \$700 million investment.

First, DAC's Global Cohorts Program. Nearly all genetic analysis of Alzheimer has been conducted on white populations of Western European origin. DAC is building an unprecedented global cohort of one million people across dozens of countries who reflect the diversity of the disease. This will enable scientists and researchers to gain a better understanding of the disease, discover new biomarkers and identify new targets for drug development. Argentina and Malaysia are already generating new data. Tanzania, Kenya, Singapore, China, and others have committed.

Second, DAC's Global Clinical Trails Network. Today, trials for Alzheimer treatments are slow, laborious, and expensive. We are creating a global network of trial sites and a trial-ready technology platform to support it – all aimed at enabling the rapid creation, enrolment, and operation of clinical trials.

Third, DAC's Healthcare System Preparedness Project. Future innovations will not be effective if healthcare systems are not prepared to deliver them. DAC is initially focussed on funding new approaches that increase rates of cognitive screening and early detection of cognitive impairment. The most promising are being incorporated into DAC Learning Labs, a network of governments and healthcare leaders, to share best practices that can be scaled globally.

Data drives scientific insight and discovery, which is why global data aggregation and information sharing forms the core of our work – and all three projects contribute different data. Through our initiatives, DAC is assembling the most robust data set for Alzheimer ever collected.

By partnering with the Alzheimer's Disease Data Initiative (ADDI), DAC aims to make this dataset accessible to

a global community of researchers through the AD Workbench, a secure cloud-based platform that enables researchers to discover, query, request, combine, and analyse data made accessible through a network of data repositories and contributors. This will attract scientists and entrepreneurs from around the world, giving them the ability to assemble teams, secure resources and launch projects. Researchers will have the ability to standardise and harmonise data across global cohorts, create analysable data sets and validate findings.

Alzheimer recognises no borders, so neither can our data or our solutions. By diversifying data to unlock breakthroughs, linking the best science to speed innovation, and preparing healthcare systems to deliver new treatments that enter the market, DAC is helping to mount a comprehensive global response to one of humanity's greatest challenges.

*Drew Holzapfel, Board Member and Secretariat, Davos Alzheimer's Collaborative, and Matt Clement, Director of Partnerships and Scientific Strategy, Alzheimer's Disease Data Initiative (ADDI)*

## World Dementia Council's Dementia Landscape project

At the G8 Dementia Summit in London in 2013, the international community made important commitments to advance the dementia cause. The World Dementia Council was established by the UK government after the summit to bring together global experts to report on the progress the international community was making and to make recommendations on how that could be accelerated. As part of that mission, the Council has been hosting the Dementia Landscape Project over the last year. The project has brought together over 500 global leaders to reflect on where we are and how we make progress.

The Council has held a series of 13 virtual dialogues on different themes reflecting the scope of the commitment the international community made in 2013, including: the development of biomarkers, care interventions, risk reduction models, clinical trials, ageing society, health system readiness, the impact of new technologies on care and research, dementia in low- and middle-income countries, psychosocial interventions, non-amyloid research, lived experience and on the perspective of early-career researchers. Alongside this, the Council has published a series of essay collections that have included contributions from governments, WHO, OECD and international leaders such as Bill Gates, as well as held a virtual research conference at the end of last year and an in-person conference that covered care and research at the Francis Crick Institute this March.

So, what does the Dementia Landscape look like? The Council will report later this year, but if you had to summarise the input of the global leaders in the various meetings, it would be one of cautious optimism. Certainly, in research there is progress; there is a better understanding of the basic science, and this is reflected in the treatment-development pipeline. There have been big advances made in the development of blood and digital biomarkers, which will have a big impact on research, trials and diagnosis. We are some way from these becoming a routine part of clinical practice, but the progress over the last few years has been impressive. Despite the many barriers, from regulatory to technical to cultural, data sharing has also improved – but given the importance of data to research, this is something that we as a community relentlessly focus on.

However, there are some who think this cautious optimism is misplaced, especially when it comes to care. There have been significant advancements in developing person-centred care models and in research into interventions to keep people well – whether in the community, in hospital and in care settings. Technology, as contributors to the Landscape project have highlighted, has huge potential here. But despite this, for too many people living with dementia today care is inadequate, fragmented, underfunded, informal and sporadic. As ADI has highlighted in many ways, the COVID-19 pandemic has worsened people's care experience.

Science is not going to solve this problem for governments – at least not over the next few decades! The first generation of disease-modifying treatments and new symptomatic treatments, which are desperately needed, will not remove the need for care. Societies are ageing, and how we finance ageing and how health and care systems are adapted to the ageing society is one of the big challenges we collectively face.

Alongside the need to improve the care bit of the health and care system, there are new challenges emerging for health systems, as biomarkers and treatments are developed. The capacity of health systems to deliver these to patients is going to be challenging. Sadly, the history of drug development is nationally and globally

one of unequal access to treatment. Health system readiness is rightly something international leaders are beginning to address, and prevention is going to be an important component of a holistic approach to reducing the impact of dementia.

We should be no more than cautiously optimistic – much more than that would be misplaced. Since the 2013 Dementia Summit, there has been progress, but as the Landscape project has highlighted if the trajectory is right the progress along the arc is too slow. We must do more.

*Lenny Shallcross, executive director, World Dementia Council*



## Puerto Rico STAGE 4F

The Puerto Rico Alzheimer's Registry (PRAR) was created in 1999 as part of the Department of Health Coordination Service Centre for People Affected by Alzheimer's Disease. Although the Centre has never been fully operational, the PRAR is being re-evaluated due to inaccuracies of the data reported since its implementation.

Unfortunately, the registry was never properly implemented due to several factors, including changes in government administrations and lack of funding. The Pan-American Health Organization's (PAHO) regional office in Puerto Rico has been funding some of the activities related to Alzheimer's awareness, as part of the PRAR, however, there has been no funding from the government.

The Alzheimer's disease ten-year action plan for Puerto Rico was developed in 2015 by the Puerto Rico Department of Health in coordination with PRAR. This plan is also being re-evaluated to become

operational. Currently, there is a working group consisting of government officials from the Health Department and other related agencies, academia and local organisations related to Alzheimer's disease in the hopes that Puerto Rico will at last have a funded national plan, and a fully operational PRAR. This can't come soon enough with an estimated 80,000 people living with Alzheimer's disease and other dementias in Puerto Rico, a figure forecast to increase to 105,000 by 2050, and with 21.3% of the population currently over 65 years of age

It is only through a properly funded plan that the benefits of a PRAR will actually be felt, which in itself should provide a stronger foundation for future support, analysis and research.

*Ana Gratacos Rodriguez, vice president of Asociación de Alzheimer de Puerto Rico, vice president of Alzheimer Iberoamérica AIB, director of Dementia Friends Puerto Rico*

### Key points



**Knowledge sharing is essential in order to collect data on incidence of dementia, treatment, and management and monitor best practices across the world. Making such information easily available is crucial to improving the accessibility and coordination of care and support for those living with dementia. While there are many success stories, information-sharing platforms and dementia registries can be underutilised. Willingness to invest in these information systems must occur if we are to stand a chance of reaching the Global plan's Action Area 6 targets.**

# Chapter 7

## Dementia research and innovation



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

**Five years into the Global action plan on dementia, we find that of all the seven action areas, dementia research and innovation lags furthest behind in reaching its goal. In its recent Global status report on the public health response to dementia, WHO confirmed that dementia research accounts for less than 1.5% of the total health research output across of WHO regions, and that only 23 of the 62 countries (37%) that have contributed data to the Global Dementia Observatory (GDO) have allocated funds specifically to dementia research. To make matters worse, ongoing fallout from the COVID-19 pandemic has impacted funding sources and caused dementia research to be deprioritised.**

But it is not all grim news. There have been pockets of progress over the past year across the dementia research continuum; from biomedical and pharmaceutical approaches all the way through to post-diagnostic care and collaborative research efforts.

In June 2021, the United States Food and Drug Administration (FDA) approved Biogen and Eisai's Aduhelm, the first new dementia drug treatment to reach the US market in almost 20 years, for use with patients with mild cognitive impairment or mild dementia stage of disease. Although many welcomed news of the new drug, its effectiveness, safety and cost were debated by others (Biogen reduced the cost of the drug by half in January 2022). At this time only one other country has approved Aduhelm, the United Arab Emirates.

To further complicate matters, in April 2022 the Centers for Medicare and Medicaid Services (CMS) – the federal United States agency that manages the Medicare programme and administers Medicaid and health insurance portability standards – finalised its Medicare coverage policy for monoclonal antibodies directed against amyloid for the treatment of Alzheimer's disease. The policy states that such therapies approved under the FDA's accelerated pathway, like Aduhelm, will only be covered when administered in eligible clinical trials. Many argue this could further restrict access to the treatment, particularly for ethnic minorities and lower-income groups who have historically been less likely to participate in clinical trials.

In a further development, Biogen announced in April its decision to withdraw its marketing authorisation application for Aduhelm to the European Medicines Association (EMA). However, the company has committed to a Phase IV study for Aduhelm as a post-marketing requirement of the FDA's accelerated approval. The study will enrol more than 1,300 people living with early Alzheimer's disease, with the primary completion date for the study expected to take approximately four years.

It is encouraging to see disease-modifying treatment developments from a number of other pharmaceutical companies, but it is essential that we retain commitment and enthusiasm to both DMT and symptomatic treatment research. The aspiration has to be for an evolution in precision-based treatments across the whole spectrum of dementia.

A key aspect of dementia research is a focus on innovation, not only in technology, but also in approaches to research and care itself. A growing emphasis is being placed on collaborative research that transcends the North-to-South, one-directional way of working. Instead, there is an increased recognition of innovation from the Global South. One such nascent initiative is being developed as a legacy of the Strengthening responses to dementia in developing countries (STRiDE) project. The STRiDE Network, to be formally launched in June 2022, will bring together a diverse group of researchers, Alzheimer and dementia associations, people living with dementia and their carers, and members of other NGOs, to increase collaboration and research that can have a positive impact on policy change.

Finally, in one example of increased funding for dementia research, the US government announced a \$289 million increase for Alzheimer's research funding, further detailed later in this chapter.

The following chapter highlights examples of advances made in dementia research funding, post-diagnostic care, technology and innovation, translational dementia research and policy impact. Most importantly, it emphasises the need for a multifaceted and collaborative approach to global dementia research.

## Reaching the target in dementia research and innovation: stakeholder participation

Increasing the global output of research on dementia can be considered under two perspectives: increasing the quantity of performed projects and published studies, or their quality. Although the two are not mutually exclusive, quality is as relevant as it is challenging.

Dementia research ranges from basic studies (e.g., examining how neurons or proteins behave in laboratory or in animal studies) to "clinical", "translational" ones. Translational studies are performed with the direct participation of patients, who generously allow researchers to use their clinical data or biological samples to devise or improve diagnostic or therapeutic tools. Often, patient participation in such studies is unidirectional: researchers define the scientific question and patients accept to provide the required information. However, translational research's aim of bringing clinical innovation to society implies more of a bidirectional interaction, and here lies a relevant opportunity to improve research quality.

Research funders for some pioneering projects solicit a greater involvement of patients and caregivers; not only to provide information, but also to contribute to designing and developing clinical research. This greater participation would increase the ability of research to detect patients' and caregivers' needs and values, and to generate more tailored results or products. Potential results would more clearly answer society's needs and be more effectively adopted in practice, approved by regulators, and reimbursed by health payers, since these institutions represent citizens' interest. This is the meaning of clinical innovation.

Are we, clinical and translational researchers, ready to incorporate a participatory approach in our research? Are best practices for participatory research in dementia established? Some projects are already working in this way, but to proceed more effectively in this direction, we may consider some specific questions and intermediate objectives.

Participation implies good communication and reciprocal understanding. Simple efforts can make our research clearer to patients and caregivers. We may provide reader-friendly summaries of our research in many contexts (laboratory websites; supplemental material of scientific publications; leaflets to disseminate in Alzheimer Cafés or other local contexts where patients and caregivers meet, in the region where

researchers work). Glossaries can explain many terms that are uncommon in everyday life. Basic language itself is a main challenge: research needs require us to be very direct in expressing our target concept, and technical terms can seem indelicate to the beneficiaries of our research. Initiatives on developing and improving a common language exist, both by patient advocates<sup>1</sup> and in research contexts.<sup>2</sup> Such efforts need further development, to include more of the terms required in research, and to generate more reciprocal understanding on their use. As researchers, we must be aware of the personal and emotional load conveyed by each term. At the same time, we should help patients and caregivers to understand that the direct, short and technical use of terms in scientific contexts is due to practical requirements, and does not convey any personal judgement or value. Only after this reciprocal understanding, can effective cooperation start.

Communicating with society means much more than including patients and caregivers. Citizens in general have their own fears about the concept of dementia. Scant communication with them can contribute to stigma. Society is also composed of institutions representing and defending the interest of citizens. Indeed, as translational researchers we should be able to communicate effectively with regulators or other institutions (e.g., health payers) or disciplines. We need to improve communication between researchers and the public in order to encourage co-development and a common language.

Adopting a participatory approach in translational research is a major challenge. This requires not only tools enabling direct involvement of different parties and institutions, but also mechanisms enabling and motivating researchers to modify their habitual methods to answer society's needs more directly.

However, improving communication on such aspects has great potential to incorporate society's values in research, provide more useful results, and reduce waste in producing studies that do not end up with improving patients' health. Improving research quality in this sense is as important as increasing the number of published studies.

*Dr Marina Boccardi, Deutsches Zentrum für Neurodegenerative Erkrankungen (DZNE), Bonn, Germany*

<sup>1</sup> Dementia Australia. Dementia language guidelines. Accessed December 30, 2020. <https://www.dementia.org.au/sites/default/files/resources/dementia-language-guidelines.pdf>

<sup>2</sup> Wolverson E, Dunn R, Moniz-Cook E, Gove D, Diaz-Ponce A. The language of behaviour changes in dementia: A mixed methods survey exploring the perspectives of people with dementia. *J Adv Nurs*. 2021;77(4):1992-2001. doi:10.1111/jan.14787

## Forward with Dementia: Co-designed resources promoting post-diagnostic support

COGNISANCE (Co-Designing Dementia Diagnosis And Post Diagnostic Care) is a five-country research collaboration involving Australia, Poland, the Netherlands, Canada and the United Kingdom. Our aim is to improve the communication of a dementia diagnosis and post-diagnostic support in the first year after diagnosis.

The project started with surveys and interviews or focus groups in every country with people living with dementia, carers and health and social care professionals. Data pooled across countries found that almost all participants were not satisfied with the amount of information and support they received after diagnosis. However, about two-thirds of people with dementia and carers said that the support they did receive was helpful to them. There were differences between countries in the unmet needs of people with dementia and carers, due in part to their varying health and social care systems.

Forward With Dementia is the result of our co-design work. All countries contributed to development of this product through multiple workshops where people with dementia, carers and professionals gave us ideas and feedback on the messaging, content and format.

Forward With Dementia promotes hope and wellbeing, uses everyday language, is practical and supports rehabilitation. User testing helped us ensure that the site is easy to use. Initial feedback has been positive.

Each country has run a campaign promoting post-diagnostic support and Forward With Dementia resources. These campaigns have differed depending on the dementia support systems, partnerships, and resources of each country. For instance, the Polish team

focused on raising public awareness and decreasing dementia stigma in Wroclaw, and the Netherlands team promoted to and through memory clinics and dementia case managers. We are now evaluating the impact of our campaigns and resources.

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“Forward With Dementia fills an informational gap and has encouraged improved practice in communicating a diagnosis and providing post-diagnostic supports.”

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Forward With Dementia fills an informational gap and has encouraged improved practice in communicating a diagnosis and providing post-diagnostic supports. However, our project had limited ability to directly reach people with dementia and carers who are not online, partly because of COVID-19 restrictions. Our team is acutely aware of the post-diagnostic service gaps that our resource cannot fill. We have been advocating for increased integrated post-diagnostic services, and upskilling of clinicians in communication and evidence-based treatments for dementia.

We are developing a playbook for others who might adapt our website and resources for their countries. Please contact us for more information.

*Lee-Fay Low and Professor Henry Brodaty, on behalf of the COGNISANCE team*

## Dementia: a complex health policy challenge needing more than simple answers

Health policy matters. It drives priorities and services; it enables funding to be directed to particular areas, and results in it being diverted from others. Health policy, in fields that are not yet optimised such as dementia, really matters. In these, the nudge of evidence is not enough to move the world of health and social care; policy, resource, will, and political and professional commitment are also needed.

The development and delivery of national and international dementia policy in the past ten years has therefore been of immense importance. It has raised public and professional awareness of dementia and identified dementia assessment, treatment, and care as a legitimate focus for health services. The message that dementia is serious, common, costly, under-diagnosed, and under-treated has moved from a niche view to the mainstream.

So far so good, but two shadows have fallen across the path to good quality care for all with dementia and their carers worldwide. The first is the COVID-19 pandemic, and the second is the desire to find simple answers to complex problems.

The latter is exemplified by the 2013 G8 summit's impact; their 13 broad commitments<sup>1</sup> were very quickly reduced to a single message: to increase dementia research to find a disease-modifying treatment by 2025. This "moon shot" approach has beguiling political attractiveness and creates a grand and attractive media message that is simple to communicate. There is also no doubt of the fundamental importance of basic biological and pharmacotherapeutic research to find the causes of, and treatments for, the illnesses that cause dementia.

However, everything else in the diagnosis, management, and care of people with dementia is potentially harmed when it becomes the only show in town. If the only priority is to find a "silver bullet", everything else that is needed, be it in research or practice, is overshadowed and it, in effect, becomes acceptable for policy makers and practitioners to do nothing other than to wait for the medication that makes it all go away. Its unintended consequence is to cast the whole world of psychological and social care, of public education, health promotion and prevention as of low or no priority. This oversimplification is therefore toxic and is likely to be part of the reason for the lack of real impact of the G8 initiative.<sup>2</sup>

What we learn from this is the need to resist the temptation of generating simple narratives.

The aphorism attributed to HL Menken that for every complex problem there is a simple solution that is "neat, plausible, and wrong"<sup>3</sup> is nowhere more apt than in the consideration of dementia. The challenges posed by dementia to all those affected are complex and there is not, and never will be, a single simple answer. If we allow policy that pretends there is, then we fail all those affected. The breadth of the impacts of dementia demonstrates just how much there is that we can do – that we are not doing – to improve the quality of life of people with dementia and those that care for them:

- We need balanced, inclusive dementia policy that validates psychosocial care and support and allows it to be prioritised and delivered.
- We need to better inform public and professionals, destigmatising dementia so they are aware of the signs of dementia to enable help-seeking and help-offering.
- We need clear messages so the public and professionals know what they should expect from services and what they will deliver.
- We need good quality diagnostic services that make timely diagnoses accurately, communicate them sensitively, and provide the treatment, care and support required.
- We need equitable access to clinical assessment and care that addresses the needs of underserved groups.
- We need post diagnostic care that is responsive to changes in needs, that makes families feel that they are not alone, and that enables the people to live their best lives.
- We need funding for research to improve dementia care, and service organisation and delivery in developed and in low- and middle-income economies.

What is more, we can act now. We do not need to wait for a medicine that makes dementia disappear or the magic biomarker that will make diagnoses for us. This is not a counsel of despair; it is an agenda for hope.

*Sube Banerjee, executive dean and professor of dementia, Faculty of Health, University of Plymouth, United Kingdom*

1 RDD/10495 G8 Dementia Summit declaration. <https://www.gov.uk/government/publications/g8-dementia-summit-agreements/g8-dementia-summit-declaration>

2 Wallace L, Walsh S, Brayne C (2021). The legacy of the 2013 G8 Dementia Summit: successes, challenges, and potential ways forward. *The Lancet Healthy Longevity*, 2, 8, e455 – e457. [https://doi.org/10.1016/S2666-7568\(21\)00145-8](https://doi.org/10.1016/S2666-7568(21)00145-8)

3 Menken HL (1920). *Prejudices: Second Series. Chapter 4: The Divine Afflatus*. Borzoi: Alfred A. Knopf, New York.

## Armenia STAGES 3A and 3B

Alzheimer's Care Armenia (ACA) and Expper Technologies sought to determine the efficacy of Robin the Robot as an emotional support for older adults living at a nursing home who had experienced isolation and loneliness during the COVID-19 pandemic. The Project, "Investigating the use of emotional support robot to improve the well-being of institutionalised older adults in Armenia", was conceptualised by Alzheimer's Care Armenia President, Dr. Jane Mahakian.

Robin the Robot is a semi-autonomous socially assistive robot, which interprets facial expressions and conversational contextual clues to understand emotions from individuals, and then uses artificial intelligence to guide its responses and develop a therapeutic interaction with patients. The project was made possible by a grant from the H. Hovnanian Family Foundation and endorsed by the Ministry of Labour and Social Affairs.

Over the course of three months in 2021, we recruited 40 adults residing in a nursing home in Armenia (average age 73.7, 42% female). Half of the participants were randomly assigned to the intervention group, which entailed interacting with the robot for one hour twice a week for 12 weeks with programming focussed on games, music and cognitive activities, in addition to other activities provided by the facility. The control group only participated in the facility's regular activities. Mood and cognitive testing were conducted for both groups at the beginning of the study and again at the end of 12 weeks.

The reception was positive among the intervention group, with subjective reports indicating high satisfaction with Robin the Robot. Participants in the intervention group achieved an improved performance on the Montreal Cognitive Assessment Test (20.8 to 24.1,  $p = 0.0023$ ). However, no significant difference was noted with the Geriatric Anxiety Test, Geriatric Depression Scale, or I-PANAS-SF. The control group testing revealed no significant change in any of the measures.



A care home resident interacting with Robin the Robot in January 2022 (Courtesy of Alzheimer's Care Armenia).

Given the aging population in many countries, loneliness and isolation in old age are worldwide concerns, especially in times of challenging events such as the COVID-19 pandemic. This pilot study demonstrated the feasibility of using a socially assistive robot to alleviate isolation and loneliness in nursing homes to improve the cognitive functioning for those who interact with the robot. This project has shown the use of innovative therapies such as robotic interventions can be effective in making a positive difference in the lives of the older person.

*Dr. Jane L. Mahakian, founder and chairman of Alzheimer's Care Armenia*



## Scotland STAGE 4A

With the pandemic, we have experienced growth in digital connection that we didn't expect to see until 2030; families have been able to remain connected, share daily life, see their grandchildren, join groups and have fun with friends thanks to technology that has been essential for the health and resilience of Scotland.

For people living with dementia and their families, digital innovation was never really promoted as a priority. But in 2015 we changed that by launching our digital charter, a call to action for us all to work together to actively promote the use of technology in health and social care to benefit the increasing number of people living with dementia in Scotland and their families.

In partnership with Scottish Government, Alzheimer Scotland has been shaping the digital future for people living with dementia in Scotland and offering support through a variety of digital innovations.

In the last five years, we have developed innovative resources for people living with dementia and their families. Here are a few examples of Alzheimer Scotland's innovations:

### ADAM:

Families living with long-term health conditions can often benefit from the adoption of readily available commodity technologies that allow them greater choice and control in their lives. However, they often don't have the time or ability to research which products might best benefit people with dementia, and can end up wasting resources purchasing the wrong things.

Adam is a digital companion that support users in choosing the types of citizen technologies that will help people in a variety of ways, from a kettle to a smart hub.



*Looking out for you*

### Purple Alert:

Purple Alert is a free app to help find people with dementia if they are lost, designed by people living with dementia and carers, Alzheimer Scotland staff, Police Scotland, Social Work, Dementia Friends Scotland, Health and Social Care Partnerships and Telecare Services.

After successfully reaching our milestone of 10,000 downloads, Purple Alert has gone through a major design and functionality upgrade serving tailored content to users, depending on where they are in Scotland or when they use the app.

### Digital Dementia Advisors:

Digital dementia advisors are digital solutions-based experts offering consultations to families affected by dementia looking to adopt and integrate digital solutions in their homes. We have appointed one advisor in Edinburgh and we are just about to appoint a second. We have been inundated with referrals for our Edinburgh service, so we are in the process of setting up a similar service in Glasgow.

*Joyce Gray, deputy director for development,  
Alzheimer Scotland*



## USA STAGE 5B

In March 2022, the United States Congress approved a \$289 million increase for Alzheimer's research funding at the National Institutes of Health (NIH) for Fiscal Year 2022, bringing total Alzheimer's research funding for the year to nearly \$3.5 billion. There has been a sevenfold increase in the amount of Alzheimer's research funding in the last decade – much of which has been achieved through the strong bipartisan advocacy efforts of the Alzheimer's Association and the Alzheimer's Impact Movement (AIM), the Association's advocacy affiliate.

Direct advancements brought about from funding increases include progress in biomarker identification and testing in order to effectively diagnose and treat the disease. Specifically, 317 Alzheimer's-related clinical trials are being conducted, with the majority of these trials focussed on non-pharmacological interventions, such as diet, sleep, and social factors related to the disease, as well as the study of caregiving interventions and care coordination.

In addition to research funding for NIH, the US government is investing in the creation and expansion of an Alzheimer's public health infrastructure. Working with a bipartisan group in Congress, the Alzheimer's Association and AIM were instrumental in the development, introduction and passage of the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act. This year, the US Congress approved a 67% increase in funding for BOLD, bringing the total investment to \$25 million in Fiscal Year 2022.

This funding is supporting 23 public health agencies across the country to undertake public health efforts to address the Alzheimer's crisis. In addition, the Centres for Disease Control and Prevention (CDC) created and funded three Public Health Centers of Excellence, including a Centre on Dementia Risk Reduction at the US Alzheimer's Association. The other two centres focus on early detection of dementia and caregiving.

The increases in funding for both Alzheimer's research and the BOLD public health efforts would not have been possible without the work of Alzheimer's advocates throughout the United States, who sent over 40,000 emails and social media messages to their elected officials stressing the critical importance of these programmes and urging them to support the increased funding levels.

To lend credibility to the request of advocates, the Alzheimer's Association and AIM had previously persuaded Congress to pass the Alzheimer's Accountability Act. This law requires the NIH scientists to annually tell Congress how much funding they need to stay on a path to prevent and effectively treat Alzheimer's by 2025 – the goal of the National Alzheimer's Plan. By bypassing the usual budgetary process and hearing directly from scientists, Congress can know that what advocates are demanding is based on solid science and grounded in achieving the national goal.

*Jennifer Pollack, Director of Access Policy, and Courtney Veatch, Associate Director of Federal Affairs, Alzheimer's Association, USA*

## Thailand STAGE 4E

In April 2021, the National Research Council of Thailand granted funds to the Faculty of Medicine Ramathibodi Hospital, Mahidol University for the first year of a three-year research project to implement the World Health Organization's Integrated Care for Older People (ICOPE) guideline to generate service innovation for persons with dementia. Alzheimer's Disease and Related Disorder Association-Thailand (ARDA-T) is a key project partner.

The research consists of two sub-projects covering all ICOPE contents to explore the feasibility of using the guidance in the Thai context. The first sub-project focusses on creating a new service to support persons with dementia and their carers in the community. Some 120,000 elders from three study sites will take part, with their intrinsic capacity observed according to ICOPE recommendations. At the end of the first year, data should reveal how many elders might have cognitive decline and where they live. In the second year, local healthcare workers will interview them for more information, then use ICOPE frameworks to design a service that will truly serve their unmet needs. It is hoped the service will become sustainable in the third year.

The second sub-project is about using innovation and technology to improve services for the elderly.

The research will develop three applications (apps) that solve basic problems in dementia care in Thailand, including:

- **ICOPE data registry application:** To collect elder data according to the first sub-project.
- **Thai online dementia screening:** A tool to help with deciding whether to go see a doctor.
- **Thai dementia carer support website:** A one-stop trusted source of information and support for carers.

These three applications will be linked to the same central database and run on "The Elderly Care Service Platform", which will be a basis of data science development for dementia care in the second and third year.

The outcome of the research will be a standard tool to deliver dementia care service in Thai communities, which may be different from the original WHO ICOPE guidance. These results will also be shared to WHO as a feedback and recommendation.

*Peach Wattanavitukul, policy analyst, Faculty of Medicine Ramathibodi Hospital, Mahidol University, Bangkok, Thailand*

## STRiDE (Strengthening responses to dementia in developing countries)

In 2018, ADI embarked on the Strengthening responses to dementia in developing countries (STRiDE) project, a four-year endeavour 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, and Dementia Alliance International.

One of the unique features of STRiDE is that it drew expertise and experience from both researchers and civil society. The project recognised that for research to have sustainable impact, it needs to be translated into policy change – and equally, civil society needs data and evidence for their advocacy to lead to policy change. The resulting partnerships between the STRiDE country teams flourished over the four years of the project and yielded important insights that instigated policy change in several of the STRiDE countries.



Much has been written about STRiDE in previous From Plan to Impact reports, but as the project comes to a close, we asked colleagues from several of the STRiDE country teams to reflect on what they learned from taking part in the project and how it changed the way they work.



### Brazil STAGE 3B

The number of Brazilian scientific publications in the area of dementia is low and not many studies involve international institutions. Furthermore, including people living with dementia in service and research design is rare. The STRiDE project provided a great networking and capacity building for researchers and non-governmental organisations (NGOs) that help overcome some of those gaps.

The project was designed in such a way that public and patient experiences and expectations were put at the forefront, from the beginning and throughout. We believe that the inclusion of this unique understanding of dementia results in evidence that is culturally tailored to the social context and realities of Brazil. The involvement of a wide variety of stakeholders – such as journalists, lawyers, psychologists, educators, social workers, civil servants, people living with dementia, carers – helped guide the research and its impact.

A National Dementia Plan, approved by the Senate at the end of 2021, is now to be discussed by the Chamber of Deputies. The lessons learned from



National advisory group meeting on 5 April 2021.

STRiDE on how to best disseminate research, engage people and inform policymaking were the flagstones that helped us pave the way to the development of this NDP. We know that it is just the beginning of a longer process and we also know that the experience from STRiDE enables us as a team, and also as a country, to focus on targets that can be met, to set timeframes and to monitor its implementation.

*Elaine Mateus, STRiDE NGO lead in Brazil on behalf of the Federation of Brazilian Alzheimer's Associations (Febraz)*



## South Africa STAGES 2A and 2E

As part of the STRiDE research project, Alzheimer's South Africa (ASA) became involved in research in the field of dementia in 2018.

South Africa does not have a Dementia Plan and dementia is not a health priority in this country. The government is only prepared to take cognisance of and prioritise dementia when evidence gathered in South Africa, highlights the prevalence and need in this regard.

The STRiDE project enabled ASA to build capacity around using data and evidence for policy change. The study confirmed that dementia is a reality in South Africa and that there are not sufficient health and social care facilities available to address the needs of people living with dementia and their families, especially in poorer communities.

There is also a lot of stigma attached to dementia, as many people don't have the knowledge to understand the condition and the medical, emotional and financial challenges accompanying a diagnosis of dementia. It was also confirmed that abuse of older persons is a reality and that vulnerable older people, especially those living with dementia, should be protected from all forms of abuse, including emotional, verbal, physical and financial abuse.

As final part of the project, a policy brief will be finalised to convince policy makers to acknowledge dementia as a health priority and to take steps to include dementia in policies in South Africa – thus enabling people to live well with dementia in this country.

*Petra du Toit, executive director, Alzheimer's South Africa, NGO Lead in STRiDE-South Africa*



STRiDE workshop in South Africa, 2018.



## Jamaica STAGE 2A

In STRiDE-Jamaica, using data and research to help with policy change and impact started with using data that already existed – not just collecting our own data. Our involvement in STRiDE Jamaica and the advocacy we needed to do to bring the issue of dementia to policy makers' attention helped us recognise that we did not have to collect original data.

In academia, we assume that policy makers are aware of synthesis and the updated findings and evidence-based best practice, but, in fact, they often need this brought to them. Participating in the wider STRiDE network changed the way we work in that it provided an avenue to orient an entire project around implementation and dissemination science. Participating in STRiDE has helped build capacity around using data and evidence for policy change by helping our team to recognise and build skills to gather knowledge from and with persons living with dementia, their carers, and stakeholders outside academia. It has facilitated awareness of the global and regional policy environment and provided the structure and access to other colleagues who are working passionately on this subject to think through best strategies and approaches together.

In doing so, it has created a ripple effect that has helped us share this information with other Latin American and Caribbean countries and even collaborators in the Middle East and throughout Africa. The STRiDE methodology has allowed us to gain more access to data and learned to implement

more creative approaches to collating and reporting data, such as using vignettes to explore and validate existing and lacking care pathways.

In our experience, one of the most effective tools was the use of traditional and social media. We took advantage of leveraging events in the calendar of specific partner organisations and entities, released press statements ahead of and after our larger events, made several radio appearances, partnered with many organisations and places of worship to deliver talks, seminars, and other activities to increase public awareness and education around what dementia is, what is needed for care, and to collate relevant resources.

In January 2020, we participated alongside other NGO representatives in a networking and capacity building session in London. This was an invaluable experience in helping to articulate the target stakeholders according to different quadrants and to clarify how to anticipate and prepare for the asks of policy makers. We encourage these types of initiatives early on in a project life and to take advantage of webinar recordings offered by organisations including ADI over the last few years.

*Dr Ishtar Govia, NGO Lead in STRiDE-Jamaica, and Rochelle Amour, Janelle Robinson, Marissa Stubbs, Tiffany Palmer, Epidemiology Research Unit, Caribbean Institute for Health Research, The University of the West Indies, Kingston, Jamaica*



Dr Ishtar Govia (second from left) meets with Minister Christopher Tufton (third from left) and Ministry of Health and Wellness team on 7 January 2020.



## Kenya STAGES 3A and 3B

In Kenya, dementia has been poorly understood for a long time. There are high levels of stigma associated with dementia and myths based on traditional cultural beliefs. Some believe that if someone has dementia, they must have wronged the gods. Others think an individual has been bewitched. Stigma is rife, and there have been cases in which people living with dementia have been burned to death as it was believed they were witches.

There is also a belief that dementia is a normal part of ageing. Lack of awareness and social stigma present significant challenges to diagnosis rates. In Kenya, we do not have statistics on the number of people living with dementia – which has meant that the governments does not prioritise the condition.

We are only in the nascent stages of raising awareness of dementia as a medical condition. The STRiDE project changed the way we work as a civil society organisation, as we have realised the need to incorporate research in what we do. Having a theory of change workshop with stakeholders helped us identify the areas we needed to target. Working on the situational analysis also helped us to understand what the key gaps in our health and long-term political economy were in Kenya and helped us develop a roadmap to change.

Capacity building has been key around the use of data in the STRiDE project. In Kenya, we have produced an anti-stigma tool kit that has been used to train and inform healthcare workers on dementia, how to deal with stigma and how to provide support. The anti-stigma intervention has been especially useful, as the training was done in a rural setting with the aim of educating the community and addressing myths.



2022 field work (Courtesy of STRiDE-Kenya).

During the STRiDE project, we also conducted stakeholder interviews, another method that has helped us to gather more information on key expectations around dementia in Kenya. We have had great recommendations from stakeholders on how to best approach the issue in the country.

We are grateful that we have been able to work with the Ministry of Health and other stakeholders on a dementia action plan that will inform policy in Kenya. The plan has identified eight key action areas which, when implemented largely at a local level, will result in significant improvements in the quality of services provided to people with dementia, their families and carers and should promote a greater understanding of the causes and consequences of dementia.

The new dementia action plan will be the first dementia-focussed document in Kenya and we are looking forward to how it will inform how people with dementia and their carers will be supported in future.

*Elizabeth Mutunga, founder, Alzheimer's and Dementia Organisation Kenya, NGO lead in STRiDE-Kenya*

### Key points



**The emergence of the first new dementia drug treatment in two decades, despite sparking debate, is far from the only development in dementia research in the past year. Research output still lags behind the goals set by the WHO, but innovations continue to abound.**

**ADI persists in calling on governments to invest a minimum of 1% of the societal cost of dementia into research. While much attention is focussed on biomedical and pharmacotherapeutic research, there is also an urgent need to produce more qualitative research on care, and to make sure any discoveries made by labs or institutes can translate into real-world changes.**

## Summary

In the long-term endeavour of tackling dementia, it is important to focus on the positive. Alzheimer and dementia associations, researchers, governments, industry, innovators and other people and organisations dedicated to the cause are doing crucial work, with and for people living with dementia and their families, every day, all around the world.

Still, more needs to be done. Dementia is the seventh leading cause of death among all diseases globally, yet remains largely neglected by governments – its effects underestimated despite the impact on individuals, families, and societies at large. The number of people living with dementia is expected to almost triple by 2050, and the costs associated with the condition are also predicted to skyrocket.

Member states must make good on their commitment to the Global action plan on dementia. With only three years left before the end of the plan in 2025, the odds are incredibly slim that most of its targets will be met on time. Nonetheless, any and all progress in the action areas identified by the WHO will make a difference in the lives of people with dementia and their carers.

Ignoring the realities of dementia today will only make the situation worse tomorrow – but any steps taken now to address the many facets of the condition will bear fruit in the future, for all of us.

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“Ignoring the realities of dementia today will only make the situation worse tomorrow – but any steps taken now to address the many facets of the condition will bear fruit in the future, for all of us.”

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## Appendix A

ADI member nations that are WHO member states, with dementia plans represented by income group, plan stage and status as of 1 May 2022

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 3A & 3B	Not yet launched, but commitment to funding for some of the 7 action areas & in development, good progress
Australia	Western Pacific region	WHO	Member	HIC	STAGE 3B	In development, good progress
Austria	European region	WHO	Member	HIC	STAGE 5B	Plan adopted, funded and monitored
Azerbaijan	European region	WHO	Potential	UMIC	STAGE 2A	Initial meetings with government, but no further progress
Bahamas	Region of the Americas	WHO	MDP	HIC	STAGE 2A	Initial meetings with government, but no further progress
Bangladesh	South-East Asian Region	WHO	MDP	LMIC	STAGE 2B & 2D	Some developments towards a plan, but progress stalled & Grouped health plan including dementia under consideration
Barbados	Region of the Americas	WHO	Member	HIC	STAGE 2B	Some developments towards a plan, but progress stalled
Belgium	European region	WHO	Member	HIC	STAGE 2B	Some developments towards a plan, but progress stalled
Bolivia	Region of the Americas	WHO	Member	LMIC	STAGE 2B & 3A	Some developments towards a plan, but progress stalled & Not yet launched, but commitment to funding for some of the 7 action areas
Bosnia and Herzegovina	European region	WHO	Member	UMIC	STAGE 3D	Grouped health plan including dementia in development
Botswana	African region	WHO	Potential	UMIC	STAGE 2A	Initial meetings with government, but no further progress
Brazil	Region of the Americas	WHO	Member	UMIC	STAGE 3B	In development, good progress
Brunei	Western Pacific region	WHO	Member	HIC	STAGE 3D	Grouped health plan including dementia in development
Bulgaria	European region	WHO	Member	UMIC	STAGE 3D	Grouped health plan including dementia in development
Burundi	African region	WHO	MDP	LIC	STAGE 2E	*Dementia referred to in existing grouped health plan, but not as a separate health condition*
Cameroon	African region	WHO	Member	LMIC	STAGE 2A	Initial meetings with government, but no further progress
Canada	Region of the Americas	WHO	Member	HIC	STAGE 5A	Plan adopted but not fully communicated
Chile	Region of the Americas	WHO	Member	HIC	STAGE 4A	Inadequate funding
China	Western Pacific region	WHO	Member	HIC	STAGE 5B	Plan adopted, funded and monitored

Country	WHO region	WHO status	ADI status	Income group	Plan stage	Plan status comment
Colombia	Region of the Americas	WHO	Member	UMIC	STAGE 2E	"Dementia referred to in existing grouped health plan, but not as a separate health condition"
Costa Rica	Region of the Americas	WHO	Member	HIC	STAGE 4B & 4D	No funding & Plan threatened
Croatia	European region	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"
Cuba	Region of the Americas	WHO	Member	LMIC	STAGE 5B	Plan adopted, funded and monitored
Cyprus	European region	WHO	Member	HIC	STAGE 3B	In development, good progress
Czech Republic	European region	WHO	Member	HIC	STAGE 4B	No funding
Denmark	European region	WHO	Member	HIC		
Dominica	Region of the Americas	WHO	MDP	UMIC	STAGE 2A	Initial meetings with government, but no further progress
Dominican Republic	Region of the Americas	WHO	Member	UMIC	STAGE 4B	No funding
Ecuador	Region of the Americas	WHO	Member	UMIC	STAGE 2A	Initial meetings with government, but no further progress
Egypt	Eastern Mediterranean region	WHO	Member	LMIC	STAGE 2B	Some developments towards a plan, but progress stalled
El Salvador	Region of the Americas	WHO	Member	LMIC		
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 5C	Grouped health plan including dementia adopted, with specific targets and funding
France	European region	WHO	Member	HIC	STAGE 4E	Grouped health plan including dementia, adopted but with no or inadequate funding
Georgia	European region	WHO	Member	LMIC		
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 2A	Initial meetings with government, but no further progress
Honduras	Region of the Americas	WHO	Member	LMIC	STAGE 3B	In development, good progress
India	South-East Asian Region	WHO	Member	LMIC	STAGE 2E & 3A	Dementia referred to in existing grouped health plan, but not as a separate health condition & Not yet launched, but commitment to funding for some of the 7 action areas
Indonesia	South-East Asian Region	WHO	Member	LMIC	STAGE 5A	Plan adopted but not fully communicated

Country	WHO region	WHO status	ADI status	Income group	Plan stage	Plan status comment
Iran	Eastern Mediterranean region	WHO	Member	UMIC	STAGE 4F	Plan adopted, but not implemented
Ireland	European region	WHO	Member	HIC	STAGE 4A	Inadequate funding
Israel	European region	WHO	Member	HIC		
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
Kazakhstan	European region	WHO	Potential	UMIC		
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
Kuwait	Eastern Mediterranean region	WHO	Potential	HIC	STAGE 4A, 4D & 4F	Inadequate funding, Plan adopted, but not implemented & Plan under threat
Lebanon	Eastern Mediterranean region	WHO	Member	UMIC	STAGE 2B	Some developments towards a plan, but progress stalled
Lesotho	African region	WHO	Member	LMIC		
Lithuania	European region	WHO	MDP	HIC	STAGE 2B	Some developments towards a plan
Macedonia (North)	European region	WHO	Member	UMIC	STAGE 2A & 2E	Initial meetings with government, but no further progress & Dementia referred to in existing grouped health plan, but not as a separate health condition
Madagascar	African region	WHO	Member	LIC	STAGE 2E and 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 3B	In development, good progress
Maldives	South-East Asian Region	WHO	MDP	UMIC	STAGE 2A	Initial meetings with government but no further progress
Mali	African region	WHO	MDP	LIC		
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 1	No current contact with government or Ministry of Health
Morocco	Eastern Mediterranean region	WHO	MDP	LMIC	STAGE 1	No current contact with government or Ministry of Health
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 3A	Not yet launched, but commitment to funding for some of the 7 action areas
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 2D	Grouped health plan including dementia under consideration
Nigeria	African region	WHO	Member	LMIC	STAGE 3A	Plan not yet launched but commitment to funding for some of the action areas
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 3B	In development, good progress
Panama	Region of the Americas	WHO	MDP	HIC	STAGE 3B or 3C	In development, good or slow progress (TBC after meeting)
Peru	Region of the Americas	WHO	Member	UMIC	STAGE 3C	In development, Slow progress
Philippines	Western Pacific region	WHO	Member	LMIC	STAGE 4E	Grouped health plan including dementia, adopted but with no or inadequate funding
Poland	European region	WHO	Member	HIC	STAGE 3A	Plan not yet launched, but commitment to funding for some of the 7 action areas
Portugal	European region	WHO	MDP	HIC	STAGE 4F	Plan adopted but not implemented
Qatar	Eastern Mediterranean region	WHO	Member	HIC	STAGE 4A	Inadequate funding
Romania	European region	WHO	Member	UMIC	STAGE 2A	Initial meetings with government, but no further progress
Russian Federation	European region	WHO	Member	UMIC	STAGE 4E & 4F	Grouped health plan including dementia, adopted but with no or inadequate funding & Plan adopted, but not implemented
Saint Kitts and Nevis	Region of the Americas	WHO	Member	HIC	STAGE 2B	Some developments towards a plan, but progress stalled
Saint Lucia	Region of the Americas	WHO	Potential	UMIC	STAGE 2A & 2E	Initial meetings with government, but no further progress & Dementia referred to in existing grouped health plan, but not as a separate health condition
Saint Vincent and the Grenadines	Region of the Americas	WHO	Potential	UMIC		
Saudi Arabia	Eastern Mediterranean region	WHO	Member	HIC		
Senegal	African region	WHO	MDP	LIC	STAGE 2B	Some developments towards a plan, but progress stalled
Seychelles	African region	WHO	Potential	LIC	STAGE 2A & 2E	Initial meetings with government, but no further progress & Dementia referred to in existing grouped health plan, but not as a separate health condition
Singapore	Western Pacific region	WHO	Member	HIC	STAGE 5A	Plan adopted but not fully communicated

Country	WHO region	WHO status	ADI status	Income group	Plan stage	Plan status comment
Slovak Republic	European region	WHO	Member	HIC		
Slovenia	European region	WHO	Member	HIC	STAGE 3A & 3C	Not yet launched, but commitment to funding for some of the 7 action areas & in development, good progress
South Africa	African region	WHO	Member	UMIC	STAGE 2A & 2E	Initial meetings with government, but no further progress & Dementia referred to in existing grouped health plan, but not as a separate health condition
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 3B	In development, good progress
Sweden	European region	WHO	Member	HIC		
Switzerland	European region	WHO	Member	HIC		
Syrian Arab Republic	Eastern Mediterranean region	WHO	Member	LIC		
Tanzania, United Republic of	African region	WHO	Member	LIC		
Thailand	South-East Asian Region	WHO	Member	UMIC	STAGE 4E	Dementia referred to in existing grouped health plan, but not as a separate health condition
Tonga	Western Pacific region	WHO	Member	UMIC	STAGE 2E	Dementia referred to in existing grouped health plan, but not as a separate health condition
Trinidad and Tobago	Region of the Americas	WHO	Member	HIC	STAGE 3B	In development, good progress
Tunisia	Eastern Mediterranean region	WHO	Member	LMIC	STAGE 3C	In development, slow progress
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
Ukraine	European region	WHO	Potential	LMIC	STAGE 2A	Initial meetings with government, but no further progress
United Arab Emirates	Eastern Mediterranean region	WHO	Member	HIC	STAGE 2A	Initial meetings with government, but no further progress
United Kingdom – England	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	Dementia referred to in existing grouped health plan, but not as a separate health condition
Venezuela	Region of the Americas	WHO	Member	UMIC		
Vietnam	Western Pacific region	WHO	MDP	LMIC	STAGE 4E	A grouped health plan including dementia, adopted but with no or inadequate funding)
Yemen	Eastern Mediterranean region	WHO	MDP	LIC	STAGE 2B	Some developments towards a plan, but progress stalled
Zambia	African region	WHO	MDP	LMIC		
Zimbabwe	African region	WHO	Member	LIC	STAGE 2A	Initial meetings with government, but no further progress

## Appendix B

ADI members that are not WHO member states, with dementia plans represented by plan stage and status as of 1 May 2022

Country	ADI member	Plan stage	Plan status
Aruba	Yes		
Bermuda	Yes	2A	Initial meetings with government, but no further progress
Bonaire	Yes	5A	Plan adopted but not fully communicated
British Virgin Islands	Yes	2A	Initial meetings with government, but no further progress
Cayman Islands	Yes	2A	Initial meetings with government, but no further progress
Curaçao	Yes	4F	Plan adopted, but not implemented
Gibraltar	Yes	4F	Plan adopted, but not implemented
Hong-Kong	Yes	3C	In development, slow progress
Macau SAR	Yes	5A	Plan adopted but not fully communicated
Puerto Rico	Yes	4F	Plan adopted but not implemented
Sint Maarten	Yes		
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 as of 1 May 2022

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
Bahrain	Eastern Mediterranean region	WHO	Non-member	HIC
Belarus	European region	WHO	Non-member	UMIC
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
Burkina Faso	African region	WHO	Non-member	LIC
Cambodia	Western Pacific region	WHO	Non-Member	LMIC
Cape Verde	African region	WHO	Non-member	N/A
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	N/A
Côte d'Ivoire	African region	WHO	Non-member	LMIC
Democratic People's Republic of Korea	South-East Asian Region	WHO	Non-member	LIC
Democratic Republic of the Congo	African 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	Region of the Americas	WHO	Non-member	UMIC
Haiti	Region of the Americas	WHO	Non-member	LIC
Hungary	European region	WHO	Non-member	HIC
Iceland	European region	WHO	Non-member	HIC
Iraq	Eastern Mediterranean region	WHO	Non-member	UMIC
Kiribati	Western Pacific region	WHO	Non-member	LMIC
Kyrgyzstan	European region	WHO	Non-member	LMIC
Lao People's Democratic Republic	Western Pacific region	WHO	Non-member	LMIC
Latvia	European region	WHO	Non-member	HIC
Liberia	African region	WHO	Non-member	LIC
Libya	Eastern Mediterranean region	WHO	Non-member	UMIC

Country	WHO region	WHO status	ADI status	Income group
Luxembourg	European region	WHO	Non-member	HIC
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
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	?
Palau	Western Pacific region	WHO	Non-member	HIC
Papua New Guinea	Western Pacific region	WHO	Non-member	LMIC
Paraguay	Region of the Americas	WHO	Non-member	UMIC
Rep. of Moldova	European region	WHO	Non-member	LMIC
Rwanda	African region	WHO	Non-member	LIC
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
Togo	African region	WHO	Non-member	LIC
Turkmenistan	European region	WHO	Non-member	UMIC
Tuvalu	Western Pacific region	WHO	Non-member	UMIC
Uzbekistan	European region	WHO	Non-member	LMIC
Vanuatu	Western Pacific region	WHO	Non-member	LMIC

## 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 D

## Full country-level data from IHME

Country	Number of people living with dementia 2019	Number of people living with dementia 2050	Percentage change
Afghanistan	55,734	288,376	417%
Albania	36,079	86,733	141%
Algeria	250,509	1,118,628	347%
American Samoa	191	622	226%
Andorra	1,066	2,897	226%
Angola	46,598	250,926	439%
Antigua and Barbuda	592	1,815	207%
Argentina	412,268	892,180	116%
Armenia	31,890	69,994	119%
Australia	348,673	796,702	128%
Austria	146,391	309,629	111%
Azerbaijan	52,070	195,210	275%
Bahamas	1,920	6,268	226%
Bahrain	5,126	60,650	1084%
Bangladesh	570,899	2,020,081	254%
Barbados	3,023	5,731	89%
Belarus	137,286	245,114	79%
Belgium	190,477	330,572	73%
Belize	1,366	6,213	355%
Benin	17,550	76,035	333%
Bermuda	865	2,066	139%
Bhutan	2,588	11,668	351%
Bolivia	43,829	136,892	212%
Bosnia and Herzegovina	48,081	92,167	92%
Botswana	6,737	26,873	299%
Brazil	1,849,981	5,666,116	206%
Brunei	1,574	7,317	365%
Bulgaria	135,285	185,719	37%
Burkina Faso	33,793	136,726	305%
Burundi	14,791	57,936	292%
Cambodia	55,230	207,476	276%
Cameroon	41,181	172,812	320%
Canada	587,364	1,308,143	123%
Cape Verde	2,546	8,324	227%
Central African Republic	8,207	24,731	201%
Chad	20,134	75,448	275%
Chile	174,921	491,617	181%
China	15,330,045	45,538,093	197%
Colombia	369,422	1,375,881	272%
Comoros	2,074	6,757	226%
Congo	11,538	47,842	315%
Costa Rica	32,637	114,227	250%
Côte d'Ivoire	34,438	178,367	418%

Country	Number of people living with dementia 2019	Number of people living with dementia 2050	Percentage change
Croatia	83,429	129,479	55%
Cuba	116,055	259,547	124%
Cyprus	14,143	38,840	175%
Czech Republic	192,748	379,742	97%
Democratic People's Republic of Korea	192,152	415,335	116%
Democratic Republic of the Congo	153,708	626,362	308%
Denmark	81,923	137,508	68%
Djibouti	2,085	11,937	473%
Dominica	574	999	74%
Dominican Republic	51,735	149,178	188%
Ecuador	87,769	268,822	206%
Egypt	305,675	1,530,167	401%
El Salvador	36,675	88,198	140%
Equatorial Guinea	2,416	14,438	498%
Eritrea	7,666	34,048	344%
Estonia	26,710	48,807	83%
Eswatini	2,416	6,950	188%
Ethiopia	174,023	945,224	443%
Fiji	3,125	8,107	159%
Finland	97,549	154,002	58%
France	1,203,439	2,191,307	82%
Gabon	5,796	21,254	267%
Gambia	3,796	12,887	240%
Georgia	46,291	78,458	70%
Germany	1,691,221	2,796,783	65%
Ghana	57,276	240,708	320%
Greece	206,366	298,617	45%
Greenland	439	1,447	229%
Grenada	1,058	1,743	65%
Guam	1,044	2,980	185%
Guatemala	60,721	238,013	292%
Guinea	21,227	61,087	188%
Guinea-Bissau	2,271	9,487	318%
Guyana	2,805	8,799	214%
Haiti	26,215	83,761	219%
Honduras	32,371	109,116	237%
Hungary	183,870	295,379	61%
Iceland	4,222	10,019	137%
India	3,843,118	11,422,692	197%
Indonesia	987,673	3,399,285	244%
Iran	524,457	2,188,336	317%
Iraq	159,548	1,050,756	559%
Ireland	53,932	142,416	164%
Israel	85,869	210,339	145%
Italy	1,487,368	2,316,951	56%
Jamaica	17,937	40,797	127%

Country	Number of people living with dementia 2019	Number of people living with dementia 2050	Percentage change
Japan	4,117,308	5,237,201	27%
Jordan	37,373	232,594	522%
Kazakhstan	107,698	356,674	231%
Kenya	86,815	361,042	316%
Kiribati	255	772	203%
Korea, Republic of	671,288	1,954,016	191%
Kuwait	18,001	171,121	850%
Kyrgyzstan	28,171	105,987	276%
Lao People's Democratic Republic	19,370	87,292	351%
Latvia	38,907	57,136	47%
Lebanon	45,952	187,024	307%
Lesotho	5,312	10,726	102%
Liberia	7,084	31,859	350%
Libya	29,286	128,595	339%
Lithuania	56,244	81,237	44%
Luxembourg	6,583	16,797	155%
Macedonia	28,279	75,147	166%
Madagascar	37,380	159,725	327%
Malawi	36,636	132,360	261%
Malaysia	142,172	495,842	249%
Maldives	1,703	11,135	554%
Mali	31,455	138,631	341%
Malta	6,651	11,674	76%
Marshall Islands	108	417	285%
Mauritania	8,404	34,368	309%
Mauritius	9,833	27,056	175%
Mexico	596,202	1,843,049	209%
Micronesia	281	904	222%
Mongolia	10,986	53,692	389%
Montenegro	8,247	14,870	80%
Morocco	225,682	826,320	266%
Mozambique	43,083	181,519	321%
Myanmar	228,825	726,358	217%
Namibia	7,738	25,993	236%
Nepal	85,635	265,658	210%
Netherlands	277,262	493,122	78%
New Zealand	65,616	148,956	127%
Nicaragua	28,540	116,953	310%
Niger	26,476	122,138	362%
Nigeria	300,332	1,462,514	387%
Northern Mariana Islands	246	1,147	366%
Norway	75,301	149,264	98%
Oman	11,965	124,803	943%
Pakistan	374,060	1,350,453	261%
Palestine	16,173	79,811	393%
Panama	26,527	99,043	273%
Papua New Guinea	13,460	55,964	316%
Paraguay	37,803	120,880	220%

Country	Number of people living with dementia 2019	Number of people living with dementia 2050	Percentage change
Peru	196,699	744,847	279%
Philippines	328,852	969,025	195%
Poland	663,408	1,323,739	100%
Portugal	200,994	351,504	75%
Puerto Rico	51,313	105,338	105%
Qatar	4,201	85,046	1926%
Rep. of Moldova	46,924	119,453	155%
Romania	341,195	577,177	69%
Russian Federation	1,949,811	4,032,617	107%
Rwanda	24,705	124,755	405%
Saint Lucia	1,217	3,314	172%
Saint Vincent and the Grenadines	830	1,921	131%
Samoa	692	1,658	139%
Sao Tome And Principe	418	1,535	267%
Saudi Arabia	85,735	855,760	898%
Senegal	29,539	107,492	264%
Serbia	129,117	178,262	38%
Seychelles	607	1,598	163%
Sierra Leone	12,993	45,849	253%
Singapore	48,906	222,784	356%
Slovak Republic	77,185	163,037	111%
Slovenia	43,038	84,735	97%
Solomon Islands	1,276	4,549	256%
Somalia	21,758	62,012	185%
South Africa	241,937	680,045	181%
South Sudan	14,107	69,983	396%
Spain	826,686	1,516,523	83%
Sri Lanka	146,778	475,050	224%
Sudan	115,705	633,251	447%
Suriname	3,070	8,843	188%
Sweden	153,805	249,290	62%
Switzerland	142,105	307,925	117%
Syrian Arab Republic	85,971	366,323	326%
TADA (Chinese Taipei)	279,296	644,733	131%
Tajikistan	29,261	135,868	364%
Tanzania, United Republic of	110,250	469,767	326%
Thailand	670,047	2,391,672	257%
Timor-Leste	4,036	12,124	201%
Togo	12,196	55,318	354%
Tonga	447	1,059	137%
Trinidad and Tobago	10,194	29,968	194%
Tunisia	95,059	329,849	247%
Turkey	803,590	3,031,455	277%
Turkmenistan	22,117	96,861	338%
Uganda	58,045	273,221	371%
Ukraine	651,773	1,007,499	55%
United Arab Emirates	11,711	221,672	1795%
United Kingdom	907,331	1,592,475	75%

Country	Number of people living with dementia 2019	Number of people living with dementia 2050	Percentage change
United States of America	5,268,893	10,520,259	100%
Uruguay	47,160	84,842	80%
Uzbekistan	108,010	408,306	278%
Vanuatu	696	1,903	174%
Venezuela	153,345	547,798	257%
Vietnam	531,633	1,756,890	230%
Virgin Islands (US)	1,039	1,680	62%
Yemen	75,189	309,394	311%
Zambia	26,055	119,644	359%
Zimbabwe	27,377	80,386	194%

## 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](http://www.alzint.org)

Alzheimer's Disease International:  
The International Federation of  
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Disorders Societies, Inc. is  
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**Alzheimer's Disease  
International**