



**Alzheimer's Disease
International**

The global voice on dementia

From Plan to Impact VII

Dementia at a crossroads



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Foreword



This edition of From Plan to Impact marks seven years since the launch of the World Health Organization's (WHO) Global action plan on the public health response to dementia. From that point forward, From Plan to Impact has become a precious resource to chart progress towards turning the global plan a national reality.

As those who have read these reports since the onset know, we at ADI have staked a lot of our energy and efforts in making national dementia plans happen. The tally of national plans is still quite disappointing: only 38 are currently in place, a few have expired, and many still do not have a budget attached to them. Progress is slow, yet it is inexorable, as more and more countries realise that, with their population ageing, the issue of dementia is not going away, on the contrary.

The momentum we have gathered with national dementia plans is not insignificant. As I write these lines, a plan has been launched in China, I have received the new plan for Mexico, a plan for Peru will be discussed in June, a Malaysian plan should be launched at the same time as this report, and the Brazilian chamber of deputies approved a new national dementia policy on the day this report was sent to print. There are even more discussions happening at earlier stages. From my perch, things are looking up.

This is why ADI will dedicate this year to ensuring that the Global action plan – due to expire in 2025 – is extended by another 10 years. The momentum is there, and everyone should benefit from it. I would like to formally thank the governments of Japan (Kosuke Wada's appeal in this report says all there is to say on the topic), and Chile. These two governments were the first to respond to our call for the extension of the plan. Their public and enthusiastic response showed they care about people living with dementia and their families beyond their borders. We are working with many more governments behind the scenes, and we

hope that, when the time comes, they will do the right thing by supporting the extension.

The constant stop-and-start of political cycles sometimes works in our favour, sometimes not – but it is always disruptive. One of the most important reasons for countries to have long-term national dementia plans is that once a plan and a budget have been set for a reasonable number of years (at least five), the plan becomes impervious to political change. This means that people living with dementia and their families are less likely to see their access to services, treatment, and support start, change, or disappear with the fluctuations of political tides. The implementation of a national dementia plan, even if imperfect, also serves as a stepping stone for further improvements in the future, at least in theory. This has worked spectacularly well in South Korea, which refines its plan at every renewal (it is currently in its fourth iteration). On the other end of the spectrum, countries like England and France have had plans expire only to lead to suboptimal and underfunded solutions with a negative impact on people living with dementia and their families. As ever, we thank our

Everything we do makes a difference. Every small act adds up and can snowball into a larger impact... Every single one of us has a role to play.

member associations for giving us their grassroots view of these developments and granting us a perspective of what is happening that is not only global, but with a unique slant on local impact.

If I were to pick up a theme for this report, it would be how much more content we were able to include around research and innovation than in previous years. We have many more essays on these topics this year, running like a golden thread throughout the report. For example, as the finish line is in sight for blood biomarkers, some organisations are thinking of how to apply these advances practically in their healthcare systems, whilst others are redefining what these would mean in clinical practice. The quotes below should give you a taste of the discussions you will find within these pages:

"Dementia diagnosis' is not what needs changing; it is diagnosis and detection of the non-dementia and earlier stages of neurodegenerative diseases like Alzheimer's disease that need to be developed," Professor Craig Ritchie and Anna Borthwick (page 42)

"The evolution of Alzheimer's disease diagnostic criteria and staging methodologies has witnessed a transformative shift from a historical syndrome-based approach to diagnosing based on biology," Drs Simin Mahinrad, Maria Carrillo, and Heather Snyder (page 43)

Things are changing, and they are changing fast. Some countries and populations may be missing out very, very soon – unless we roll up our sleeves and make sure we help people living with dementia and their families in our communities so that they aren't left out amid these leaps and bounds in new diagnostic tools and disease-modifying treatments.

In the meantime, the matrix that keeps us all together is care, love, and compassion. A wonderful essay from Indonesia will really make you reflect on how each one of us has a contribution to make and lives to change, if we only devote a little of our time to help others:

"In 2018, the journey of caring for my father came to an end when he passed away. As I grieved, I moved on with my life,

getting married and having a child. Yet surprisingly, the life I had dreamed of wasn't as fulfilling as I expected. I felt like something was missing. Taking care of my father had given me a sense of purpose beyond my own interests – and so, I decided to continue my journey as a caregiver in a different way," Ratu Tita Quritama (page 51)

Stories like Ratu Tita's will inspire you and remind you that everything we do makes a difference. Every small act adds up and can snowball into a larger impact. It will also remind you that every single one of us has a role to play.

As I write this, I am emerging tired but elated from our biennial conference in Krakow. To see so many selfless, committed, motivated, and happy people under one roof has energised me for the year to come. To all of you who work tirelessly at every level in order to make dementia the health priority it needs to be, I thank you from the bottom of my heart. You are amazing. We will succeed.



Paola Barbarino
Chief Executive Officer
London, May 2024

Extending the WHO Global action plan on dementia: an appeal by Japan

The WHO Global action plan on dementia is a basic agreement for advancing national dementia policies around the world. All countries will experience increasingly ageing societies, and dementia will be a common matter every state will face. It is a universal prescription to gain knowledge, remove stigma, and promote community-based approaches to address this growing issue. National cross-sectional approaches will be most effective in order to detect social and environmental risk factors for dementia. That approach should be inclusive, not exclusionary.

In order to continue building societies that live with dementia, international cooperation is essential. Japan is determined to lead the way as an advanced super-ageing country. As the host country of the G7 in 2023, Japan held a session on dementia at a meeting of health ministers in Nagasaki and included the importance of dementia measures in the ministerial declaration. We are supportive of developing age-friendly and dementia-inclusive communities through initiatives such as medical and long-term care coordination, multi-stakeholder consultations including public and private sectors, and participation of individuals with dementia and their caregivers to accumulate and exchange good practices and evidence to pursue more effective measures.

This year, the Japanese government has endorsed a Basic Act on Dementia to promote the realisation of an inclusive society, and a new priority basic action plan for dementia will be formulated in 2024. These efforts will be carried out by fully reflecting the opinions of individuals living with dementia and caregivers. In collaboration with ADI, we hope to expand these efforts worldwide.

In order to continue building societies that live with dementia, international cooperation is essential. Japan is determined to lead the way as an advanced super-ageing country.

In the field of research and development, the emergence of disease-modifying therapies for Alzheimer's disease has been vast and outstanding. We should encourage the development for the next generation of medicine ahead for other types of dementia.

As the deadline of the WHO Global action plan in 2025 fast approaches, global efforts towards dementia should be enhanced. We think it is necessary to extend this action plan and further advance global efforts. This will require further international emphasis and cooperation on these necessary steps and mark an incredible opportunity to measure the progress of actions regarding dementia worldwide.

Let us continue to promote international cooperation so that we can create inclusive societies for people living with dementia.

Kosuke Wada, *director for Dementia Policy and Community Care, Bureau for the elderly health, Ministry of Health Labour and Welfare, Japan*

Executive summary

When all 194 member states of the World Health Organization (WHO) adopted the Global action plan on the public health response to dementia 2017–2025,¹ the move was hailed as a landmark moment acknowledging the importance of recognising dementia as a significant global health priority.

Many reading this report will already know the grim statistics – but they bear repeating. Dementia is the seventh leading cause of death in the world.² The WHO projects that the number of people living with dementia will more than double from an estimated 55 million people in 2019 to 139 million by 2050. The annual costs associated with the condition, meanwhile, are expected to soar from US\$1.3 trillion in 2019 to a projected \$2.8 trillion by 2030. These numbers make it all the more crucial for the international community to work together to face the challenges of our ageing world.

The Global action plan is an ambitious and comprehensive tool for action, 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 worldwide. With only a year left before the scheduled end of the plan, however, the majority of targets set are far from being reached. The COVID-19 pandemic, geopolitical conflicts, and other global disasters have seemingly relegated dementia to an afterthought for many governments. And yet one thing remains consistent: the global population continues to age rapidly, and dementia will only become a more pressing issue as years go on.

In this seventh edition of From Plan to Impact, ADI has called upon thought leaders across the global dementia community to share their expertise in order to demonstrate that at this crucial point when dementia is at a crossroads, we must not abandon our efforts.

Following the structure of the Global action plan, we have gathered insights to highlight each of the seven action areas, including: new dementia plans and G7/G20 multilateral priorities for dementia; the importance of challenging stigma and new initiatives raising awareness; global efforts to reduce dementia risk and new initiatives around precision risk reduction; brain health and how the emergence of disease-modifying drugs is impacting diagnosis, health systems readiness, and care; the crucial role of family carers; the importance of collecting dementia-related data and core sets of indicators to improve research, treatment, and care; and finally, how new scientific breakthroughs can open the way to better understanding ageing and exploring combination and precision therapies. Each chapter opens with an essay

-  **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**

from a leading expert laying out why policy is crucial to advancing each of the plan's action areas.

These past few years have seen incredible advances in dementia research, with new diagnostic tools and disease-modifying drugs opening up broader horizons for precision treatment and personalised care. Greater awareness of the benefits of brain health have ushered in a new cohort of risk reduction strategies. Meanwhile, advocates around the world continue to push for better understanding and inclusion of people living with dementia, changing the negative narrative that so often pervades discourse about the condition.

We have come too far to falter at the finish line. This is why ADI has been calling for WHO member states to vote for a ten-year extension of the Global action plan for dementia until 2035, so that this tool can continue to guide us towards better outcomes. The future of dementia, it appears, is at a crossroads; will the millions of people affected worldwide continue to struggle to obtain timely diagnosis, adequate care, and effective treatment with little to no support? Or will the powers-that-be realise that investing time, funding, and resources into dementia now will reap benefits for all of us down the road?

If we let this opportunity pass, we are walking blindfolded into a predictable crisis. It is up to all of us to make sure we do not short-change our own futures.

¹ 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

² <https://www.who.int/news-room/fact-sheets/detail/dementia>

Key messages



- The number of national dementia plans (NDPs) implemented by WHO member states has dropped since 2023, down from 39 to 38. This equates to 26 percent of the 146 target, and less than a fifth of all 194 member states who agreed to implement plans in 2017. As of May 2024, 47 countries or territories (including non-WHO member states) had NDPs.
- Dementia plans across WHO member states include 19 in Europe, nine in the Americas, six in the Western Pacific, two in the Eastern Mediterranean, two in Southeast Asia, and none in Africa.
- 27 countries are currently developing an NDP or are integrating dementia within a wider health plan.
- The stagnation on the targets set by the Global action plan on dementia is disappointing, yet people living with dementia and their carers still need governments to live up to their commitments. ADI is therefore calling for WHO member states to vote unanimously for a 10-year extension of the Global action plan on dementia until 2035.
- ADI estimates that, globally, 75 percent of people with dementia are undiagnosed and up to 85 percent are not accessing post-diagnostic care. Health systems need to be able to provide a clear pathway for timely diagnosis and access to ongoing care and support, especially as new disease-modifying treatments emerge.
- Dementia care is far too often overlooked in favour of new treatments, despite being an essential pillar of the dementia response. While pharmacological treatments are incredibly important and should be made accessible to all those who might benefit from them, more means and consideration should also be given by governments to care, in order to ensure that people living with dementia and their families face the condition with the psychosocial support and compassion that they deserve.
- While many actors in the private, non-governmental, and community-level sectors spare no efforts every day to address the many facets of dementia – from risk reduction to diagnosis, treatment, care, support, and research – experts agree: national dementia plans and policies can multiply the impact of these initiatives. States should not sit on the sidelines of this urgent public health issue.

Recommendations

- **ADI calls for WHO member states to extend the Global action plan on dementia until 2035**

The creation of the Global action plan on the public health response to dementia reinvigorated efforts to have the condition be taken seriously by governments across the world. By its very existence, it affirmed the first of its action areas: dementia is a public health priority.

The Global action plan gave new impetus to advocacy efforts at the national, regional, and international levels, providing much needed leverage to inspire governments to create, implement, and fund national dementia plans that addressed the essential needs of people living with dementia in their country. Importantly, it also provided a framework – a best practice blueprint that could be adapted to each country's unique context and priorities. Yet with only a year left, too many governments have failed to meet the goals of the Global action plan.

ADI calls on WHO member states to vote to extend the Global action plan by 10 years until 2035, so that this international instrument can continue to serve as a guiding light for governments seeking to build robust dementia policies. We hope this extension will channel efforts towards the shared goal of finding a cure for dementia, and strengthen health systems in the meantime to ensure access to new treatments as well as much-needed care to make life better for people living with the condition and their carers.

- **Health systems must adapt to the emergence of new treatment and diagnostic tools and ensure equitable access**

The past few years have seen groundbreaking progress in the fields of dementia treatment and diagnosis, bringing a renewed sense of hope that, step by step, we are getting closer to understanding how the brain works, what factors cause neurodegeneration that leads to dementia, and how we may slow down – and perhaps, one day, reverse or prevent – the condition's progression.

What these scientific advancements have put in the spotlight, however, is the widespread inequity between (and within) health systems around the world. Some 60 percent of people living with dementia are believed to be living in lower- and middle-income countries (LMICs), where many disease-modifying treatments and diagnostic tools are unavailable. Many people in high-income countries also face barriers to accessing the treatments they need.

Dementia does not discriminate, and neither should the health response to the condition. It is crucial for health systems at all levels to push for the equitable integration of these innovations so that they aren't exclusively accessible to a privileged few.

Dementia does not discriminate, and neither should the health response to the condition.

- **Care and support must be at the heart of national dementia policies**

While the emergence of new disease-modifying treatments has grabbed headlines around the world, and deservedly so, post-diagnosis care and support remains the heart of good dementia policy. Drugs alone cannot replace the proven need for social, psychological, and human support. In fact, non-pharmacological responses can often be more cost effective, easily accessible and adaptable to various cultural, geographical, and economic contexts.

By building robust post-diagnostic support (PDS) models that incorporate care, states will be better able to include new treatments as they roll out in their countries.

ADI argues that any successful national dementia plan needs to enshrine care and support at the core of its efforts to address the condition. An estimated 85 percent of people living with dementia worldwide are not accessing proper PDS; it is the duty of every state that cares for its citizens to ensure that we address these gaps, which will not only benefit people living with dementia, but also their carers and wider communities.

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



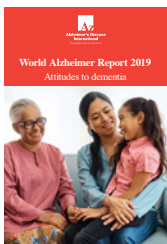
7 Dementia research and innovation



ADI publications that showcase innovation, research, and underpin policy development

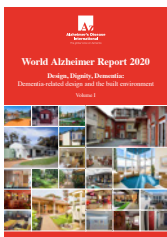
In addition to advocating for over a decade for the Global action plan on dementia to be created, adopted, and implemented, ADI has long been a trusted source of landmark reports on the issues addressed by the plan, combining essays from experts in academia, research, advocacy, and lived experience with case studies showing best practice.

Here are some of ADI's most prominent World Alzheimer Reports in recent years, tackling the Global action plan's major action areas. All of these authoritative resources, as well as past editions of From Plan to Impact, are available on our ADI website: www.alzint.org/reports-resources.



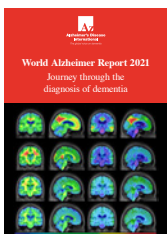
World Alzheimer Report 2019: Attitudes to dementia (Action area 2: Dementia awareness and friendliness)

In this report, ADI explored the issue of stigma through our first attitudes to dementia global survey – to-date, the largest of its kind. The survey was supplemented by case studies and examples of tangible best practice from scores of countries.



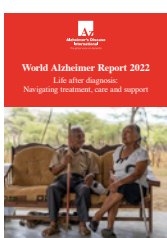
World Alzheimer Report 2020: Design, dignity, dementia: Dementia-related design and the built environment (Action area 2: Dementia awareness and friendliness)

In 2020, ADI turned our focus to the important area of dementia-related design, progress to date, best practice, pioneers and innovators across multiple environments including in home/ domestic settings, day and residential care, hospitals and public buildings and spaces.



World Alzheimer Report 2021: Journey through the diagnosis of dementia (Action area 4: Diagnosis, treatment, care, and support)

The World Alzheimer Report 2021 examined the crucial topic of diagnosis – exploring key processes for an accurate diagnosis, new technologies, types of dementia, the impact of diagnosis, and issues around access.



World Alzheimer Report 2022: Life after diagnosis: Navigating treatment, care, and support (Action area 4: Diagnosis, treatment, care, and support, and Action area 5: Support for dementia carers)

A companion piece to the 2021 report, the World Alzheimer Report 2022 centred around post-diagnosis; providing a global perspective on post-diagnosis care models, barriers, and best practice, through expert essays, case studies, commentary and perspectives from people living with dementia and carers.



World Alzheimer Report 2023: Reducing dementia risk: never too early, never too late (Action area 3: Dementia risk reduction)

The World Alzheimer Report 2023 examined the drivers behind risk reduction, including lifelong risk reduction and the steps that individuals can take to reduce their risk as well as the role of government in providing population-based systemic changes to promote risk reduction and the importance of dementia research.

Introduction

Since its adoption in May 2017, the Global action plan on the public health response to dementia has served as a crucial framework for the World Health Organization's (WHO) 194 member states to improve the quality of life of people living with dementia, their carers, and communities over the span of eight years. The plan outlines seven key action areas and encourages regular reporting from governments on their progress.

The From Plan to Impact report series was initiated by Alzheimer's Disease International (ADI) to not only evaluate governments' progress in fulfilling their commitments to the Global action plan, but to highlight inspiring examples of good policy, research, and practice that might encourage others to emulate and adapt these efforts in their local contexts. This report offers an up-to-date (as of May 2024) and comprehensive assessment of progress towards the Global action plan objectives.

Dementia, currently the seventh leading cause of death worldwide, is an ever more urgent public health issue as the global population ages. Projections from the WHO indicate a staggering predicted rise in the number of people living with dementia, expected to increase from an estimated 55 million people in 2019 to 139 million by 2050. Alarming, 60 percent of those affected reside in lower- and middle-income countries (LMICs), where access to treatment and resources remains limited.

The anticipated surge in dementia cases is forecasted to lead to a rise in annual costs associated with the condition, soaring from US\$1.3 trillion in 2019 to a projected \$2.8 trillion by 2030.

Despite the global call outlined in the Global action plan, there has been a troubling decline in the number of national dementia plans, with only 38 WHO member states having active plans as of May 2024 – one fewer plan than recorded in 2023. This marks a disappointing setback in the collective pledge to prioritise dementia and meet the targets set by the plan by 2025.

As the scheduled end of the Global action plan approaches with only one year remaining, the goals of the plan appear increasingly out of reach. Rather than conceding defeat, however, ADI urges governments to acknowledge the urgency of the situation. People living with dementia, their families, and communities cannot afford for us to give up on them.

ADI calls upon WHO member states to recognise the imperative for sustained efforts to address dementia effectively and vote unanimously to extend the Global action plan by 10 years until 2035. This extension should serve as an opportunity for nations to reaffirm their commitments and revitalise their endeavours in prioritising dementia on the global health agenda.

Rather than conceding defeat, however, ADI urges governments to acknowledge the urgency of the situation. People living with dementia, their families, and communities cannot afford for us to give up on them.

What is a national dementia plan?

In 2017, the World Health Organization (WHO) adopted the Global action plan on the public health response to dementia, aiming to improve the lives of people with dementia and their carers, whilst mitigating the impact of dementia on communities and countries. Member states voted unanimously to accept and commit to the plan.

People living with dementia and their carers require specialised and multifaceted support throughout the progression of the condition. Identifying and addressing these needs requires action at the global, regional, national, and community levels.

The Global action plan identified seven key action areas that effective dementia policy should address, with Action area 1 encouraging member states to implement national dementia plans (NDPs) or strategies.

The WHO characterises national dementia plans as the following:¹

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.

There are two main types of dementia plans: standalone and integrated. Standalone national dementia plans

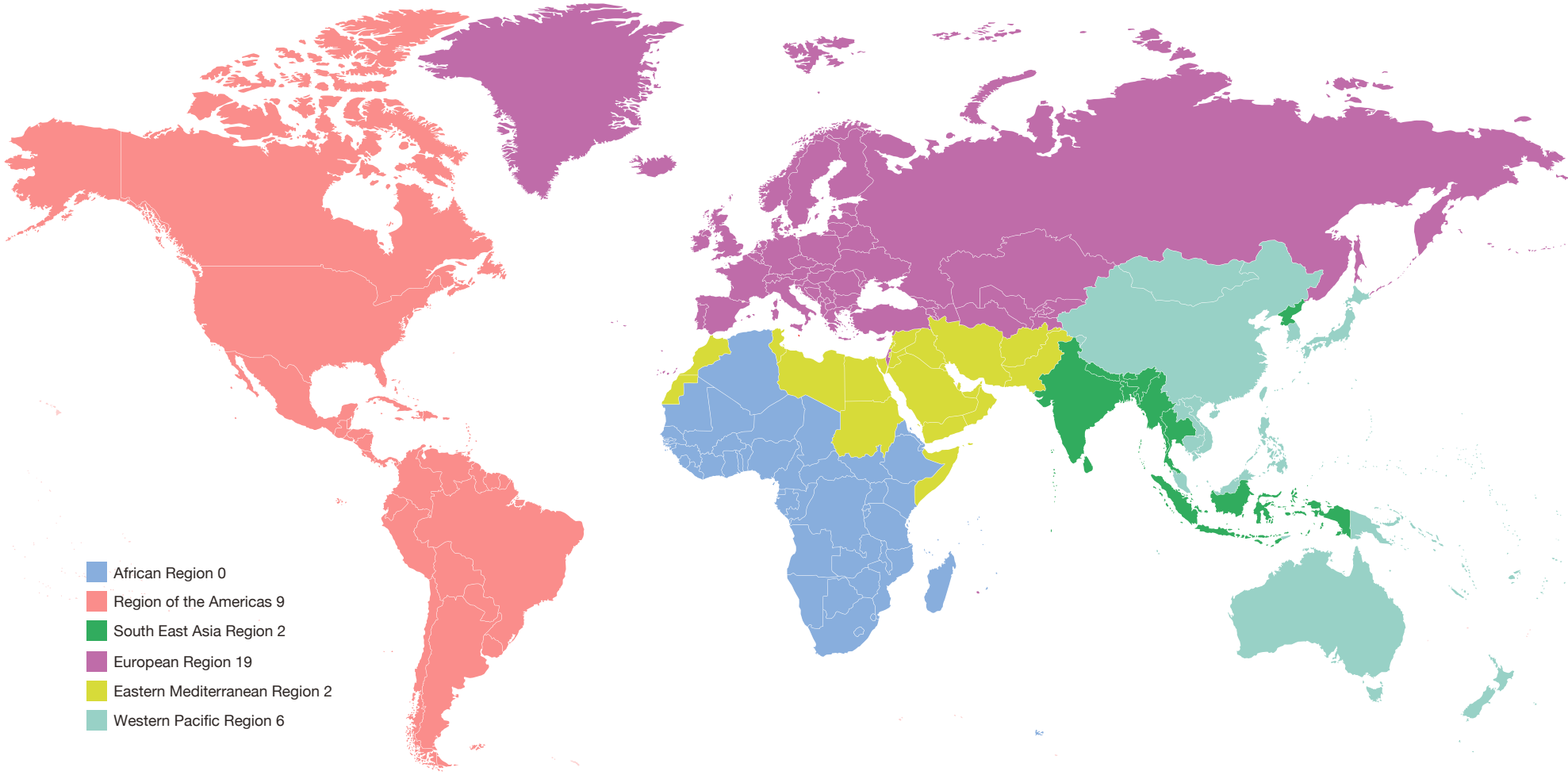


focus exclusively on dementia, while integrated plans incorporate dementia within broader policy frameworks addressing ageing, non-communicable diseases, mental health, or neurodegenerative disorders. Regardless of the approach chosen, governments should dedicate funding exclusively for dementia, as well as address as many of the seven action areas outlined in the Global action plan as possible to ensure effectiveness.

Due to the significance of dementia as a condition projected to affect 139 million people worldwide by 2050 and the complexities associated with care and support, ADI advocates for standalone national dementia plans encompassing all seven action areas of the Global action plan as the most robust way to manage the many challenges dementia poses to healthcare systems, governments and the people directly impacted by the condition. In order to be as effective as possible, these plans should be developed by expert multidisciplinary teams that include individuals with lived experience of dementia and their carers.

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

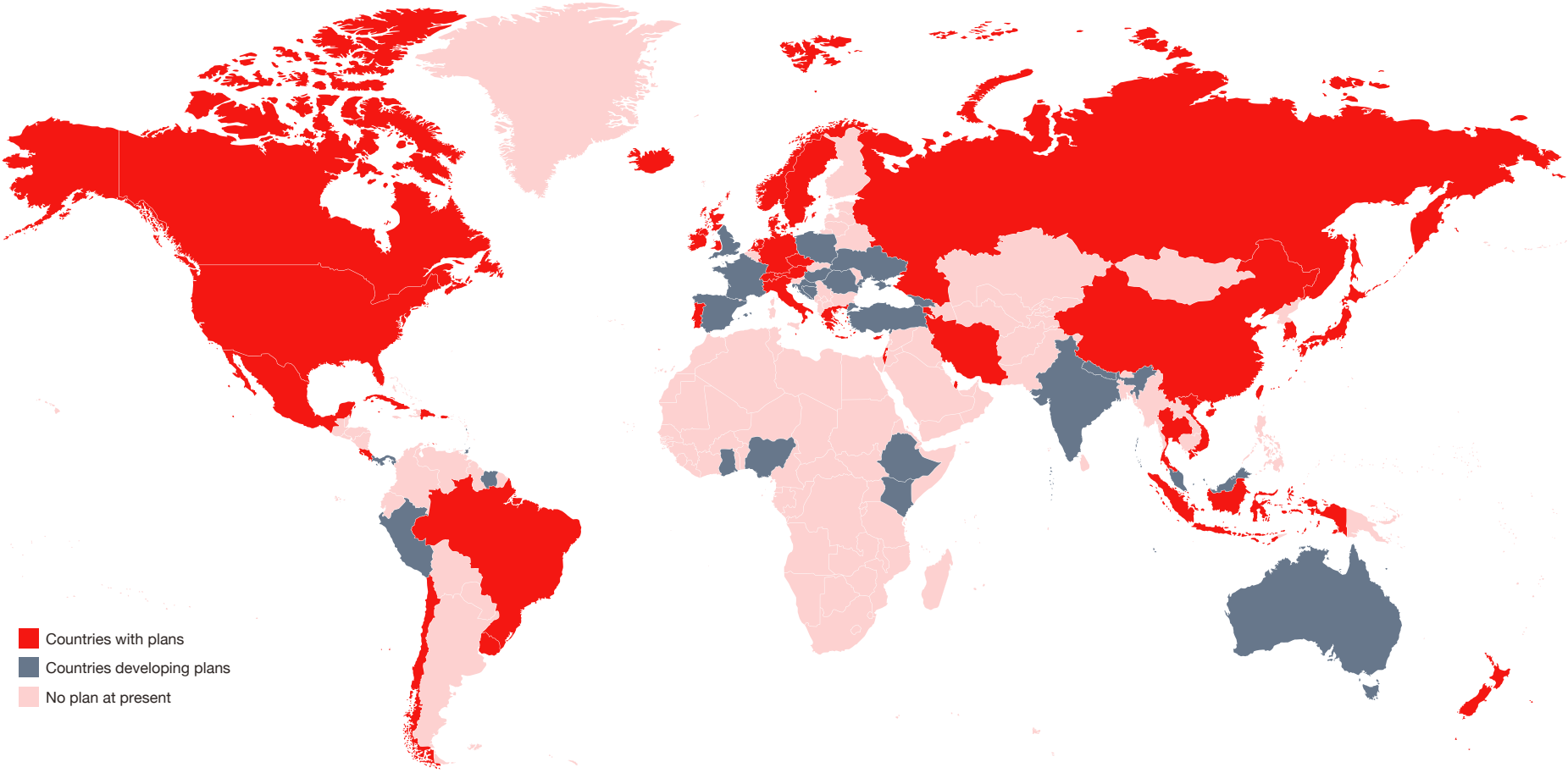
National Dementia Plans by World Health Organization Region



- African Region 0
- Region of the Americas 9
- South East Asia Region 2
- European Region 19
- Eastern Mediterranean Region 2
- Western Pacific Region 6

Based on information received from Alzheimer and dementia associations, May 2024

Current national dementia plans and plans in development



- Countries with plans
- Countries developing plans
- No plan at present

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

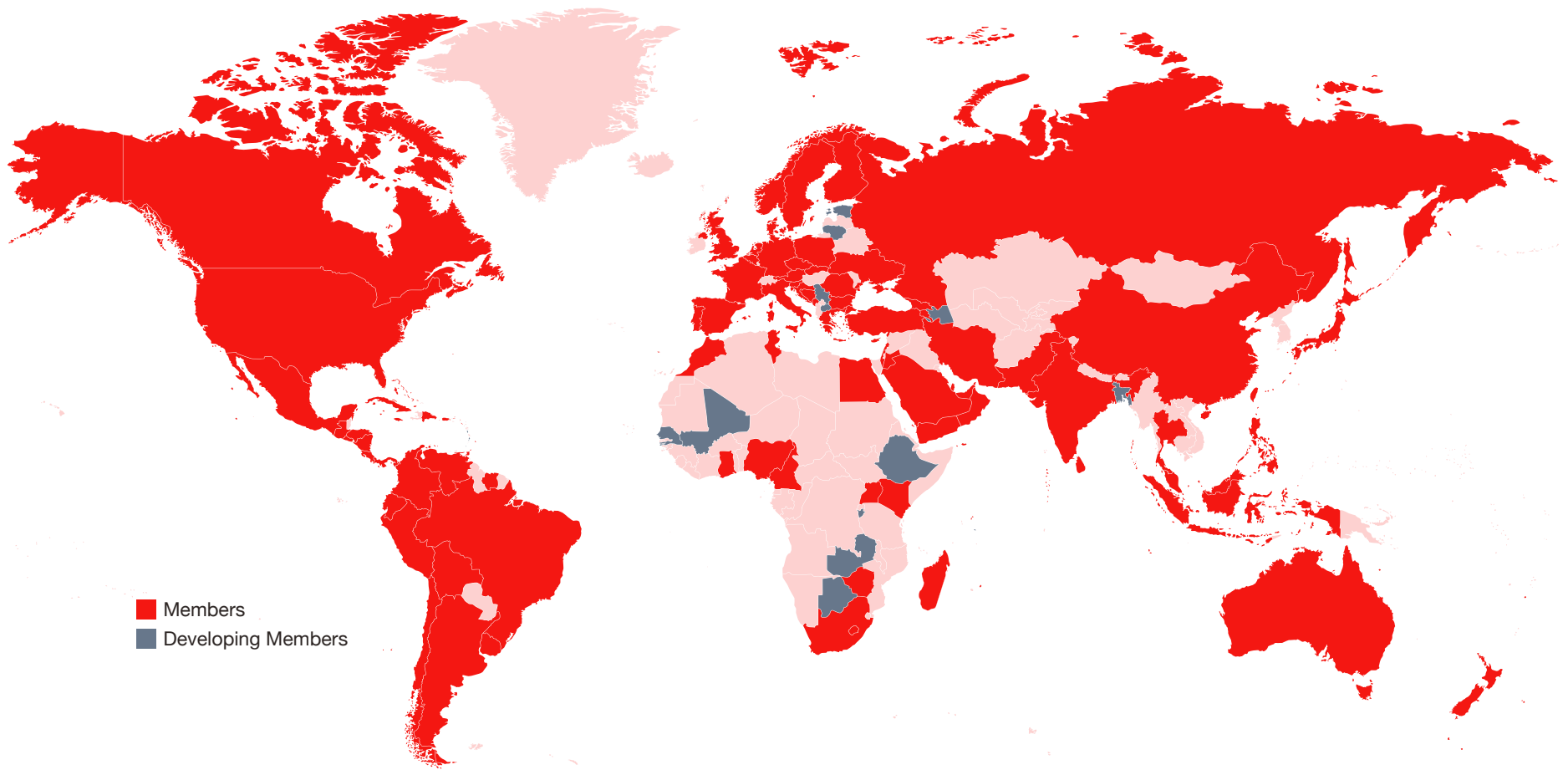
Armenia	Costa Rica	Germany	Israel	Mexico	Russian Federation	Thailand
Austria	Cuba	Gibraltar	Italy	Netherlands	United Kingdom -	United Kingdom -
Bonaire	Curacao	Greece	Japan	New Zealand	Scotland	Northern Ireland
Brazil	Cyprus	Iceland	Korea, Republic of	Norway	Singapore	United Kingdom - Wales
Canada	Czech Republic	Indonesia	Luxembourg	Portugal	Sweden	United States of America
Chile	Denmark	Iran	Macau	Puerto Rico	Switzerland	Uruguay
China	Dominican Republic	Ireland	Malta	Qatar	TADA Chinese Taipei	Vietnam

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

Australia	Ethiopia	India	Panama	Trinidad and
Bosnia and	France	Kenya	Peru	Tobago
Herzegovina	Georgia	Malaysia	Poland	Turkey
Brunei	Ghana	Maldives	Romania	Ukraine
Croatia	Hong-Kong	Nepal	Spain	United Kingdom -
Dominica	Hungary	Nigeria	Suriname	England

Based on information received from Alzheimer and dementia associations, May 2024

ADI Members and Developing Members (as of April 2024)

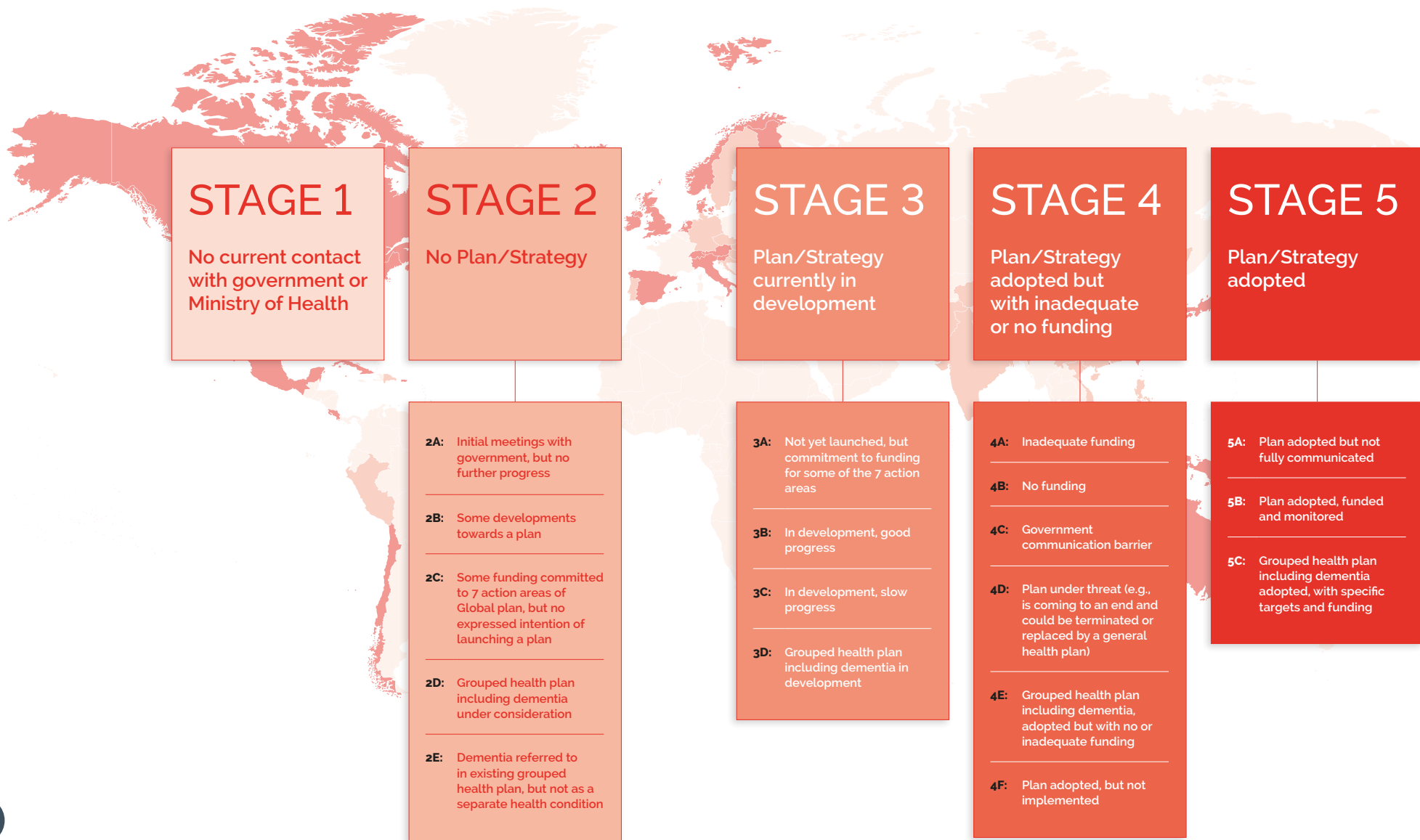


■ Members
■ Developing Members

ADI Members										
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Austria	Bulgaria	Curaçao	France	India	Lesotho	Netherlands	Poland	Slovak Republic	The Bahamas	Venezuela
Barbados	Cameroon	Cyprus	Georgia	Indonesia	Macau SAR China	New Zealand	Portugal	Slovenia	Tonga	Yemen
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Ethiopia	Zambia
Grenada	
Lithuania	
Mali	

Stages of national dementia plan development



Methodology

In order to measure states' activity against the WHO Global action plan, ADI distributed a survey in January 2024 to our 103 member associations, 21 developing associations, and 10 other associations preparing to join ADI's Membership Development Programme.*

Each member association is a national Alzheimer or dementia organisation in that country or territory. 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 if dementia was integrated into another policy area (Action area 1) in each country based on five stages (listed in the graphic on page 17). The survey also asked for examples of advocacy, and policy updates in relation to the remaining six action areas. The survey received a 69,5 percent response rate, with a total of 93 replies. Where a survey response was not received, ADI conducted desk research in order to estimate a stage.

Report structure

This report is divided into seven chapters, each one based on an action area of the WHO Global action plan on the public health response to dementia:

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

Each chapter begins with an essay from a thought leader in the field examining how dementia policy can positively impact efforts related to the related action area. Expert commentary is included throughout showing innovations, projects, and considerations related to each action.

* Accurate as of January 31, 2024.

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.

Of all the action areas of the Global action plan on dementia, the first forms the foundation from which the rest follow. Without governments recognising the importance of prioritising dementia, Alzheimer's and dementia associations are often the only actors available to advocate for support for people living with dementia and their carers as they face the myriad of challenges the condition throws at them. As you will see in this chapter through the testimonies of associations from around the world, the work of these organisations is made infinitely harder when there are no policies or structures in place to support their efforts.

As Drs Daniel Salinas and Ignacio Amorín expertly lay out in their essay, Uruguay's longstanding commitment to the fields of neurology and public health laid the groundwork for the country to establish a strategy towards a national dementia plan (NDP) in 2023. "Our institutional tradition has allowed successive governments, regardless of party affiliation or individuals in power, to articulate policies that protect the less

privileged," they write – creating a fertile ground for dementia strategies to make an impact on the long term. ADI has chosen to highlight Uruguay as a prime example of how national dementia plans are essential to ensuring the implementation of Action area 1 of the Global action plan, one that we hope may inspire other countries to follow suit.

While NDPs are the most comprehensive tool to ensure dementia gets the recognition it deserves on the national stage, Chris Lynch stresses that international forums remain important avenues to advancing dementia policy worldwide. Meanwhile, Professor Martin Orrell and Briony Harden remind us that having a national dementia plan is good, but having one that incorporates a human-rights-based approach is better. Not all dementia policy will by default be good policy – it is essential to take into consideration the specific needs of the people who will be impacted in the country or region, whether they be people living with dementia, informal carers, healthcare workers, or the community at large.

Why are national dementia plans important to ensure dementia is a public health priority?

In order to become more (and better) involved in the various aspects of caring for people living with dementia and their families, and to prepare for a challenging future, the Uruguayan government signed a basic document establishing the strategy towards a national dementia plan in March 2023. Programmes officially endorsed by governments, and aligned with international organisations, ensure that public health priorities both take into consideration and are considered by healthcare providers, patients, families, caregiver organisations, and related institutions. Without a written plan setting out the guiding thread aligning

all these actors with clear and precise objectives and allowing for audit of results, a substantive modification of the current reality is not possible.

Uruguay has a long tradition in the scientific approach to dementia. Our Institute of Neurology, founded in 1926, was the first in Latin America and the second in the Americas. In parallel, Uruguay built a welfare state with a strong commitment to public health, while developing a vigorous social security system. AUDAS (Asociación uruguaya de Alzheimer y similares) was founded in 1991, bringing together scientists, doctors, family members,

and caregivers dedicated to dementia in civil society. The National Institute for the Elderly was meanwhile created in 2012 under the umbrella of the Ministry of Social Development.

Uruguay also became the first country in Latin America to establish a brain health programme under its Ministry of Public Health in 2020. This programme adheres to the call by different organisations – including the United Nations, the World Health Organization, ADI, the Global Brain Health Institute, the Global Council on Brain Health, the Pan American Health Organization, and several governments around the world – for dementia to become a global public health priority.

Uruguay's plan establishes dementia as a public health priority, with a vision of a world... where people with dementia and their carers live well, and receive the care and support they need to fulfil their potential with dignity, respect, autonomy, and equality.

As stated in *The Lancet* in 2017,¹ brain health is the greatest challenge for 21st century societies, in a call for governments and global organisations to place neurology at the top of their priorities. Our country, like the rest of the world, is undergoing dramatic demographic changes. Uruguay is one of the most rapidly ageing countries in Latin America and the Caribbean, with 22 percent of the population projected to be 65 or older by 2050, representing a great challenge for public policy, especially in the realms of health, social security, care, and social services.

The ageing of the population has a direct impact on the country's epidemiology, since 80 percent of the disease burden is made up of non-communicable diseases and degenerative diseases whose main risk factor is precisely age. Currently, some estimates say 50,000 people in Uruguay live with Alzheimer's disease or other forms of dementia, but that number is projected to rise to 112,000 by 2050.

People are living longer, many with chronic illnesses requiring medication and repeated hospitalisations, coming at a high cost for households and institutions. Health spending is expected to reach US\$3.689 billion

in 2050 in Uruguay, with 26 percent of this increase attributed to these demographic changes.

All of this makes it necessary to develop and implement a national strategy and state policy on the issue.

Uruguay's national dementia plan establishes dementia as a public health priority, with a vision of a world in which dementia is preventable, where people with dementia and their carers live well, and receive the care and support they need to fulfil their potential with dignity, respect, autonomy, and equality.

We believe that this written document provides a starting point and a doctrinal basis towards these goals, bringing together and coordinating the efforts of ministries, social organisations, academics, researchers, health care providers, and care systems. The main objective of this strategy is not to provide an immediate solution to all aspects of a major public health problem, but to outline and establish some main guidelines for action and development of a first national plan, with some main strategic components, where it is assumed that it is a problem of national priority, to give visibility, political, and technical orientations from a perspective of rights for people with dementia and their families.

Uruguay's long history in neuroscience, its demo-epidemiological profile, and the efforts of civil society and the state to provide care for disadvantaged populations have enabled the country to draw up its national dementia plan roadmap. Our institutional tradition has allowed successive governments, regardless of party affiliation or individuals in power, to articulate policies that protect the less privileged.

But when it comes to concrete actions and budget allocations, regional and international frameworks must be developed to make these problems visible and encourage decision-makers to prioritise these policies. We hope that Uruguay can be an example in this regard, and that we can learn from the rich international experience of many entities and governments around the world.

Dr Daniel Salinas, 38th minister of public health of Uruguay (2020–2023), Dean of the Faculty of Health Sciences of Universidad Católica del Uruguay, and **Dr Ignacio Amorin**, former director of the Brain Health Programme of the Ministry of Public Health of Uruguay (2020–2023), Professor of the Faculty of Medicine of Universidad de la República – Uruguay

¹ [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(18\)31612-X/abstract](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(18)31612-X/abstract)

Multilateral prioritisation of dementia; the importance of the G7 and G20

In 2017, after 10 years of advocacy for the World Health Organization (WHO) to create its Global action plan on dementia, ADI's advocacy strategy pivoted to focus on the delivery of the global plan,¹ and in particular governments' commitment to create and deploy national dementia plans (NDPs). However, multilateral and regional advocacy remains central to our work, leveraging opportunities including the G7 and G20 forums in a complex policy jigsaw that has been both challenging and rewarding under the rotating presidencies of each group around the world. With over two thirds of the world's population living in G20 countries, and with these countries accounting for 85 percent of the global GDP, it is now more vital than ever to galvanise these nations to support our call for an extension to the Global action plan.

ADI's work has always been about translating research and policy into practice in order to make a tangible difference. Sometimes, multilateral advocacy can feel pedestrian in pace; noisy and complex, with so many voices competing for their area of work to get a priority focus, be that global health, pandemic response, the environment, human rights, gender equality, technology, energy, justice, education, anti-corruption, and – sadly ever more frequently – humanitarian

With over two thirds of the world's population living in G20 countries, and with these countries accounting for 85 percent of the global GDP, it is now more vital than ever to galvanise these nations to support our call for an extension to the Global action plan.

response. Establishing and maintaining dementia as a global and national priority is increasingly difficult and in the aftermath of the COVID-19 pandemic the condition has dropped down the priority list for many countries. That is why opportunities like the G7 and G20 remain so vital, not just in terms of the responses of the countries in these two groups, but of the wider group of nations engaged, including the European Union, and the message that a G7 or G20 commitment can send globally.

Each year since 2018, when Argentina held the G20 presidency, ADI has worked alongside our national member associations in the C20 (Civil Society 20), advocating for dementia to be a healthcare priority (C7



G7 health ministers met in Nagasaki, Japan in May 2023 to discuss dementia.

¹ Alzheimer's Disease International (2023) From plan to impact VI: Making every step count. London: Alzheimer's Disease International

performs a similar role alongside the G7 process). We have increasingly adopted a strategy of stakeholder partnership and direct communication with G7 and G20 state governments. Japan's G20 presidency in 2019 resulted in the most tangible of outcomes, with six distinct actions around dementia featured in the Health Ministers' Okayama Declaration. In the years since, characterised by pandemic challenges and varying political agendas, it proved more difficult to leverage attention for dementia under the presidencies of Saudi Arabia, Italy, and Indonesia, with some focus returning under India's presidency in 2022. Japan's presidency of the G7 in 2023 also proved critical, with a rare, dedicated side event in Nagasaki and with dementia specifically featuring in both the communiqués from health ministers' and G7 leaders. The 2023 outcome documents both focussed attention on our call for an extension to the Global action plan, underlining its importance as the best tool governments have available to tackle the multifaceted challenges that dementia represents for countries, healthcare systems, communities, and, most importantly, to people living with the condition and their loved ones.

Opportunities like the G7 and G20 remain so vital, not just in terms of the responses of the countries in these two groups, but of the wider group of nations engaged... and the message that a G7 or G20 commitment can send globally.

During the launch of our *From Plan to Impact* report at the World Health Assembly in May 2023, ADI turned up the volume around our call for the extension to the Global action plan, building on the foundation of the G7 Nagasaki dementia meeting. In October 2023, the Dutch government hosted the Defeating Dementia summit in The Hague, alongside the World Dementia Council. This provided a prime opportunity to build momentum with multiple ministries of health and with a resounding outcome in the summit's communiqué, a clear call for extension to the Global action plan.

Since The Hague summit, ADI has been in constant communication with governments around the world to work towards the inclusion of the call for extension on the agenda of World Health Assembly 2025. This requires a number of supportive member states to request the extension as a specific agenda item at the next WHO Executive Board meeting, triggering a vital reflection on the progress towards the Global action plan. We are aiming for an agreement to a 10-year extension.

In 2024, we continue our multilateral advocacy working with our national associations in Italy and Brazil, as their governments take on the relevant presidencies of the G7 and G20 respectively. Our attention is already turning to Canada and South Africa for 2025 – a truly important year for the Global action plan.

Chris Lynch, ADI deputy CEO and policy, communications, and publications director

National dementia plans – where next?

In 2012, the World Health Organization and Alzheimer's Disease International declared dementia a public health priority in a landmark report.¹ Five years later, all 194 member states affiliated with the WHO unanimously adopted the Global action plan (GAP) on the public health response to dementia 2017–2025.² This bold foundation helped establish dementia as an essential global health priority – but seven years on, we know that the lofty ambitions of the GAP are progressing far too slowly.

Central to this action was the proposal for all WHO member states to develop national dementia plans with a series of action areas for improving dementia care in their territory. In 2018, the WHO published a guide on how to establish a national dementia plan, together with a situational analysis and main themes, and ADI has since published a structured guide on how to assess impact and implementation of the plans.³ However, ADI noted in 2023 the slow overall progress, and, in some countries, the impression that initially good steps were now moving in reverse. To date, more than 50 national dementia plans have been recorded, although not all are available online. Moreover, for some countries, the implementation period has finished and there are no current plans in place. This led ADI to recommend that the GAP be extended until 2035 to reach the target of 75 percent of member states having their own dementia plan.

Our own work on the plans includes a detailed content analysis looking at whether available plans have highlighted human rights in dementia care and the person-centred approach. We looked meticulously at each of the plans, examining them with key criteria in relation to the United Nations Convention on the Rights of Persons with Disabilities (CRPD),⁴ which was adopted by the United Nations General Assembly in 2006 and came into force in 2008. As of February 2024, the CRPD has 164 signatories and 190 parties (189 states and the European Union).

Many of the plans involved people with lived experience of dementia in their development, and around half of the dementia plans mentioned the GAP.⁵ However, less than a third mentioned the CRPD, even though it has been formally ratified across the world. Most plans were good at acknowledging basic human rights such as legal capacity and community inclusion. However, there was a need for a greater awareness of coercive practices and the actions needed to stop them.

Focusing on a human rights-based approach in dementia care is essential because people with dementia are rights holders and states and governments have a responsibility to uphold their human rights. As Steele (2018) acknowledges in her book 'Dementia and human rights', dementia is a human rights problem because a diagnosis can lead to increased chances of marginalisation, inequalities, and discrimination.⁶ Our work on the rights content of national dementia plans can help ADI, the WHO, and governments across the globe to adapt their policies and practices to encompass a more rights-based approach to dementia.

There has been some disappointment with the comparatively slow progress of nations to develop and adopt national dementia plans. Nevertheless, efforts to develop new dementia plans across the world are bound to highlight the importance of good quality dementia care. This means that the production of more dementia plans will, in itself, improve awareness of dementia. This will have the added benefit of keeping the importance of good quality dementia care in the public eye.

Professor Martin Orrell, director, and **Briony Harden**, PhD student, WHO Collaborating Centre for Mental Health, Disabilities and Human Rights, Institute of Mental Health, University of Nottingham, UK

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- 1 World Health Organization. (2012). Dementia: a public health priority. World Health Organization. <https://iris.who.int/handle/10665/75263>
 - 2 Alzheimer's Disease International & Dementia Alliance International. (2016). Access to CRPD and SDGs by persons with dementia. Alzheimer's Disease International. <https://www.alzint.org/resource/access-to-crpdc-and-sdgs-by-persons-with-dementia/>
 - 3 Alzheimer's Disease International. (2023). From plan to impact VI: Making every step count. Alzheimer's Disease International. <https://www.alzint.org/resource/from-plan-to-impact-vi/>
 - 4 United Nations. (2006). Convention on the Rights of Persons with Disabilities. United Nations. <https://social.desa.un.org/issues/disability/crpdc/convention-on-the-rights-of-persons-with-disabilities-crpdc/>
 - 5 World Health Organization. (2017). Global action plan on the public health response to dementia 2017–2025. World Health Organization. <https://apps.who.int/iris/handle/10665/259615>
 - 6 Steele, L. (2018). Dementia and human rights. Policy Press.

Why national dementia plans matter, in the words of advocates

Over the 40 years of its existence, ADI has built a global network of more than 100 Alzheimer's and dementia associations, each fighting for people living with dementia in their respective countries or territories. This broad coalition brings together non-profit organisations facing vastly different circumstances – from strong state support for their activities to being completely ignored by their governments. In light of ADI's call for an extension to the WHO Global action plan on dementia, we asked our member associations and other dementia advocates across the world one simple question:

How has the presence or absence of a dementia plan in your country or region affected your work?

Here are some of their answers, edited for clarity and brevity, showing the impact of dementia policy on non-governmental actors at every level. The associations based in countries with strong national dementia plans see their efforts bolstered on many levels; those dealing with governments either indifferent or unable to act on dementia often struggle with the responsibility of meeting the needs of people living with dementia and their carers on their own.

Armenia – Stage 5B



Armenia's national dementia plan has created more visibility, awareness, and support from governmental officials to develop research projects, awareness campaigns, and other brain health initiatives.

Chile – Stage 5A



Having a plan has helped us to create more awareness, make the problems that people and their families have visible, but also to make this issue a responsibility for society as a whole to address. A plan is an excellent tool for the articulation of actions and the elaboration of an approach, not only for treatment, but also for social, legal, and social community actions.

Bahamas – Stage 2A



A national dementia plan for the Bahamas is desperately needed. Without a government-supported plan, the rising burden of dementia will cripple the health and social system, as dementia not only involves the patient but their families, employers, religious groups, health and social care providers, and consequently, the country.

Denmark – Stage 5A



Since the creation of the national dementia plan, the Danish Alzheimer's Association has been establishing, creating, and maintaining relationships with politicians at both municipal and national levels with regards to many areas within dementia (waiting times, access to treatment, care, caregivers etc.). The Danish Alzheimer's Association is also represented in various reference groups related to the dementia action plan, influencing dementia efforts in Denmark in a positive and qualified way.

Canada – Stage 5B



We have a national strategy that is funded, with calls for proposals coming out that allow for many diverse organisations to contribute to the plan and get funding around research, programmes (pilots and expansions), awareness programmes (risk reduction and stigma).

Democratic Republic of the Congo – Stage 2A



As a neurologist, the absence of a national dementia plan affects my work in terms of diagnosis rates, awareness campaigns, support for caregivers, and access to treatment and related support.

Germany – Stage 5B



Regardless of problems with implementation, the national dementia strategy is important! It sends a signal both to politicians and to society. A positive aspect of this is that the perception of the German Alzheimer's Association as an advocacy group for people with dementia and their relatives has increased significantly, even if direct positive effects for families have hardly been noticeable or quantifiable so far.

Macau SAR – Stage 5A



The dementia policy has a positive effect, as the government of Macau SAR has taken great strides to improve waiting times, diagnosis rates, and integrated care.

Greece – Stage 5B



The national dementia plan has positively affected the allocation of funds by the Greek government for the creation of new dementia structures (day care centres, mobile units, dementia homes, etc.).

Malaysia – Stage 3D



The presence of a national dementia plan would enable Alzheimer's Disease Foundation Malaysia (ADFM) to have greater and more comprehensive outreach across the country, particularly in rural areas due to ADFM's limited financial and human resources. The development of a national dementia plan would definitely help with more medical care and support, as the burden of care is growing with the ageing population of Malaysia.

Kenya – Stage 3B



The absence of a national dementia plan has implications for access to treatment and support services for individuals living with dementia and their caregivers. There may be inconsistencies in the availability of dementia-specific services, such as memory clinics, respite care, and support groups, leading to unequal access based on geographic location and socioeconomic status. The absence of a coordinated plan may also result in limited research funding opportunities and hinder efforts to advance knowledge about dementia prevalence, risk factors, and effective interventions in Kenya.

New Zealand – Stage 4B



With no decision by the government to implement the Dementia Mate Wareware Action Plan or funding to support services, there are gaps across the whole dementia journey from pre-diagnosis to end of life. Access to services that do exist is uneven and inequitable and the quality of services is variable. We estimate that, at best, 50 percent of people are able to get a diagnosis and around 40,000 are missing out on the community-based dementia services they need.

Lithuania – Stage 2C



The focus on dementia as a national priority is dispersed. The absence of a dementia plan has an impact on diagnostic rates, access to treatments and technical support, public awareness, support for informal carers, prevalence of stigma, lack of investment in research and innovation, gaps in professional training, etc.

Panama – Stage 3A



Families need support from the health and social system, but there is a lack of treatment, and no data. The only dementia awareness campaign is from Asociación de Apoyo a los Familiares de Pacientes con Alzheimer y Otras Enfermedades Demenciales (AFAPADEA) during World Alzheimer's Month, but we need more than a one-month campaign. People living with dementia need support 12 months of the year, not just in September.

Philippines – Stage 2D



The absence of a national dementia plan is the main reason we do not even have the data to support future policy and practice. NGOs like the Alzheimer's Disease Association of the Philippines (ADAP) undertake huge efforts towards awareness and support without funding from the government.

Thailand – Stage 5C



The new policy makes Alzheimer's and Related Disorders Association of Thailand's (ARDA) work easier. Thai people are now more likely to access dementia care facilities near their homes. With Ministry of Public Health campaigning, people are hearing more about dementia, helping our work on risk reduction and support for people living with dementia, and getting closer to our ultimate goal of having a dementia-friendly community in Thailand.

TADA Chinese Taipei – Stage 5B



The existence of a national dementia plan provides an organised framework and national resources that enable more relevant parties to collaborate in addressing challenges associated with dementia. There are now more extensive post-diagnosis support services, a more accurate public understanding of dementia, and an increasing number of families affected by dementia willing to seek assistance from medical and social resources.

Yemen – Stage 2D



The work of the Yemen Foundation against Alzheimer Dementia (YFAAD) is affected in a negative way by the lack of recognition of dementia in our national health strategy. We are alone with the people living with dementia in Yemen.

Key points



Progress on the Global action plan has been slow since its inception in 2017, and the sluggish pace at which we have seen states adopt national dementia plans has been a key indicator of this. Yet people living with dementia, their carers, and communities cannot afford for us to collectively declare defeat. We know that policy is the most powerful driver of change in dementia, and it is never too late for governments to make it a priority.

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.

In order for dementia to be understood as a public health priority, it first must be understood, full stop. Awareness may feel like the most elementary of aspects to the fight against dementia, but it mustn't be underestimated. Dementia is a complex condition and knowledge exchange around causes, impact, treatment, and care requires multilayered explanations and responses depending upon the audience.

As ADI's Lewis Arthurton and Robbie Appleton-Sas discuss in their essay, World Alzheimer's Month has been a key part of global efforts towards dementia awareness for the past 12 years, because ADI and fellow advocates know misinformation remains a major barrier to progress in the field of dementia.

When ADI carried out its first global attitudes to dementia survey in 2019, it discovered that stigma about the condition was still rife – not only within the general public, but also among healthcare professionals. In this chapter,

Wendy Weidner explains why ADI is doing a follow-up survey in 2024, to see whether the past five years have witnessed a shift in perceptions about the condition.

Dementia awareness and friendliness programmes are much more than simply telling the public basic facts about the condition and beseeching them to be kinder to people living with dementia. Awareness needs to embed itself into the very fabric of our societies – as Dr John Zeisel demonstrates in his overview of environmental design for dementia, and the necessity of its inclusion in national dementia plans.

Walk the Talk for Dementia, as narrated by Fernando Peres, is also a welcome reminder that preconceived notions about dementia can be challenged in a myriad of ways – and that even those among us who have dedicated their careers to the condition can always learn something new.

Why national dementia plans need dementia design – and dementia design needs dementia plans

Research has demonstrated over the past five decades the major positive impacts of appropriately designed physical environment on quality of life, wellbeing, and reduced challenging behaviours for people living with dementia. Physical environment includes the design of spaces, signage, access to nature, garden design, the way doors are kept closed, technologies that control a setting, and more.

In the World Alzheimer Report 2020, titled *Design, Dignity, Dementia*,¹ the authors – Richard Fleming, Kirsty Bennett, and myself – made a strong argument for the physical environment, together with psychosocial engagement approaches for people living with dementia, as a viable, fully evidence-based “ecopsychosocial”² therapeutic treatment.

¹ Fleming, R., Zeisel, J., and Bennett, K. (2020). Design Dignity Dementia: dementia-related design and the built environment. Volume I. World Alzheimer Report 2020: London, Alzheimer's Disease International.

² Zeisel J., Reisberg, B., Whitehouse, P., Woods, R., Verheul, A. (2016) Ecopsychosocial Interventions in Cognitive Decline and Dementia: A New Terminology and a New Paradigm. American Journal of Alzheimer's Disease & Other Dementias 1–6

To reflect the latest research, national dementia plans (NDP) need to acknowledge that evidence-based built environments are an essential dementia treatment modality. Every NDP needs to include a section promoting environmental design as a contributor to the wellbeing of persons living with dementia and to reducing symptomatic behaviours such as getting lost, not recognising family members, and so on. Yet most national dementia plans implemented since 2020 have not included references to this considerable evidence-based dementia treatment modality. The Dignity, Design, Dementia Principles highlighted in the World Alzheimer Report³ serve as an excellent starting point for any NDP section focused on environmental design for dementia.

Evidence-based dementia-related design has positively evolved in groundbreaking ways since the report's publication. No self-respecting designer today plans a living environment or public setting for persons living with dementia without first consulting the massive amount of evidence-based design knowledge in articles, books, book chapters, and conference presentations.

The development and conceptual refinement of Alzheimer Villages – a concept in dementia living and care generated and inspired by Hogeweyk in Weesp, Holland, and highlighted in our report – has been a major addition to this field. Such "villages" have been developed in Australia, Canada, Italy, the US, France, and other countries.

The Village Alzheimer Landais⁴ in the southwest French town of Dax, which I have visited and observed several times, is an exceptional example of conceptual refinement inspired by Hogeweyk. With three distinct levels – homes for seven to eight people, neighbourhoods of 30, for a total population of 120 persons – it presents a clear roadmap of how a carefully planned and designed "village community" can bolster a positive, continuous, and comprehensive – thus understandable – life for persons living with dementia.

As important as its physical design, the Village Landais includes an integrated "engagement programme"

connecting all three levels – home, neighbourhood, village – bringing life to the community and its residents, staff, family members, visitors, and many volunteers who donate their time to improve the lives of residents through structured engagement programmes.

In the US, with which I am most familiar, there are also recent excellent and instructive examples of evidence-based dementia design in Georgia, such as A.G. Rhodes,⁵ Canterbury Court,⁶ and Sterling Estates,⁷ which include "household" models of care and "enriched" gardens⁸ among several dementia-friendly design considerations. Certainly, there are other recent examples in the US and other countries that are moving the environmental design for dementia "space" forward.

These examples are clearly rooted in evidence-based design for residential settings, healthcare facilities of all types, and outdoor settings, all of which can help address some of the consequences of dementia and improve quality of life.

In order to remain relevant, national dementia plans must address the ways physical environments can improve the lives of those living with dementia, including in their audience those who operate such settings and those who create them – architects, designers, planners, and landscape architects.

National dementia plans that include requirements for evidence-based dementia design will go a long way towards increasing both private and public sector investment necessary to make dementia-friendly design commonplace.

It is high time we recognise that the physical environment and the engagement-oriented programmes they contain can be organised to support better care, address behavioural symptoms, and reduce stigma, demonstrating that people living with dementia can live authentically engaged lives and remain vibrant members of society.

Dr John Zeisel, PhD, Hon D.Sc., I'm Still Here Foundation

³ John Zeisel Interviews Janette Spiering, World Alzheimer's Report, 2020 (https://www.youtube.com/watch?v=TNUoVf_MEVg)

⁴ Renault, M. (2022) A French Village's Radical Vision of a Good Life with Alzheimer's: Every resident of the Village Landais has dementia—and the autonomy to spend each day however they please. The New Yorker, 23 November 2022 <https://www.newyorker.com/culture/annals-of-inquiry/a-french-villages-radical-vision-of-a-good-life-with-alzheimers>

⁵ <https://www.agrhodes.org/our-homes/cobb-senior-rehabilitation-services/>

⁶ <https://memorycare.sterlingestateswestcobb.com/>

⁷ <https://www.canterburycourt.org/memory-support/>

⁸ Bourdon E, Belmin J. Le concept de jardin enrichi, une innovation en gériatrie. Soins Gerontol. 2022;27(157).

World Alzheimer's Month 2023: Never too early, never too late

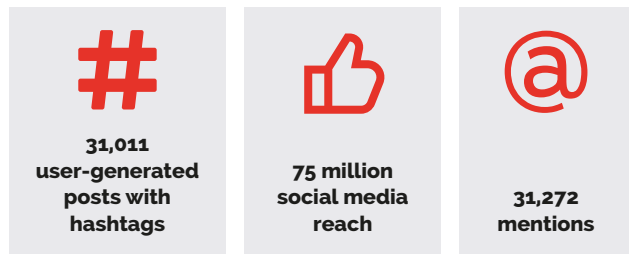
Every year, World Alzheimer's Month is a poignant reminder of the global impact of dementia and the stigma and disinformation that remains prevalent around the condition. Linked to Action area 2 of the Global action plan, World Alzheimer's Month seeks to promote a dementia-friendly society free of stigma and discrimination. The World Health Organization recognised World Alzheimer's Day in 1994, which has been observed on 21 September each year ever since. The extended World Alzheimer's Month campaign, which occurs throughout September, entered its 12th year in 2023.

The 2023 World Alzheimer's Month campaign focused on dementia risk reduction. A study published by the Lancet Commission in 2020 estimated that as many as 40 percent of all cases of dementia could be delayed or avoided by addressing 12 modifiable risk factors, which could equate to 55.6 million fewer cases by 2050, exceeding the number of people estimated to be living with the condition today. The campaign also sought to highlight the importance of addressing post-diagnosis risk reduction, to help ensure those living with dementia remain healthy and independent for as long as possible.

This year's World Alzheimer's Month was officially inaugurated by ADI Ambassador Her Royal Highness Princess Muna Al Hussein of Jordan. As a renowned advocate for health and the nursing profession, Princess Muna's endorsement of the campaign solidified its significance and importance on a global level:

Through this month, we also raise awareness through the use of the hashtags – #NeverTooEarly, reminding us that action can begin at any moment; #NeverTooLate, assuring us that it's never too late to make a difference; #ReduceRiskNow, a challenge and an opportunity; and #WorldAlzMonth, uniting us all in our pursuit.

World Alzheimer's Month 2023 online



In Madagascar, advocates took to the streets to raise awareness of dementia.

The World Alzheimer's Month campaign in 2023 achieved its most widespread coverage in social media and in the traditional media to date. On social media the campaign achieved a reach of 75 million, with the hashtags being used over 30,000 times. In traditional media, the campaign and the World Alzheimer Report were mentioned in at least 1,334 articles.

On World Alzheimer's Day, ADI launched the World Alzheimer Report 2023, entitled *Reducing Dementia Risk: Never too early, never too late*.¹ With Simon Long, renowned editor-at-large for The Economist, as lead writer, the report examined the drivers behind risk reduction and provided an accessible overview of modifiable and non-modifiable risk factors, as well as the benefits of lifelong risk reduction. Journalists from around the world also contributed articles showing how theory and policy can be turned into effective practice.

Lewis Arthurton, ADI communications and policy manager, and **Robbie Appleton-Sas**, ADI digital lead



Alzheimer's Care Armenia had cookies for the occasion.



Alzheimer Indonesia volunteers once again marked World Alzheimer's Month in their trademark purple.

¹ Long, S., Benoist, C., Weidner, W. 2023. World Alzheimer Report 2023: Reducing dementia risk: never too early, never too late. London, England: Alzheimer's Disease International.

Attitudes to dementia – why measuring stigma matters

Challenging global stigma related to dementia has been a major strand of Alzheimer's Disease International's (ADI) work for the past 40 years. We have led efforts to raise global awareness of dementia through the World Alzheimer's Month campaign every September since 2012 and have supported dementia-friendly initiatives through the work of our member associations around the world. Based on a small survey, our 2012 World Alzheimer Report¹ explored the nature of dementia-related stigma and provided case studies of practices to reduce stigma.

Despite these efforts, our member associations kept sharing stories of how dementia-related stigma created barriers to accessing treatment, care, and support. Worse, it often led to isolation and discrimination – and in some cases, physical harm.

In 2019, ADI decided it was time to take stock of the true global impact of dementia. We commissioned the London School of Economics and Political Science (LSE) to help us run a global survey on attitudes to dementia. We wanted to know, once and for all, what people around the world *really* thought about dementia.

Some 68,000 people responded to our survey at the time – making it the largest global survey on dementia to date. We were astounded by some of our findings, all of which can be found in our 2019 World Alzheimer Report,² but one misguided belief is worth mentioning here: globally, two out of three people believed that dementia is a normal part of ageing. More astoundingly, 62 percent of healthcare professionals thought the same thing.

Why does this matter? If people do not realise that dementia is not a normal part of ageing, they won't seek out a diagnosis. And worse yet, if health professionals do not recognise dementia as a progressive health condition, they won't *provide* a diagnosis – leaving the person and their family to cope without access to treatment, care, and support.

Armed with this and other evidence from the survey, ADI was able to ramp up its advocacy at global, regional, and local levels alongside our member associations. We spoke directly to governments, emphasising how access to national dementia plans could give the sort of structured framework necessary to prioritise dementia awareness and inclusion, provide a pathway to timely

Join thousands of others
and help us to build the
world's largest
international survey
on attitudes towards dementia.



diagnosis and access to treatment and care, ensure education and training of health and long-term care professionals, and encourage risk reduction strategies.

Five years on, ADI has commissioned LSE once again to help us carry out an updated version of the 2019 survey to see what – if anything – has changed regarding attitudes to dementia. The world is a different place now. We have endured a global pandemic in which people with dementia experienced marked discrimination;

¹ Batsch, N.L. and Mittelman, M.S. (2012) World Alzheimer Report 2012. "Overcoming the Stigma of Dementia". Alzheimer's Disease International. <https://www.alzint.org/u/WorldAlzheimerReport2012.pdf>

² Alzheimer's Disease International. 2019. World Alzheimer Report 2019: Attitudes to dementia. London: Alzheimer's Disease International. <https://www.alzint.org/u/WorldAlzheimerReport2019.pdf>

several geopolitical conflicts have created humanitarian crises during which people with dementia are often forgotten. Conversely, there are new disease-modifying drugs and new diagnostic technologies coming onto the market. Are these factors, good or bad, impacting how people view dementia?

We want to find out. ADI's 2024 World Alzheimer Report will revisit the subject of stigma. Translated into dozens of languages, the global survey is once again focusing on four key groups: people living with dementia, caregivers, health and care professionals, and the general public.

The survey will run until late spring 2024, meaning that and at time this report is published, there will still be some time to take the survey or find out more about our findings at: <https://www.alzint.org/get-involved/attitudes-to-dementia-world-alzheimer-report-2024-survey>.

The Attitudes to Dementia survey will form the heart of the report, supplemented by case studies from around the world highlighting best practices and innovation.

The worldwide dementia community is at the brink of great change – some say this will be the 'decade of the brain'. But stigma could cause us to falter. This is why measuring stigma matters. We need to know where we are if we are going to change things for the better. Dementia policy needs to be informed by real-world evidence so it can be developed in an impactful and sustainable way – and all of us can play a small part in making this happen.

Wendy Weidner, director of research and publications, ADI

Walking the Talk for Dementia: A transformative journey

Kevin Quaid, 63, is a strong man with a powerful presence and deep blue eyes. Diagnosed with Lewy Body dementia six years ago, he continues to live an active life in a quiet Irish town with his wife Helena, becoming a steadfast advocate for people living with dementia in Europe. But when I invited him to join the first Walking the Talk for Dementia (WTD) in May 2023, Kevin hesitated: "Do you think I can?" he asked.

The idea for the WTD was inspired by the *Camino de Santiago de Compostela*, a historic pilgrimage in northern Spain, and my personal journey with my beloved grandmother. To walk the Camino had been one of her unrealised dreams – first because of financial constraints, and later because her diagnosis of Alzheimer's had her (and others) believe she wasn't capable. Years later, I reached out to Clara Dominguez,

a colleague in the Atlantic Fellows for Equity in Brain Health programme, to create an experience that could challenge how people perceive and behave towards dementia. It all started with a question: What if we could bring people living with dementia to walk the Camino? This is when Gustavo San Martin, María Eugenia Godoy, and others embraced our dream.

WTD is more than a conference; it's an immersive experience designed to reshape individual and collective approaches to dementia, aiming to change how we share knowledge, empower those impacted by dementia, encourage collaboration, and help break the stigma around the topic.

This experience brings together healthcare professionals, policymakers, researchers, artists, advocates, people



living with dementia, and care partners for a four-day, 40-km walk on this famous pilgrimage route. Along the way, our diverse group of participants engages in discussions about their challenges associated with dementia in various contexts, sharing personal thoughts, inspiring initiatives, professional expertise, and lived experiences. It is here that connections start to form. Following the walk, the group participates in a two-day symposium to consolidate reflections and collaborations. Our aim was to establish an event that goes beyond conventional knowledge silos. WTD was envisioned as a gathering where egos and power dynamics were set aside, providing an opportunity to connect with the individuals behind the professional titles and challenge both our bodies and minds, pushing us beyond our comfort zones.

I lived with my grandmother for six years after her diagnosis, and left college and work to care for her, my best friend. But how many professionals working with dementia understand what it's really like to be living with dementia? How many turn the lights off and shut the doors of the labs, to return home accompanied by dementia?

During WTD 2023, a neurologist said: "[Before this experience,] if any of these people with dementia here had asked me if they could participate in this project, I would have said no; this group is changing the way I practice medicine." An entrepreneur in dementia and technology meanwhile stated: "I feel like I have new superpowers in advocacy after this experience."

Walking side by side, we realised that the person with dementia isn't always the one who needs support, and that we all care for each other. When Desmond O'Sullivan, who lives with Lewy Body dementia, had a fall during the walk – he wasn't hurt – and everyone came to support his wife and care partner, who was deeply concerned. While 70 people were there willing

to help, Desmond looked at his wife and asked: "Do you want me to get you a glass of water?" This helped us rethink the relationship between someone living with dementia and their caregivers.

The walk was transformative. We had renowned researchers used to major conferences where they speak to thousands of people, but who, for the first time, had the opportunity to really get to know their audience before taking the stage. As a result, the speakers all changed their presentations, making it a unique and engaging experience.

Last year, WTD brought together 70 people, including 10 with dementia from various countries. In 2024, WTD will take place from August 25 to September 1 ahead of World Alzheimer's Month, with over 20 nationalities confirmed to participate. We believe that WTD complements traditional conferences on dementia, championing inclusivity, diversity, empathy, and collective leadership. As an approach, Walking the Talk translates into 'act in accordance with what you say', and I think the big question that remains after this experience is: are we turning our narratives into tangible actions to address the challenges posed by dementia worldwide?

This is a journey of empathy, a transformative experience fostering a deeper understanding of dementia, bringing together diverse perspectives, promoting collaboration, and empowering individuals to make a real impact in dementia care and research.

Kevin Quaid agreed to participate. He said he would make me proud. He never needed to prove anything to me. But I can assure we are all proud.

Fernando Peres, *Global Atlantic fellow for equity in brain health at the Global Brain Health Institute, and co-founder of the Walking the Talk for Dementia.*

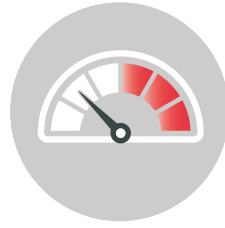
Key points



It is crucial for governments seeking to make a positive difference for people living with dementia and their carers to think about how stigma, indifference, and misinformation affect many aspects of their lives, from the environments that they navigate to the hurdles they may face at the doctor's office, in the workplace, or on the street. Dementia awareness and friendliness is a broad topic, but it is also one that can be addressed in many ways. Understanding what beliefs are broadly held in one's country or community is an important first step to countering any misconceptions or negative narratives about the condition and the people affected by it.

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.

With the world's population growing inexorably older, experts have warned that dementia is more and more likely to become an unavoidable global public health issue. But the projected rise in incidence of dementia is not inevitable; in the absence of a cure for the time being, reducing risk is key. Professor Gill Livingston highlights in this chapter the extensive guidelines set by The Lancet regarding modifiable risk factors for dementia.

As highlighted by Dr Agustín Ibáñez in his essay introducing this chapter, dementia risk reduction is not one size fits all. Disparities in biological and environmental factors, as well as access to treatments and resources, between the Global North and the

Majority World necessitate tailored interventions at the national level to tackle specific risks that may be more prevalent in some places than in others. This impulse is what guides the efforts of the AFRICA-FINGERS project. Dr Chinedu Udeh-Momoh writes, in implementing sustainable and culturally sensitive interventions for dementia risk reduction across the continent.

Risk reduction doesn't end once someone develops dementia, however. Niranjana Bose and Professor Miia Kivipelto remind us that ensuring a timely diagnosis is key to providing the best post-diagnosis risk reduction strategies possible so that people with dementia can live life to the fullest for as long as possible.

Multidiversity and tailored dementia plans: the path forward for dementia risk reduction in the majority world

National dementia plans and government policies are critical for enhancing the lives of individuals with dementia and their caregivers. These are essential policy tools to guide the provision of care and support, address the societal and economic impact of dementia, and the strategic allocation of limited resources. But their effectiveness hinges on the availability of sufficiently detailed and contextualised evidence, which can capture variability across contexts and can inform adequately adapted solutions. In the majority of the world, and especially in the Global South, population diversity and disparity¹ bring heterogeneous biological and environmental factors that impact dementia and dementia risk across dimensions.

Despite the urgent need to bring diversity and tailored recommendations, an imbalance in the knowledge of dementia across regions persists.^{1,2} Most research has been conducted in high-income settings within the North America and Europe, often overlooking the diverse, disadvantaged, and non-stereotypical populations in the Global South.³ The Middle East/ North Africa region and Latin America currently exhibit the highest dementia prevalence, with Central Europe having the lowest, and the projected increase in prevalence is much faster in the Global South than in the north.

Such difference is associated with socioeconomic and multimodal disparities. Cardiometabolic disorders, a

¹ Risk factors related to population diversity and disparity determine healthy aging. *Nature medicine* 2023; 29(9): 2183–4.

² Ibáñez A, Legaz A, Ruiz-Adame M. Addressing the gaps between socioeconomic disparities and biological models of dementia. *Brain: a journal of neurology* 2023; In press.

³ Baez S, Alladi S, Ibáñez A. Global South research is critical for understanding brain health, ageing and dementia. *Clin Transl Med* 2023; 13(11): e1486.

significant risk factor for dementia, are more prevalent among underserved populations.^{3,4,5} Genetic and environmental risk factors are not homogenous across ancestries and regions, and our knowledge of these is far from global.^{4,5,6} Health and social disparities induce larger and heterogenous risks in Latin America, more than traditional factors like age and gender.⁷ Brain-phenotype models trained with homogenous populations from the Global North will likely misrepresent the characteristics of more diverse populations.⁸ Diagnosis, availability of care services, and awareness are lower in Eastern countries compared to Western ones.⁴ The caregiver burden is increased in Latin America compared to other regions.⁹ Most neuropsychological tests have been developed for educated, English-speaking Western populations and are less suitable for other cultures.^{4,5}

Taken together, this evidence highlights that our brain health and brain capital are not universal.⁸ A single, monolithic, and unidimensional body of knowledge on dementia does not represent the best strategy for all nations,³ particularly in the majority world.

The prevailing knowledge of dementia, heavily influenced by research and practices from the USA and Europe, may not be directly applicable or practical in other contexts. Tackling diversity, disparity, and situated knowledge can enhance customised strategies for policymakers.

Efforts to harmonise and tailorise methodologies and assessments across regions are urgently needed. These initiatives have been primarily focused on Caucasian populations, neglecting underrepresented populations. Harmonisation frameworks across various disciplines (epidemiology, clinical research, neuroscience, social sciences) are needed to inform local governments. Incorporating diversity, locally validated protocols, and specific risk factors are relevant for tailored regional plans proposed for Latin America⁵ and Africa.¹⁰ Tailored computational predictive models generated with local data and treatments for dementia that fit the needs of diverse populations should be part of long-term plans.

Challenges triggered by diversity of dementia across the globe cannot be met with a one-size-fits-all approach. The current and projected prevalence, particularly in

the Global South, call for locally informed strategies considering the unique sociocultural and biological landscapes of these regions. Governments must make concerted efforts to create better local knowledge regarding disparities, poverty, and healthcare access that significantly contribute to dementia risk.

Integrating structural change with individual behavioural interventions is paramount to achieving meaningful progress in prevention and treatment. While individual behavioural change is crucial in addressing risk prevention and diagnosis, reliance solely on traditional approaches is insufficient. Without addressing structural inequalities, messaging around prevention can become misleading or counterproductive, mainly when focusing on vulnerable populations.

Moreover, the inaccessibility of disease-modifying therapies due to economic and infrastructural barriers calls for developing alternative, region-specific pathways and strategies. These inequalities make risk reduction an even more critical primary strategy. Without reliable access to therapies, preventing dementia becomes the key intervention for managing public health outcomes in the Global South. Risk reduction can also help mitigate the long-term societal and economic burdens of dementia in regions where healthcare systems may already be under-resourced and overstretched.

We need a sustained commitment from all stakeholders. Governments, healthcare providers, researchers, and civil society must unite, leveraging a wealth of local knowledge and evidence and confronting the social determinants of health head-on. Only through a deep understanding of the complexities within each distinct context can we forge national plans that are effective, equitable, and compassionate. We call upon global leaders and policymakers to act decisively and innovatively, paving the way for dementia care that genuinely respects and responds to the diversity of the populations it aims to serve.

Dr Agustín Ibáñez, *Latin America Brain Health Institute (BrainLat), Universidad Adolfo Ibáñez; and Global Brain Health Institute (GBHI), Trinity College Dublin.*

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- 4** Maestre G, Carrillo M, Kalaria R, et al. The Nairobi Declaration-Reducing the burden of dementia in low- and middle-income countries (LMICs): Declaration of the 2022 Symposium on Dementia and Brain Aging in LMICs. *Alzheimer's & dementia : the journal of the Alzheimer's Association* 2023.
- 5** Parra MA, Baez S, Sedeño L, et al. Dementia in Latin America: Paving the way toward a regional action plan. *Alzheimer's & dementia : the journal of the Alzheimer's Association* 2021; 17(2): 295-313.
- 6** Ibanez A, Zimmer E. Time to synergize mental health with brain health. *Nature Mental Health* 2023.
- 7** Santamaria-Garcia H, Sainz-Ballesteros A, Hernandez H, et al. Factors associated with healthy aging in Latin American populations. *Nature medicine* 2023.
- 8** Greene AS, Shen X, Noble S, et al. Brain-phenotype models fail for individuals who defy sample stereotypes. *Nature* 2022; 609(7925): 109-18.
- 9** Ibáñez A, Pina-Escudero SD, Possin KL, et al. Dementia caregiving across Latin America and the Caribbean and brain health diplomacy. *Lancet Healthy Longev* 2021; 2(4): e222-e31.
- 10** Akinyemi RO, Owolabi MO, Okubadejo N, Ogunniyi A, Kalaria RN. The African Dementia Consortium. *The Lancet Neurology* 2023; 22(1): 28-9.

The way forward for dementia risk reduction: policy and The Lancet's modifiable risk factors

We live in exciting times for dementia prevention, with increasing understanding of its possibility and importance. In survey after survey, people in midlife cite dementia as the condition they most fear. Risk reduction and prevention would benefit individuals but also families, who provide most of the care, and the economy.

What changes would reduce risk?

An overview of risk in our Lancet commissions (2017, 2020)^{1,2} discussed 12 factors with scientifically robust, consistent evidence that changing or removing them had the potential to prevent or delay onset in 40 percent of cases of dementia: less education, hearing loss, hypertension, physical inactivity, diabetes, less social participation, excessive alcohol consumption, air pollution, smoking, obesity, traumatic brain injury, depression.

In keeping with this finding, many high-income countries in the US and Europe have seen a reduction in the age-specific incidence of dementia, even as the number of people with dementia increases as more people live to old age. Dementia in other countries has increased or remained steady. It is important when considering risk reduction to keep in mind that there are many people with neuropathological or vascular brain changes that theoretically might lead to dementia, but who do not develop dementia. This ability to withstand such changes is labelled cognitive reserve or brain resilience.

Risk reduction can therefore be informed by a two-pronged theoretical approach. One of these would be to prevent pathological changes in the brain, and the other to increase people's brain resilience, so they are less likely to develop dementia despite neuropathology.

12 dementia risk factors

Source: Livingston et al. A. et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission

www.alzint.org

Alzheimer's Disease International
The global voice on dementia

¹ Livingston G et al. Dementia prevention, intervention, and care. Lancet. 2017 Dec 16;390(10113):2673-2734. doi: 10.1016/S0140-6736(17)31363-6. Epub 2017 Jul 20. PMID: 28735855.

² Livingston G et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. Lancet. 2020 Aug 8;396(10248):413-446. doi: 10.1016/S0140-6736(20)30367-6. Epub 2020 Jul 30.

Which individuals reduce their risk?

The findings around dementia risk factors have empowered some individuals to change their lifestyle, increase their brain health, and reduce their risk of dementia.

People who do this tend to have a variety of resources, including access to knowledge and, often, the cultural, social, and financial capital that means they can choose, for example, to go out to exercise and to access foods that are lower in salt and sugar and make hypertension and diabetes less likely. Thus, people implementing these beneficial changes are more likely to have higher education and the linked outcome of living in areas where it is safer to walk around and where healthier food is more available than people who are at higher risk. Therefore, those who benefit from this knowledge are often the people who are at lower risk of dementia.

Have policy changes reduced risk?

The reduction in age-related incidence of dementia in some countries has been linked with policy changes, such as increasing the availability and length of universal education, or better detection and treatment of hypertension. In many countries, cigarette smoking has been reduced by an approach that restricts places where people can smoke and the advertising of cigarettes, and increased cigarette prices. There is clear evidence from cohort studies that stopping smoking reduces or removes the excess risk of dementia of cigarette smokers compared to non-smokers.

The way forward

Policy-level interventions are a way forward in dementia prevention and risk reduction, which is likely to include those at higher risk and lead to individual health and societal benefits. We have shown that energetic

treatment of hypertension and interventions for hearing loss should save money and be cost effective in dementia. The US government has responded to the evidence by making hearing aids available over the counter and more affordable. The UK government has incorporated cardiovascular interventions to reduce dementia in midlife health checks.

Other policies that potentially reduce the risk of dementia include:

- Education for all.
- Mandatory reduction in salt and sugar in food and subsidies for healthy foods to reduce obesity, hypertension, and diabetes in the entire population.
- Policies to reduce cigarette smoking as outlined above in countries that do not have these in place.
- Minimum price levels for the sale of units of alcohol.
- Policies to reduce air pollution, including subsidising the replacement of more polluting vehicles.
- Reducing exposure to noise that damages hearing, advertising campaigns for designer hearing appliances (as is the case with glasses) to reduce stigma and making hearing aids affordable and available.
- Provision of safe green spaces which people can walk or exercise in.
- Creation of socially connected housing with natural spaces where people who live alone can meet, in line with the WHO's Global Age Friendly Cities Guide.³

Most of these policies will be cost-saving or neutral in terms of dementia alone. They will also reduce other illnesses and improve individual's quality of life – a no-brainer to improve brain health.

Gill Livingston, *professor of psychiatry of older people, Faculty of Brain Sciences, University College London*

³ World Health Organization. (2007) Global Age-Friendly Cities: A Guide. Geneva: World Health Organization. <https://www.who.int/publications/i/item/9789241547307>.

Timely diagnosis as a risk reduction strategy: the AD-RIDDLE project

The pathology of Alzheimer's Disease (AD) can begin decades before people start showing symptoms. This gradual progression creates a window of opportunity for patients if the condition is detected early. Earlier detection enables patients and healthcare providers to utilise the full spectrum of options for risk reduction and treatment, including new advances in AD diagnostics and therapeutics.

The Real-World Implementation, Deployment, and Validation of Early Detection Tools and Lifestyle Enhancement (AD-RIDDLE) project aims to develop, test, and deploy a modular toolbox platform that can improve detection, diagnosis, prevention, and treatment of AD. A key objective of AD-RIDDLE is to make AD management more efficient and effective for all stakeholders, leading to better outcomes for patients and their families. This means ensuring people with preclinical (before symptoms are detectable with cognitive tests) or prodromal (mild cognitive impairment) AD receive a timely diagnosis, enabling them to receive personalised interventions (pharmacological and non-pharmacological) within the timeframe that will benefit them most.

Although Alzheimer's Disease is a global challenge, the different health systems, clinical approaches, and varying cultural contexts from country to country call for tailored solutions.

In 2023, the EU Innovative Health Initiative (IHI), a cross-sectoral public-private partnership, issued a call for a "screening platform and biomarkers for prediction and prevention of diseases of unmet public health need." We launched AD-RIDDLE in January 2024 with the support of IHI and UK Research and Innovation (UKRI). The AD-RIDDLE Consortium will leverage the deep expertise of its 24 partners – a unique, interdisciplinary collaboration of academic researchers, healthcare providers, industry, regulatory bodies, and patient advocacy organisations – to develop and test the toolbox platform. The project will span five years, including a three-year test in eight primary care and memory clinics in six European countries (Sweden, Finland, Netherlands, Spain, Italy, and the UK). The toolbox components will be adjusted based on feedback and data collected from these test sites.

The AD-RIDDLE project understands that, although AD is a global challenge, the different health systems, clinical approaches, and varying cultural contexts from country to country call for tailored solutions.

Consequently, the platform will be flexibly designed to allow users to mix and match component tools to meet varying needs across healthcare settings.

The AD-RIDDLE toolbox platform will include:

- 1. Digital engagement portal:** This will be the "front door" of the platform, easy to access and navigate. Its goal is raising awareness and encouraging screening in the general population. Individuals will be able to engage in online cognitive pre-screening tools, chatbots, a contact management system to enable self-guided assessment and follow-up communications, patient and family/care partner resources, and more. It will be refined during testing to ensure individuals can interact with it seamlessly, regardless of their digital literacy.
- 2. Digital cognitive assessments (DCAs) and tools:** DCAs are accessible and cost-effective alternatives to paper-based tests, and possibly exhibit higher sensitivity to early detection. The toolbox will offer a variety of DCAs. This will allow healthcare providers and researchers to not only predict AD risk in cognitively healthy individuals, but also monitor the real-world impact of prevention and treatment, sharpening our understanding of the efficacy of these treatments.
- 3. Blood-based biomarkers (BBM) in Alzheimer's Disease:** BBMs are a cost-effective and less invasive alternative to detect dementia. Despite the exciting breakthrough research in recent years, identifying high-performing BBMs have yet to be implemented because they have not been studied prospectively and validated in patients with memory impairment in memory clinics. Thanks to the healthcare infrastructure, research, and BBM contexts in the European countries selected for this project, AD-RIDDLE has a unique opportunity to study the clinical robustness and accuracy of high-performing plasma AD biomarkers prospectively in diverse real-world populations in both memory and primary care clinics. Validating these advances in clinical practice is a critical step towards increasing the availability of BBMs worldwide and accelerating the development of precision therapies to prevent or delay AD dementia.
- 4. Predictive algorithms for early risk/disease detection and a decision support toolkit for precision prevention therapies:** The AD-RIDDLE project is uniquely positioned to harness several large datasets that Consortium members maintain spanning the full

spectrum of AD stages, in order to seamlessly connect risk prediction to real-world preventive interventions, including lifestyle modifications. We have the rare opportunity to develop and validate predictive algorithms for AD, which have been extensively researched but are limited in clinical use. This could increase accuracy in early risk detection and deepen our understanding of various prevention therapies.

These tools will enhance access to early detection and preventive therapies. As a result, healthcare professionals will have more validated tools at

their disposal to identify and treat at-risk patients, researchers will benefit from validated biomarkers to expedite development of precision therapies, and health systems will save on the costly resource utilisation that accompany delayed diagnoses. Most of all, these tools will improve the lives of people with AD.

Niranjan Bose, co-lead, AD-RIDDLE and managing director, Gates Ventures, and **Professor Miia Kivipelto**, MD, PhD, Professor in Clinical Geriatrics, Karolinska Institutet and Karolinska University Hospital

Advancing dementia risk reduction research and practice in Africa: addressing gaps and exploring opportunities

Africa is a continent of unparalleled diversity, its vast landscapes encompassing a multitude of ethnicities, languages, traditions, and belief systems, reflecting millennia of human history and migration. This diversity extends to the genetic makeup of its populations, with distinct ancestral lineages and genomic variations shaping individual susceptibility to diseases, including dementia. While research on dementia risk reduction has garnered attention globally, there exists a critical gap in addressing the unique needs and challenges faced by Africa, alongside untapped potential for opportunities within the region.

AFRICA-FINGERS represents the first attempt to synchronise and implement culturally sensitive multidomain interventions for dementia risk reduction across Africa, with a strong emphasis on sustainability.

By 2050, the global prevalence of dementia is projected to triple from the current 55 million cases, with over 60 percent of instances concentrated in lower- and middle-income countries (LMICs), including in the most impoverished regions like Sub-Saharan Africa.^{1,2} The escalating incidence of dementia across Africa is poised to introduce significant social, health, and economic challenges in these resource-constrained areas.^{1,2} Mixed dementias, such as Alzheimer's Disease (AD) and

vascular dementia, are prevalent among individuals of African descent.^{3,4} The distinct pathologies that drive the clinical presentation manifest gradually, an estimated 15–25 years before dementia onset,⁵ thereby allowing a window of opportunity for prevention measures. Evidence indicates that modifiable risk factor reduction implemented at the population level (e.g. physical and cognitively active lifestyle; smoking cessation; healthy diet, and vascular/metabolic risk management) could impact brain health and prevent or delay dementia onset.^{6,7} Indeed, pilot studies from our team using data from the indigenous African cohort of the Indianapolis-Ibadan-Dementia study remarkably noted modifiable risk factors as the most significant predictors of incident dementia. The 2019 World Health Organization (WHO) Guidelines for reducing the risk of cognitive decline and dementia highlighted the importance of addressing multiple risk factors concurrently, given the limited effectiveness of singular interventions.

However, at present, there are currently no systematic, community-based dementia prevention programmes tailored for Africa.

The groundbreaking long-term randomised controlled trial (RCT) known as the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER) was the first to demonstrate that a multifaceted lifestyle intervention encompassing nutrition, exercise, cognitive training, vascular/metabolic risk management, and social activities yielded significant cognitive advantages compared to standard health

1 WHO. World Health Organisation. (2017).

2 GBD 2019 Lancet Public Health 7, e105–e125 (2022).

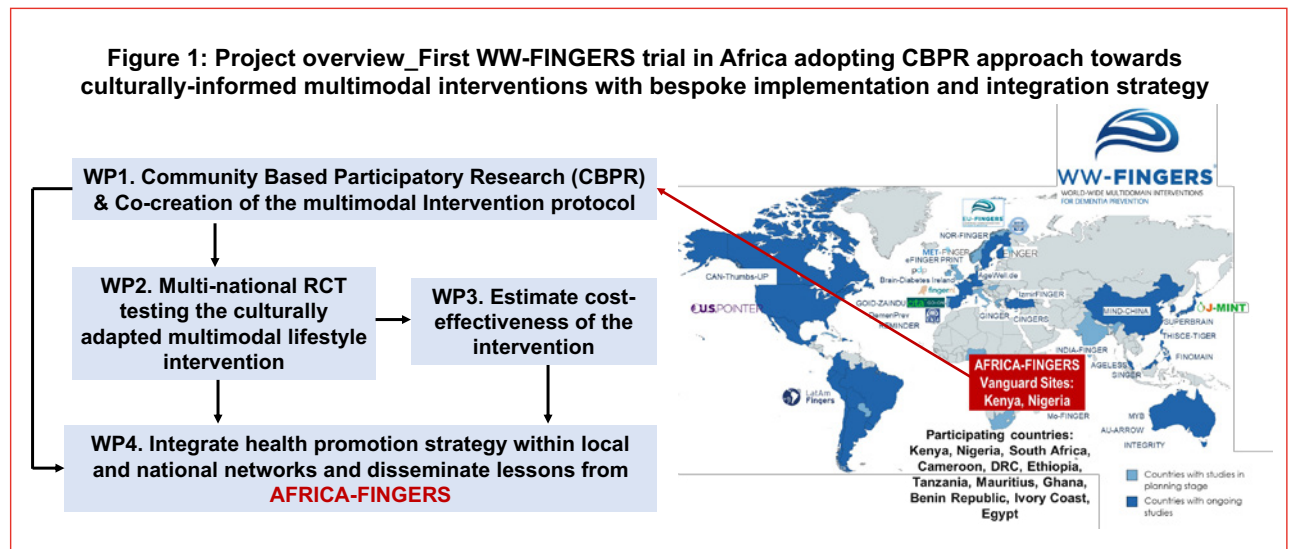
3 Barnes, L. L. et al. Neurology 85, 528 (2015).

4 Akinyemi, R. O. et al. Alzheimers. Dement. 18, (2022).

5 Vermunt, L. et al. Alzheimers. Dement. 15, 888–898 (2019).

6 Kivipelto, M., Mangialasche, F. & Ngandu, T. Nat. Rev. Neurol. 14, 653–666 (2018).

7 Livingston, G. et al. Lancet 396, 413–446 (2020).



advice in an older population at risk.^{8,9} As emphasised by the WHO, substantial knowledge gaps persist regarding effective prevention strategies in LMICs and diverse populations. Towards this goal, World-Wide FINGERS (WW-FINGERS, now spanning over 62 countries), was launched; establishing the first-ever network of RCTs to test, refine, and implement the FINGER model on a global scale.¹⁰

For dementia prevention strategies to yield effectiveness within resource-constrained settings like in Africa, it is imperative to consider contextual variables, such as distinct multimorbidity/non-communicable disease (NCD) patterns, strained and underfunded healthcare systems, cultural beliefs and attitudes, awareness regarding brain health, and socioeconomic conditions. Solutions must be tailored to fit the cultural context, be financially viable, and feasibly implemented on a systematic basis.

With these considerations in mind, we initiated the AFRICA FINGERS Program, a collaborative effort spanning multiple nations (see Figure 1) aimed at advancing and promoting optimal brain health and ageing in Africa. AFRICA-FINGERS represents the first attempt to synchronise and implement culturally sensitive multidomain interventions for dementia risk reduction across Africa, with a strong emphasis on sustainability. The primary goal of our initiative is to prevent cognitive impairment and foster healthy ageing among African populations by optimising the management of fundamental modifiable risk factors identified by the Lancet Commission, the WHO guidelines for addressing NCDs, and insights gleaned from members of our teams working directly with these indigenous communities, as well as, critically, input from the indigenous community members themselves.

Embedded within the WW-FINGERS network and drawing inspiration from the multi-site US-POINTER project and the Latin-America FINGER trial, which encompasses various LMICs, AFRICA-FINGERS pioneers efforts to undertake culturally sensitive trials and implementation programmes for dementia risk reduction in Africa. Our central conjecture posits that the most effective and enduring reduction of dementia risk will be attained through a multimodal precision prevention approach, with tailored interventions informed by cultural nuances to specific, clearly defined at-risk cohorts. Additionally, we hypothesise that, by addressing the complexity of Alzheimer's disease and related dementias (ADRD) through the targeting of multiple risk factors, we can expedite the development of pertinent strategies for ADRD prevention among African populations.

This initiative has been collaboratively developed with input from key local stakeholders and leverages expertise from WW-FINGERS, the Alzheimer's Disease Data Initiative (ADDI) platform, Davos Alzheimer's Collaborative (DAC), ADI, the Global Brain Health Institute (GBHI) and Global Dementia Prevention Program (GloDePP). The multidimensional intervention will be meticulously crafted to ensure its seamless integration into routine clinical practice and applicability across similar cultural contexts through comprehensive testing of acceptability, feasibility, and efficacy. It is poised to serve as a model for prevention research in LMIC settings, as well as for diasporic populations, who are often marginalised and underrepresented in high-income country research.

By embracing diversity, fostering interdisciplinary collaboration, and prioritising community engagement; studies such as AFRICA-FINGERS will advance our understanding of dementia risk factors, develop

⁸ Ngandu, T. et al. The Lancet vol. 385 2255–2263 Preprint at [https://doi.org/10.1016/s0140-6736\(15\)60461-5](https://doi.org/10.1016/s0140-6736(15)60461-5) (2015).

⁹ Yaffe, K. et al. J. Alzheimers. Dis. 70, S207 (2019).

¹⁰ Kivipelto, M. et al. The Lancet Neurology vol. 17 27 Preprint at [https://doi.org/10.1016/s1474-4422\(17\)30431-3](https://doi.org/10.1016/s1474-4422(17)30431-3) (2018).

contextually appropriate interventions, and promote brain health equity across diverse African populations.

Ultimately, addressing dementia in Africa requires a holistic approach that integrates genetics, culture, environment, and social determinants of health, empowering individuals, and communities to age healthily with dignity and wellbeing.

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Key points



In the absence of a cure, dementia risk reduction is a field with enormous potential, whose repercussions on health and wellbeing of the general population throughout the life course make it a worthwhile investment for all states. Like all health interventions, dementia risk reduction needs to be tailored to the specific needs and profiles of populations locally and acknowledge the structural and cultural specificities that may impact risk. It is also important to note that risk reduction does not end at diagnosis; people living with dementia still have many opportunities to ensure that they live as well as possible and potentially slow the progression of the condition.

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.

Perhaps the vastest of the Global action plan's action areas, Action area 4 encompasses many aspects of life for people with dementia from diagnosis onwards, as exemplified by the scope of essays included in this chapter.

Professor Craig Ritchie and Anna Borthwick exhort us to rethink brain health to consider the spectrum of neurodegeneration long before one is diagnosed with dementia and how it could impact dementia public health policy. Regarding the specificities of Alzheimer's disease, Drs Simin Mahinrad, Maria Carrillo, and Heather Snyder from the Alzheimer's Association detail how advances in the understanding of the biological underpinnings of the condition have led to a revision of the criteria for diagnosis and staging, in order to better represent the evolution of the field. While recent years have witnessed the emergence of many new diagnostic and treatment tools, Fiona Carragher shows us how important it is to consider the challenges – and

opportunities – that come with trying to integrate these innovations within public health systems.

Often underestimated among the numerous modalities of dementia treatment is the concept of rehabilitation, a multipronged approach that empowers people living with dementia to maintain optimal levels of functioning and independence for as long as possible. The WHO Rehabilitation programme compiled in 2023 is a package seeking to provide guidance on how to implement such interventions.

Finally, Professor Sube Banerjee reminds us that, amid all the headline-grabbing changes in diagnosis and treatment, care often gets the short shrift, despite being essential to people with dementia's everyday lives. While we can – and should – be optimistic about where progress takes us, he says, we shouldn't be blinded by "the lure of the shiny."

Rethinking brain health, diagnosis, and dementia

In many ways, how we diagnose and detect neurodegenerative diseases 'must' change if the public is going to benefit from the rapid advances in science. This new science has brought us knowledge of the early stages of neurodegenerative disease, their detection, and (now available) therapeutic interventions, with both disease-modifying therapies and risk factor management.

The first step in the change is a conceptual one: 'dementia' is not synonymous with neurodegenerative disease – the 'dementia phase' of these conditions is in fact the end-stage of a clinically, functionally, and behaviourally defined syndrome.

Bearing this in mind, 'dementia diagnosis' is not what needs changing; it is diagnosis and detection of the

non-dementia and earlier stages of neurodegenerative diseases like Alzheimer's disease that need to be developed. The second step is a workforce and training one. Alzheimer's disease is a brain disease and as such is **not** a mental illness. Its early stages will, more often than not, initiate before 'old age' is reached. A new plan for brain health must therefore accommodate an abandonment of the primacy in some countries of 'old age' and 'psychiatry' in the public perception and clinical location of assessment and management of dementia. Thirdly, the public should be a partner in the development and initiation of the new narrative and associated awareness-raising of the opportunities that the new science has brought us.

The notion of inevitability of decline, the pervading passivity in action, and pessimism of outcomes must

be countered. The confrontation of these legacy issues from the 20th century can only be achieved by a consensus of policymakers, clinicians, the public, and advocates, founded on belief in science – that which is available now, and that which is yet to come.

Policies should therefore incorporate an earlier public health approach to risk factor development, management, and mitigation. They should include access to detection methodologies for early brain changes through blood, imaging, and spinal fluid assessment as easily as necessary tests in similar (previously) fatal conditions like cancer or chronic conditions like heart disease and diabetes. For as long as we see neurodegenerative diseases through the prism of dementia, we will remain stuck instead of

advancing interventions that will turn these illnesses into chronic conditions, as opposed to fatal ones.

Policymakers must set policy for the future, not for the past century. In the 21st century, countries should be developing brain health strategies within which 'dementia' diagnosis, treatment, care, and support should be chapters which, over the passage of time become smaller and less and less important. This is because, as we fund and deliver brain health approaches that bring early detection and intervention, we will prevent dementia.

Craig Ritchie, CEO and founder of *Scottish Brain Sciences*, and **Anna Borthwick**, head of impact and innovation, *Scottish Brain Sciences*

Evolution of Alzheimer's disease diagnosis and staging criteria

The evolution of Alzheimer's disease (AD) diagnostic criteria and staging methodologies has witnessed a transformative shift from a historical syndrome-based approach to diagnosing based on biology, similar to how other chronic conditions are defined and diagnosed. For over two decades, the diagnosis of AD in living individuals relied on the assessment of clinical syndromes through medical history and neurological examination.^{1,2,3} However, advancements in imaging and biofluid biomarkers, coupled with a deeper understanding of their correlation with the biological progression of AD, suggested that relying solely on clinical syndrome lacks specificity and sensitivity for the underlying AD neuropathology.³ In 2011, the National Institute on Aging and the Alzheimer's Association (NIA-AA) published separate recommendations for the diagnosis and staging of AD as a continuum through its preclinical, mild cognitive impairment, and dementia stages, emphasising the integration of biomarkers

alongside clinical symptoms.^{4,5,6} In 2018, the NIA-AA reflected on the scientific progress and introduced a research framework that operationalised biomarkers across the entire AD continuum. This research framework represented a pivotal step in advancing the biologically grounded understanding of AD, while emphasising the necessity of future updates in response to scientific advances.³

The 2024 Revised Criteria for Diagnosis and Staging of AD represent the latest milestone in this evolving landscape.⁷ Released by a workgroup sponsored by the Alzheimer's Association in the United States, the revised criteria serve as an update to those previously published in 2011 and 2018³⁻⁶ prompted by two major developments in the field: the emergence of novel FDA-approved therapies for AD that target the core disease pathology, highlighting the need for conceptual alignment between various stakeholders around the diagnosis and staging

- 1 Reisberg B, Ferris SH, de Leon MJ, Crook T. The Global Deterioration Scale for assessment of primary degenerative dementia. *Am. J. Psychiatry*. 1982;139:1136–1139.
- 2 McKhann G, Drachman D, Folstein M, Katzman R, Price D, Stadlan EM. Clinical diagnosis of Alzheimer's disease: report of the NINCDS-ADRDA Work Group under the auspices of Department of Health and Human Services Task Force on Alzheimer's Disease. *Neurology*. 1984;34:939–944.
- 3 Jack CR, Bennett DA, Blennow K, Carrillo MC, Dunn B, Haeberlein SB, Holtzman DM, Jagust W, Jessen F, Karlawish J, et al. NIA-AA Research Framework: Toward a biological definition of Alzheimer's disease. *Alzheimers Dement. J. Alzheimers Assoc*. 2018;14:535–562.
- 4 Sperling RA, Aisen PS, Beckett LA, Bennett DA, Craft S, Fagan AM, Iwatsubo T, Jack CR, Kaye J, Montine TJ, et al. Toward defining the preclinical stages of Alzheimer's disease: recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimers Dement. J. Alzheimers Assoc*. 2011;7:280–292.
- 5 Albert MS, DeKosky ST, Dickson D, Dubois B, Feldman HH, Fox NC, Gamst A, Holtzman DM, Jagust WJ, Petersen RC, et al. The diagnosis of mild cognitive impairment due to Alzheimer's disease: recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimers Dement. J. Alzheimers Assoc*. 2011;7:270–279.
- 6 McKhann GM, Knopman DS, Chertkow H, Hyman BT, Jack CR, Kawas CH, Klunk WE, Koroshetz WJ, Manly JJ, Mayeux R, et al. The diagnosis of dementia due to Alzheimer's disease: recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimers Dement. J. Alzheimers Assoc*. 2011;7:263–269.
- 7 NIA-AA Revised Criteria for Diagnosis and Staging of Alzheimer's [Internet]. AACI. [cited 2023 Oct 20]; Available from: <https://aaic.alz.org/diagnostic-criteria.asp>

of AD;^{8,9} and the development of increasingly accurate blood-based biomarkers (BBMs) that hold the promise making AD diagnosis more accessible.¹⁰

The 2024 revised criteria retain fundamental principles from the 2018 research framework and the 2011 NIA-AA preclinical recommendations.⁴ Unlike previous iterations, however, it has progressed from an exclusively research framework to criteria that are intended to inform both research and clinical care. While not intended as step-by-step clinical practice guidelines, the 2024 revised criteria serve as a general principle for diagnosis and staging of AD to reflect current science.

The 2024 criteria further emphasise that, in the absence of approved interventions in asymptomatic individuals, routine diagnostic testing in this population is inappropriate. Although this recommendation may change in the future, the current stance of the workgroup emphasises that the results of AD diagnostic testing in asymptomatic individuals would not produce medically actionable information. Consequently, there is no clinical rationale for biomarker testing in this specific population at the moment.

Another notable departure from the 2018 research framework is the inclusion of BBMs beyond reliance on cerebrospinal fluid (CSF) or neuroimaging biomarkers alone. BBMs represent one of the most significant advances in AD diagnostics in recent years, with some assays showing increasingly accurate diagnostic performance, with regulatory approvals anticipated in the near future.¹¹ BBM will make the biological diagnosis of AD more accessible.¹⁰ Recognising that BBMs are a recent development, the 2024 criteria outline rigorous standards regarding BBMs, noting a minimum diagnostic accuracy of 90 percent or more with respect to an accepted reference standard in the intended context of use.¹¹ Furthermore, a need for testing and prospective evaluation of BBMs in more representative populations is strongly endorsed.

In the revised criteria, biomarkers are categorised into three main categories:

- Core biomarkers of AD neuropathologic changes that are specific to AD (Core 1 and Core 2 biomarkers, differentiated by the timing of abnormality onset and intended use).
- Non-core biomarkers of AD that are not specific to AD but still important in AD pathogenesis (inflammation or immune activation and neurodegeneration).
- Biomarkers of non-AD co-pathologies (cerebrovascular disease and neuronal α -synuclein disease).

The 2024 revised criteria additionally propose separate biological and clinical staging systems. The biological staging is a 4-point alphabetical scale (A-D) based on the ordering of biomarker events in the natural history of the disease, while the clinical staging adopts a six-point numeric scale spanning from stage 1 (asymptomatic) to stage 6 (severe dementia). The revised criteria recognise factors that could contribute to a common mismatch between clinical and biological stages and acknowledge the modifying influence of common co-pathologies (such as neuronal α -synuclein disease, TDP-43, and cerebrovascular disease), cognitive reserve, and resistance.

The groundbreaking advancements in imaging and biofluid biomarkers have facilitated a paradigm shift in AD diagnosis and staging criteria, providing an avenue for a biologically based characterisation of AD. The 2024 Revised Criteria constitute a major milestone paving the way towards bridging research and clinical care. While the feasibility of implementing these criteria in clinical practice varies across regions, even within high-income countries, enhancing the availability and accuracy of BBMs is expected to make these criteria more widely applicable. This improvement is particularly relevant for lower- to middle-income countries where PET- and CSF-based biomarkers may not be readily accessible.

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8 van Dyck CH, Swanson CJ, Aisen P, Bateman RJ, Chen C, Gee M, Kanekiyo M, Li D, Reyderman L, Cohen S, et al. Lecanemab in Early Alzheimer's Disease. *N. Engl. J. Med.* 2023;388:9–21.

9 Sims JR, Zimmer JA, Evans CD, Lu M, Ardayfio P, Sparks J, Wessels AM, Shcherbinin S, Wang H, Monkul Nery ES, et al. Donanemab in Early Symptomatic Alzheimer Disease: The TRAILBLAZER-ALZ 2 Randomized Clinical Trial. *JAMA.* 2023;330:512–527.

10 Hansson O, Edelmayer RM, Boxer AL, Carrillo MC, Mielke MM, Rabinovici GD, Salloway S, Sperling R, Zetterberg H, Teunissen CE. The Alzheimer's Association appropriate use recommendations for blood biomarkers in Alzheimer's disease. *Alzheimers Dement. J. Alzheimers Assoc.* 2022;18:2669–2686.

11 Janelidze S, Bali D, Ashton NJ, Barthélemy NR, Vanbrabant J, Stoops E, Vanmechelen E, He Y, Dolado AO, Triana-Baltzer G, et al. Head-to-head comparison of 10 plasma phospho-tau assays in prodromal Alzheimer's disease. *Brain J. Neurol.* 2023;146:1592–1601.

The challenge of bringing blood tests for dementia into the UK health system

Diagnosis is the key to unlocking better outcomes for people living with dementia – but current methods are expensive, not widely available, and in some cases, invasive.

Guidelines in the UK recommend using lumbar punctures or FDG PET scans to detect and diagnose suspected cases of Alzheimer's disease. However, it is estimated that less than 2 percent of people can currently access specialised tests such as these. The UK's PET scanning infrastructure has failed to keep up with demand. There are just 88 PET scanners in the UK, meaning 0.5 scanners per million citizens, compared with 1.6-to-5.1 scanners per million in France, Germany, Italy, Spain, or the US.

Blood tests, on the other hand, are simple to carry out, so do not require specialist training, can be done in a GP (general practitioner) surgery (or even in someone's home), and are inexpensive.

Dementia is the UK's biggest killer, yet fewer than two-thirds of people living with dementia here get a diagnosis. This means people are missing the vital care and support a diagnosis can bring.

The introduction of blood tests could not only increase the number of diagnoses, but also give patients an accurate diagnosis earlier in their disease progression. We are already seeing an increase globally in the number of tests being developed which can detect tau and amyloid, particularly for Alzheimer's disease.

The Blood Biomarker Challenge

Blood tests have the potential to transform the landscape for dementia diagnosis. This is why Alzheimer's Society, along with Alzheimer's Research UK and the NIHR (National Institute for Health and Care Research), launched the Blood Biomarker Challenge.

This project – which is supported by £5m in funding raised by the People's Postcode Lottery – will gather the information needed to introduce a blood test for dementia into UK healthcare systems. This blood test would be a crucial step in speeding up how quickly and how early we are able to diagnose dementia.

The project will gather the evidence needed to show that the blood test is safe and effective and can work in a clinical – rather than laboratory – environment in the UK. People living with dementia will be involved in the project, which will also reflect the ethnic and geographic diversity of the UK. Those living with additional health conditions will also be part of the project groups.

The Challenge will explore the possible benefits for patients who could get earlier and accurate diagnoses if a blood test is available and will show whether blood tests for dementia are economically viable.

With dementia currently costing £34.7bn per year in the UK, a strong case for change is being built through this effort to demonstrate that blood tests can be easily adopted into UK health systems and can positively impact wider society.

It is early days for these five-year projects and rigorous testing needs to be done, but they offer real hope.

Many people do not get a diagnosis or are simply told they have 'dementia' rather than a specific sub-type. This leaves them unable to access vital support, take part in clinical trials, or put care plans in place.

A blood test available through the National Health Service (NHS) that can safely and accurately indicate dementia could revolutionise diagnosis.

Disease-modifying treatments

Timely and specific diagnosis is also essential if people are to access new disease-modifying treatments that may be approved for use within the NHS later this year.

There are around 900,000 people living with dementia in the UK.¹ Estimates on the number of people who would be able to access new treatments vary widely, from 30,000 according to one study² to between 50,000 and 280,000 according to NHS England.³

Should these drugs be approved, we will likely see more people coming forward for a diagnosis, at a younger age and with less obvious symptoms, as well as those concerned about their risk of developing dementia in the future.

¹ London School of Economics (2019) https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf

² Laurell et al (2024) <https://pubmed.ncbi.nlm.nih.gov/38235531/>. Br J Psychiatry

³ NHS England (2024). <https://www.england.nhs.uk/long-read/dementia-programme-and-preparation-for-new-alzheimers-disease-modifying-treatments/>

We therefore need plans to be published in England, Wales, and Northern Ireland for how the NHS and HSC (Northern Ireland) system intend to deliver disease-modifying treatments. These must include a focus on diagnosis, including an investment in the infrastructure and skilled workforce required to identify eligible patients.

Action to push up diagnosis rates, reduce barriers to diagnosis, gather better data on diagnosis, and prepare our health system for potential disease-modifying treatments all remain top priorities for Alzheimer's Society.

The Major Conditions Strategy in England, a refreshed Dementia Action Plan in Wales, and the implementation of the Regional Dementia Care Pathway in Northern Ireland are all vehicles through which we could seek to achieve these objectives. However, as we await a General Election, the results of the Welsh leadership election, and further news on the plans of the newly formed Executive in Northern Ireland, we must remain flexible on the most appropriate opportunities to influence change.

Fiona Carragher, director of research and influencing, Alzheimer's Society (UK)

The World Health Organization's package of interventions for rehabilitation for dementia

Rehabilitation is an essential health services that enables and empowers people with dementia to achieve and maintain their optimal levels of functioning in order to participate in their daily physical, social, and community activities, as well as to maintain independence in interactions with personal and broader environments.¹ Rehabilitation consists of interventions (including compensatory approaches) that are effective to promote or restore functioning, and to prevent decline in functioning and secondary conditions. Optimising the individual's physical and social environment and the provision of assistive products complete rehabilitation measures. Rehabilitation programmes are tailored to an individual's needs, capacities, and preferences and most effective when provided by a multidisciplinary workforce.

Despite the known benefits of rehabilitation in dementia, and the appreciation for rehabilitation by a wide range of people with dementia and their families,² the gap between existing rehabilitation needs and access to rehabilitation is evident, particularly in contexts with limited resources. In 2019, it was estimated that 52

million people globally would have benefited from rehabilitation,³ whereas in many countries, specifically in lower- and middle-resource context, access to rehabilitation is very limited.⁴

According to the proposed actions in the *Global status report on the public health response to dementia*⁵ and with the endorsement of the resolution on *Strengthening rehabilitation in health systems* by the World Health Assembly in 2023,⁶ member states are now asked to increase access to rehabilitation for people in need. The WHO supports countries with a considerable number of technical tools to strengthen rehabilitation in health systems. Among these tools, which have been developed within the *Rehabilitation 2030 initiative*,⁷ the *Package of interventions for rehabilitation (PIR)*⁸ launched in 2023 provides information that specifically targets rehabilitation service delivery.

This PIR for dementia is included in Module 3 of the PIR.⁹ Forty-four experts representing 22 countries, relevant professions and consumer perspectives contributed to its development. The PIR for dementia

- 1 Jeon YH, Krein L, O'Connor C, Mowszowski L, Duffy S, Seeher K, Rauch A. A systematic review of quality dementia clinical guidelines for the development of WHO's Package of interventions for rehabilitation. *Gerontologist*. 2023;63(9):1536-1555. doi: 10.1093/geront/gnac105.
- 2 Laver K, Crotty M, Low LF, Clemson L, Whitehead C, McLoughlin, Swaffer K, Cations M. Rehabilitation for people with dementia: a multi-method study examining knowledge and attitudes. *BMC Geriatrics*. 2020;20:531-532. doi.org/10.1186/s12877-020-01940-x.
- 3 Cieza A, Causey K, Kamenov K, Wulf Hanson S, Chatterji S, Vos T. Global estimates of the need for rehabilitation based on the Global Burden of Disease study 2019: a systematic analysis of the Global Burden of Disease Study 2019. *Lancet*. 2020; 396(10267): 2006-2017.
- 4 Kamenov K, Mills JA, Chatterji S, Cieza A. Needs and unmet needs for rehabilitation services: a scoping review. *Disabil Rehabil*. 2019 May;41(10):1227-1237. doi: 10.1080/09638288.2017.1422036.
- 5 Global status report on the public health response to dementia. Geneva: World Health Organization; 2021 (<https://iris.who.int/handle/10665/344701>, accessed 13 March 2024).
- 6 Landmark resolution on strengthening rehabilitation in health systems. Geneva: World Health Organization; 2023 (<https://www.who.int/news/item/27-05-2023-landmark-resolution-on-strengthening-rehabilitation-in-health-systems>, accessed 13 March 2024).
- 7 Rehabilitation 2030 initiative. Geneva: World Health Organization; 2017 (<https://www.who.int/initiatives/rehabilitation-2030>, accessed 13 March 2024).
- 8 Package of interventions for rehabilitation. Geneva: World Health Organization; 2023 (<https://www.who.int/activities/integrating-rehabilitation-into-health-systems/service-delivery/package-of-interventions-for-rehabilitation>, accessed March 13 2024).
- 9 World Health Organization. (2023). Package of interventions for rehabilitation: module 3: neurological conditions. Geneva: World Health Organization; 2023 (<https://iris.who.int/handle/10665/370504>, accessed March 13 2024).

Interventions for rehabilitation included in the WHO Package of interventions for rehabilitation for dementia

Target of the intervention	Interventions
Cognitive functions	<ul style="list-style-type: none"> • Cognitive stimulation; cognitive training; reminiscence therapy • Provision and training in the use of assistive products for cognition
Sleep disturbances	<ul style="list-style-type: none"> • Person-tailored activities
Problems with behaviours	<ul style="list-style-type: none"> • Behavioural interventions; person-tailored activities
Speech, language and communication	<ul style="list-style-type: none"> • Speech therapy; communication skills training • Provision and training in the use of assistive products for communication
Swallowing	<ul style="list-style-type: none"> • Swallowing therapy
Pain	<ul style="list-style-type: none"> • Referral to specialist services • Psychological support
Sexual functions and intimate relationships	<ul style="list-style-type: none"> • Referral to specialist services • Psychological support
Motor functions and mobility	<ul style="list-style-type: none"> • Muscle strengthening exercises; balance, gait, and mobility training • Functional positioning • Provision and training in the use of assistive products for mobility
Exercise and fitness	<ul style="list-style-type: none"> • Aerobic exercises
Activities of daily living (ADL)	<ul style="list-style-type: none"> • Cognitive rehabilitation; ADL training • Provision and training in the use of assistive products for self-care • Modification of the home environment
Interpersonal interactions and relationships	<ul style="list-style-type: none"> • Psychosocial interventions
Self-management and lifestyle	<ul style="list-style-type: none"> • Education, advice and support for self-directed exercises, healthy lifestyle, and self-management
Carer and family needs	<ul style="list-style-type: none"> • Carer and family training and support
Prevention (treatment) of secondary conditions	
Mental health (depression, anxiety) and emotional distress	<ul style="list-style-type: none"> • Antidepressants (only in people with moderate to severe depression) • Psychological therapies (incl. cognitive behavioural therapy, stress management training) • Physical exercise training
Malnutrition	<ul style="list-style-type: none"> • Nutritional management

consists of a set of evidence-based interventions that are considered as essential to people with a health condition since they target aspects of functioning that are frequently impaired or limited and are amenable to rehabilitation but also aspects of the environment to which modifications help to improve the functioning of a person with dementia (see Table). The interventions are effective, and the cost–benefit ratio favours the benefit. For all interventions included in the PIR, information relevant to the service delivery (required assistive products, equipment, consumables, and workforce) is available. Specific consideration for the selection of interventions and required resources PIR was given to the low- and medium-resource context.

The PIR for dementia is intended to support ministries of health in planning, budgeting, and integrating

rehabilitation in their health systems and thus to increase access to all service delivery platforms and along the continuum of care, according to national needs and available resources. As such, the PIR is a useful resource to plan the integration of rehabilitation into health benefit packages. Furthermore, the PIR is also useful for service planners, researchers, academics, and service providers when developing rehabilitation services at the different delivery levels, curricula for the rehabilitation workforce that include interventions that address the needs of people with dementia, and to research agendas that address potential gaps in evidence on interventions.

WHO Rehabilitation programme

Care and the lure of the shiny

The lure of the shiny is a powerful force. In *Finding Nemo*, our small blue hero Dory is drawn to a tiny shiny jellyfish she calls Squishy, only to be surrounded by Squishy's much bigger and more poisonous fellows and almost dying in the process. In dementia, there is reason to believe that the lure of the shiny – the first generation of disease-modifying treatments (DMTs) for Alzheimer's disease – may have a similarly chilling effect on the provision of care for people with dementia. The trouble is that the drugs are shiny, and care is not.

It is unequivocally great news that we now have the first DMTs. It is a triumph of science. Taking a step back to appraise the overall impact of the new and shiny treatments, however, there is no rational scenario where these DMTs will abolish the immense personal, familial, and societal impacts of dementia – and it is not fair to expect them to do so. They are an exciting and expensive *partial* answer to one specific question in Alzheimer's disease, not the answer to dementia.

The fear is, however, that they will consume the limited bandwidth politicians and policymakers have for dementia and, with it, the resources associated with dementia care. An unintended and unforeseen consequence of the lustre of DMTs may be that policy makers yield to the lure of the shiny and forget about or deprioritise supporting and improving the care that is at the heart of life quality in dementia. There is unfortunately nothing particularly shiny about care, but it is the everyday miracles of care, love, person-centredness and attention, very largely provided by families all over the world, that enable people with dementia to live the best lives they can. Added to family care, the input of health and care services from diagnosis through to the end of life is absolutely pivotal and can enable people to care well and provide help even in the most difficult of circumstances.

Why care about care? Because compared with the modest effect of DMTs, there is a huge amount of health gain that policymakers could generate by commissioning case finding, good quality diagnosis (independent of fluid and other biomarkers), support, and non-drug care and treatments that enable people with dementia and their families to live their best lives with dementia. Good quality diagnosis, care planning, and tailored post-diagnostic support can enable harm prevention, treatment of neuropsychiatric symptoms, and promotion of quality of life for people with dementia and family carers. The problem we have now is not that we do not have treatments that work; the problem is that we do not commission or provide services that deliver them at scale to all that would benefit from them. We could already provide great care for people with dementia, yet for vast majority we do not.

The identification of dementia as one of the great health challenges this century by the G7 in 2013 was a major step forward. However, an unforeseen consequence was that the shiny commitment to developing DMTs by 2025 smothered, as Squishy's family almost did to Dory, the other items on the agenda of improving care and services. In a competition with the magic promise of drugs to make it all go away, all other actions were effectively deprioritised or forgotten.

There is unfortunately nothing particularly shiny about care, but it is the everyday miracles of care, love, person-centredness and attention, very largely provided by families all over the world, that enable people with dementia to live the best lives they can.

Policy matters. In England, there are worrying signs of the deprioritisation of dementia. Last year, the government abandoned its commitment to a 10-year comprehensive dementia strategy. Instead, there is to be an as-yet ill-defined and non-specific "major conditions strategy" including cardiovascular disease, chronic respiratory disease, mental health conditions, cancer, and dementia. However well intentioned, any such a generic approach runs a major risk of entrenching and even broadening inequity, since the evidence base and systems of service provision and research for those other conditions are so much further developed than those that exist for dementia.

The amazing work of the past two decades in moving dementia from obscurity into the light has been powered by the need to address the deep unmet need, injustice, and inequalities faced by people with dementia and their family carers in health and social care systems. It has been driven by imaginative policymakers who have seen the economic, political, and human value of improving services and care for people with dementia.

It is brilliant that we now have DMTs available, and we must all work hard to deepen and broaden that pipeline – but given the size of the global challenge of dementia, we need to be able to fight on more than one front at a time. We need policy that prioritises **care and treatment**, making the case for more resource for dementia, not just switching what little we have around.

Sube Banerjee, pro-vice chancellor and professor of dementia, Faculty of Medicine and Health Sciences, University of Nottingham, UK

Key points



The field of dementia diagnosis, treatment, care, and support is far-reaching and complex, and involves many challenges, but also countless opportunities. We have witnessed diagnostic tools and disease-modifying treatments progress in leaps and bounds in recent years – but the question that remains is how to ensure that this scientific progress benefits all those who need it, and that it does not come at the detriment of the social, psychological, and other person-centred needs of people living with dementia.

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.

While people living with dementia should rightfully be at the centre of all efforts to address the condition, carers – whether they are informal carers, such as a friend or family, or health or care professionals – are essential to the wellbeing of people with the condition. They too deserve support to keep caring for people living with dementia to the best of their ability. Professor Henry Brodaty opens this chapter by laying out why national dementia plans form a crucial framework to provide this much needed support, which takes many forms.

Very often, however, it is carers who buoy up fellow carers. In this chapter, we hear from two of them. "I often wish I had received better assistance to learn how to care for my father without feeling like I was abandoning my own life," Ratu Tita Quritama writes. Her own incredible personal experience

inspired her to become a care navigator in Indonesia, assisting families like hers throughout their journey with dementia. In the United States, her husband's younger-onset dementia diagnosis led Diane Shulla Cose to create Lorenzo's House in his honour, with the goal of helping families, especially children, deal with the unique ripple effect of early onset dementia on young people. "Our connection was an instant relief," one young person said of their experience with Lorenzo's House peer-to-peer network. "Someone my age knew what I was going through without even having to explain my whole story."

Standing on the frontline of dementia, formal and informal carers deserve access to the tools, material and psychological support they need to be able to accompany people with dementia with dignity, respect, and compassion.

How national dementia plans can help support dementia carers

National dementia plans (NDPs) are important for people with dementia, for carers, and for service providers. NDPs provide a framework for ensuring that the needs of people with dementia, their families, and carers are met.

But what are these needs? Persons living with dementia and their carers want and need to know that they can access equitable, high-standard services at a reasonable cost that provide quality diagnosis, post-diagnostic care, reablement/rehabilitation services, community support, interventions for behaviours and psychological symptoms associated with dementia, acute hospital care, residential care, and end of life care; and that they will be able to access

such services in a timely manner, regardless of their income, native language, or geographical location.

National plans for dementia provide the framework for governments to ensure these needs are met. Ideally, plans should be developed in partnerships with people with dementia, their families and carers, healthcare providers, and bureaucrats. Plans should establish basic principles such as equity, accessibility, standards, outcomes, affordability, 'no one left behind', human rights, protection for the rights of people with dementia, protection from abuse and exploitation, and services for marginal groups such as migrant populations, those living in rural and remote areas, people with intellectual disabilities and dementia, and people living alone with dementia.

Yet, NDPs are not without their challenges, including how to translate lofty ideals and praiseworthy aims into strategies and actions that are meaningful to the everyday lives of people with dementia and their carers, all while meeting the budgetary constraints that all countries face amid competing demands for funding and monitoring whether the plans are delivering what they promise.

NDPs can reduce stigma so making it easier for those affected, whether they have been diagnosed with dementia themselves or care for a loved one with the condition, to reach out to others for help and support. NDPs can drive dementia prevention programmes, which can be reassuring as people with dementia and their families worry about what lies in store for their children. Legal and financial issues are stressful and often complex for people with dementia and their carers; NDPs can drive uniform legislation across jurisdictions to ensure safe and easy-to-navigate systems for proxy financial and legal support for those with dementia, and for long-term care insurance and for financial safety nets for those unable to pay for care.

NDPs can and should support dementia research across the spectrum from prevention, diagnosis, drug discovery, rehabilitation, carer support, long-term care, and palliative care. In our ageing world, NDPs must address workforce shortages and quality, especially as the ratios of people of working age to those who are older are dwindling. This is becoming critical for service providers in many developed countries.

People with dementia and their carers can judge the success of NDPs by how well they drive improvements to services and systems. Health care practitioners and care providers can judge success by how well the plan develops structures and delivery models so that they can provide the best services. Nationally, we can judge success by how well NDPs can engage and involve the whole community in actions to achieve a society that promotes the best possible quality of life for people living with dementia and their carers, including their emotional wellbeing and identity.

Professor Henry Brodaty, AO, MB BS, MD, DSc, FRACP, FRANZCP, FAHMS, FASSA, ADI honorary vice president

A caregiver's journey to establishing a care navigation system in Indonesia

My name is Ratu Tita, and I am the youngest of four siblings in a family acquainted with dementia. This life-changing experience began in 2013 when my father was diagnosed with both Alzheimer's and vascular dementia at the age of 65, a decade after his retirement. Like many people in the face of such unexpected news, my family went through a phase of denial. Even though the doctor's diagnosis was clear, and medication was prescribed, we kept ignoring it because we didn't see physical signs. Dad wasn't sick, or so we thought.

A pivotal moment for my family came in 2015, two years after my father's diagnosis. During a family trip to Bandung, West Java, my father suddenly went missing. He was found four days later all the way in Yogyakarta, Central Java, 485 kilometres away. Until now, we still don't know how he got there, or what he did during those four days. It was both a miracle and a lesson from The Almighty – a second chance for which we will forever be grateful.

At just 19 years old, I had never imagined that I would have to bear as huge of a responsibility as tending to my father as his condition deteriorated. Fear was always with me during that time. I worried about my future: How I would manage a job with set hours? Would I ever have a family of my own? How could I think of pursuing



NARAZI care navigators

anything else when the constant demands of dementia care left me feeling overwhelmed, with little time for myself? It wasn't that I did not want to help; I just didn't know how to do it properly, or if there was even a right way to begin with. These feelings of hopelessness and cluelessness led me to Alzheimer Indonesia (ALZI), a non-profit organisation aiming to improve quality life for people with dementia and carers like me. Joining allowed me to share my struggles and connect with other caregivers.

In 2018, the journey of caring for my father came to an end when he passed away. As I grieved, I moved on with my life, getting married and having a child. Yet surprisingly, the life I had dreamed of wasn't as fulfilling as I expected. I felt like something was missing. Taking care of my father had given me a sense of purpose beyond my own interests – and so, I decided to continue my journey as a caregiver in a different way.

During the COVID-19 pandemic, as everyone had to stay home, I joined ALZI's post-diagnostic support, screening, and counselling programme called NARAZI (Navigasi Perawatan ALZI/ ALZI Care Navigation). This service assists family caregivers in caring for people with dementia and helps them navigate this journey. My experience caring for my father, learning from fellow carers, getting information from doctors and books, as well as joining workshops on Alzheimer's and dementia, had equipped me to become a care navigator. To this day, I have helped families in more than 90 NARAZI service sessions. I have also contributed to co-training and organising the first ever Alzheimer's Indonesia Care Navigators Training Programme in Jakarta, in collaboration with Unika Atma Jaya. Last year, I was honoured to become the lead care navigator for NARAZI. I lead other junior care navigators to help family caregivers from diverse cultures and backgrounds care for people with dementia in 32 cities in Indonesia and abroad. Meeting these family carers really helped me better understand the personalised aspects of dementia care.

Taking care of my father had given me a sense of purpose beyond my own interests – and so, I decided to continue my journey as a caregiver in a different way.

I often wish I had received better assistance to learn how to care for my father without feeling like I was abandoning my own life. In retrospect, having someone



Ratu Tita and her father

to talk to really helped me understand my role better while at the same time keeping me from losing sight of my life and identity. Caregiving isn't easy, but it's not impossible either. It's something you might grow to love if you learn how to do it. While we can't change the past or predict the future, we can always offer help to those in need. My experience as a caregiver has taught me empathy and leadership skills, and I'm confident I can provide better help to others because of it.

I'm sure there are a lot of Titas and Ayahs (fathers) out there who are trying their best to survive, despite all the uncertainty. I hope those Titas don't feel lost, wondering what they should or could do, because this Tita will always be ready to be by their side. I hope the bond between my father and me can be a guiding light, even after he's gone. May his legacy live on in me forever and have an impact in supporting more family caregivers in navigating their journey of caring, in Indonesia and all over the world.

Ratu Tita Quritama, Lead Care Navigators, NARAZI, Alzheimer Indonesia

Bringing connection, community, and light to children of those affected by younger-onset dementia

After her personal family experience with younger-onset dementia, Lorenzo's House founder Diana Shulla Cose recognised how younger families, especially children, who experience this condition were unseen, misunderstood, and under-resourced. She imagined a place where families could shift this narrative, build community together, cure their isolation, and push for new dementia justice worldwide.

There has been a 200 percent uptick in individuals diagnosed with younger-onset (YOD) Alzheimer's and other forms of dementia in the United States.¹ With nearly 4 million individuals diagnosed with YOD worldwide,² assuming each of them has a nuclear family of four, means at least 16 million people are directly affected and in need of connection, resources, and light.

Today, Lorenzo's House is that light and a global hub of support for young people and their families affected by younger-onset dementia. As a non-profit virtual organisation, we offer free programming to families, with a focus on young people ages 5 to 35 whose parent has lived with or is living with any form of YOD.

Our programmes are designed to cure isolation (MATCH), build community (CLUBS), and drive dementia justice (SUMMIT).

MATCH is a one-on-one, caregiver-to-caregiver connection with a peer with whom to share insights, resources, and friendship. Carers are welcomed into Lorenzo's House with a 30–45-minute Lighthouse virtual meeting with a trained volunteer to understand what they are looking for in a "match" – whether it is the ability to meet in person, to a similar family structure to the same diagnosis. From the words of two 26-year-olds from the US who were matched: "There was a common thread in our stories, and an immediate sense of validation, visibility, and understanding. It was surreal to drop the mask I wear with my peers every day and have someone meet me;" "Our connection was an instant relief. Someone my age knew what I was going through without even having to explain my whole story."

CLUBS are our brave safe virtual spaces for carers to find community, share resources, and bring light. Our youth clubs are organised by age groups: young children (ages 4–7), children (8–12), teenagers (13–17), and young adults (18+) and held twice monthly. Our adult carer clubs –



Diana Shulla Cose with her husband Lorenzo, who was diagnosed with younger-onset dementia, and their sons Justin, 15, and Lucas, 11.

¹ <https://www.bcbs.com/the-health-of-america/reports/early-onset-dementia-alzheimers-disease-affecting-younger-american-adults>

² <https://www.thelancet.com/action/showPdf?pii=S2468-2667%2821%2900249-8>

Bright Brunch and Light Lounge – are held once monthly. The clubs are co-facilitated by a Lorenzo's House "Dementiator" (trained and experienced in dementia and passionate about educating others), and an adult or youth lead trained volunteer. "When I was 10, I found the Light Club," a 12-year-old from the US shared. "It has helped me learn how to show light to my dad and how to cope with all of my stress and emotions." Meanwhile, one 14-year-old carer from the US said: "I feel calm, relaxed after Light Club. I think deeply there. It's a place where I can talk about my dad's condition. I get tips from other kids too. We all can relate to each other."

"Our connection was an instant relief. Someone my age knew what I was going through without even having to explain my whole story."

We recently added the Shine On club for young people (ages 8–35+) whose parent has passed away after living with younger-onset dementia. For one 16-year-old US carer, "after feeling isolated many times during my mom's journey and after her passing, I find the kinship with others in Shine On to be healing and uplifting."

SUMMIT is our worldwide virtual youth event designed to educate and empower, connecting youth living a

common experience and building dementia advocates and thought leaders. This transformative event is often the first time young people are connected to peers who share a similar journey. Session choices include Mindfulness, Positive Vibes with Arts & Music, Brain Health, and Ask the Neurologist. In the words of a 26-year-old Canadian carer: "I didn't talk about my dad's diagnosis for years, for fear of being judged and no one understanding my journey. I realised how important it is to share my story and raise awareness. I am thankful to Lorenzo's House for giving me the space to be able to do this."

During the event, we explore our EmpowermentPLUS model, while developing our toolkit to turn stigma in to strength driving dementia justice. In the words of a 23-year-old carer from the United Kingdom: "Often, people are unaware about our parent's diagnosis and may make unnecessary comments, causing uncomfortable feelings and placing us in unfair situations. At Lorenzo's House, we grapple together and are designing our own tools and mindsets to respond, restore our own sense of family dignity, and ultimately shine light on stigma and dismantle it."

Diana Shulla Cose, founding executive director, Lorenzo's House

Key points



It is far from uncommon for informal carers to feel isolated and exhausted while navigating the journey of dementia. There is no universal roadmap for how to best accompany a loved one with a neurodegenerative condition. Whether caring as a family member or as a formal health or care professional, building a sense of community and having tools and support can give all carers the skills and confidence to face these challenges head on.

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.

As the adage goes, information is power – and information systems are a powerful tool to coordinate the vast knowledge of dementia accumulated over the decades. For Professors Robert Perneczky and Frank Jessen, national dementia plans can strengthen the collection of dementia-related data, which in turn reinforces these strategies thanks to evidence-based policies. These systems, Perneczky and Jessen argue, should not only exist at the national level, but be encouraged on the international stage, increasing researchers' access to information and resources exponentially.

But what should these information systems for dementia include? Adelina Comas-Herrera breaks down

in a compelling and accessible manner what "core sets of indicators for dementia" – obscure terminology for the uninitiated – mean in practice, and why it is so important to collect this information in order to continuously improve the provision of dementia care, treatment, and research.

One key example of a worldwide dementia information database is the WHO's Global Dementia Observatory, monitoring the response to the Global action plan on dementia, and encouraging knowledge sharing among member states. In Latin America, the 10/66 Dementia Research Project seeks to address the underrepresentation of lower- and middle-income countries in dementia research.

Improving dementia information systems: the importance of national dementia plans and real-world data collections

National dementia plans are strategic frameworks developed by governments to address the multifaceted aspects of dementia. While the specifics vary across countries, common objectives include early diagnosis, quality care, research funding, and public awareness. National dementia plans can also facilitate the establishment of robust data collection mechanisms. By standardising data elements and promoting collaboration among healthcare providers, researchers, and policymakers, these plans enhance the accuracy and completeness of dementia-related information, which in turn strengthens dementia policy by enabling evidence-based decision-making.

Ideally, national dementia plans should encourage integration across healthcare settings, extending to electronic health records and information systems. By linking primary care, specialist services, and long-term care facilities, information flow becomes seamless. Clinicians can better access patient histories, medication

lists, and care plans, improving overall management. Dementia plans should promote the use of standardised assessment tools for diagnosis and monitoring, to be incorporated into electronic systems, ensuring consistency and comparability, allowing clinicians tracking of cognitive decline, behavioural symptoms, and functional abilities over time to aid personalised care planning. National dementia plans should also facilitate allocation of resources for research, improving collaborative efforts between academia, healthcare institutions, and industry to increase the likelihood of breakthroughs.

Information systems play a pivotal role in sharing research findings, clinical trials, and best practices. Accessible databases enhance knowledge dissemination. Integrated information systems enable care coordination among various providers, including physicians, nurses, social workers, and therapists. Real-time communication ensures timely interventions,

reduces hospitalisations, and enhances quality of life. Dementia plans also set quality indicators for care facilities, and information systems, allowing continuous monitoring of adherence to these standards. Regular audits and feedback loops ensure that care services meet established benchmarks.

However, there are several challenges associated with data usage, and balancing data sharing with privacy protection remains a challenge. National plans must address data security and consent issues. Interoperability remains another challenge, therefore, ensuring that different systems can communicate seamlessly is essential. Standardised formats and protocols are critical. International cooperation can enhance information exchange, research collaboration, and policy learning. Practice-based registries to collect real-world data, rather than just clinical trial outcomes, play an increasingly important role.

The current landscape of dementia and Alzheimer's disease registries globally is fragmented. There are several data collections operating at local or national levels, but they lack standardisation and comprehensive collection of real-world data, and most countries do not have registries at all, limiting our ability to advance research and patient care.¹ One example is the US Alzheimer Association's ALZ-NET registry,² a voluntary provider-enrolled resource collecting information on people with Alzheimer's disease in the US evaluated for or treated with novel FDA-approved therapies, making a significant step towards improving the collection and utilisation of real-world evidence. Similar efforts are required internationally.

By collecting comprehensive, harmonised data on a global scale, an international registry will provide valuable insights into disease progression, treatment effectiveness, and patient outcomes. It will foster collaboration among various stakeholders, promote knowledge sharing and innovation, and facilitate patient recruitment for clinical trials. Furthermore, it will provide real-world evidence of treatment effects and safety, filling gaps left by clinical trials that often exclude certain patient populations and suffer from limited follow-up periods. An international registry will also help to identify patients most likely to respond to specific treatments, allowing for a more personalised approach to care, and long-term tracking of patient outcomes will provide insights into optimal treatment strategies. Moreover, standardised biomarker assessments will facilitate the detection of Alzheimer's disease in its

earliest stages, allowing for earlier intervention and more effective treatment.³

Comprehensive practice-based evidence from an international real-world data registry will help to identify patterns and characteristics of patients who are more likely to benefit from the new disease-modifying treatments. This will include demographic measures, disease progression markers, genetic factors, and more. Without a comprehensive registry, the required data is unlikely to be available from the patients' routine medical records, and local/national registries will never achieve the complete picture of a global real-world data collection. By tracking the long-term outcomes of patients treated, the registry will provide valuable insights into optimal care strategies, such as the best time to start (and stop) treatment, dosage adjustments, and managing side effects. The registry will also serve as a platform for post-marketing surveillance, monitoring the safety and effectiveness of disease-modifying treatments in a real-world setting. This will lead to early identification of any potential issues and ensure that the benefits of a drug continue to outweigh any risks. Fluid and imaging biomarkers are needed for a personalised precision-medicine approach to Alzheimer's disease diagnosis and treatment, and an international real-world registry will set global standards to improve quality of care and provide incentives to use biomarkers more regularly in clinical routine, also helping to avoid unnecessary treatments in individuals unlikely to benefit.

The International Registry for Alzheimer's Disease and Other Dementias (InRAD),⁴ was launched in March 2024 as a new global effort to effectively collect real-world data, based on a wide stakeholder consensus on a minimum and extended dataset to be collected, facilitating harmonisation with other local registry efforts. InRAD's global impact will increase if governments embrace the importance of data systems for dementia.

Robert Perneczky, professor of translational dementia research, LMU Hospital, Ludwig-Maximilians-University Munich & German Centre for Neurodegenerative Disorders (DZNE) & Imperial College London & University of Sheffield; founding chairman International Registry for Alzheimer's Disease and Other Dementias (InRAD); incoming president German Memory Clinic Network (DNG) and **Frank Jessen**, professor and chairman of psychiatry and psychotherapy, University Hospital Cologne & DZNE; founding board member InRAD; past president DNG; chairman European Alzheimer's Disease Consortium (EADC)

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2 <https://www.alz-net.org>

3 Miller MC, Bayakly R, Schreurs BG, et al. Highlighting the value of Alzheimer's disease-focused registries: lessons learned from cancer surveillance. *Front Aging* 2023;4:1179275 doi: 10.3389/fragi.2023.1179275 [published Online First: 20230505]

4 <https://www.inradnetwork.org>

Understanding core sets of indicators for dementia: why do they matter?

Ideally, people living with dementia would be able to live well,¹ free of discrimination, and neither their families nor themselves would risk impoverishment as a result of the costs of care.² But for this to be the case, we need to have well-coordinated health and long-term care systems that offer seamless care, treatment, and support to all people with dementia, as well as social protection mechanisms to ensure that family and other unpaid carers are not shouldering excessive costs of care.

In the last decades, many countries have developed national dementia strategies or plans to advance towards making this aspiration a reality. To support this, and to encourage more countries to do so, the World Health Organization's Global action plan on dementia provided policy guidance to support countries in this process, as well as to monitor progress.

So how do we know how well we are doing in advancing towards better?

The first way would be to measure the extent to which people living with dementia are "living well," which would involve collecting data directly from them about their experiences. There are measures, including some co-developed with people with dementia, available to do this. For example, a Core Outcome set for people with dementia living in the community³ considers 13 items organised around four categories (friendly neighbourhoods and home, independence, self-managing dementia symptoms, and quality of life). Another 10-item questionnaire for people with mild to moderate dementia has also been co-produced and has been validated.⁴ There are also measures

developed specifically to be used for people with advanced dementia through proxy respondents, and for unpaid carers of people living with dementia, such as the ASCOT-Proxy and ASCOT-Carer.⁵

Ideally, all countries would have registers of people diagnosed with dementia that could potentially support the monitoring of outcomes, as well as access to services and treatments also covering outcomes for unpaid carers. However, this would require very well-established health- and long-term care information systems, which are not in place even in most high-income countries.

Another much less costly and rapid tool are nationally representative surveys designed, not just to be able to estimate the prevalence of dementia and care needs, but also to see what the patterns of care and support are available, and what are the impacts of dementia and of potentially unmet needs. This is particularly important in the Majority World countries with lower resources and where only relatively small shares of all people with dementia are diagnosed.

We have experience from the 10/66 studies⁶ and the STRiDE project⁷ of how to carry out these surveys. Extending their coverage to more countries and revisiting countries where these data have been collected in the past could be an important step in helping us understand how care systems are advancing – or not – in responding to dementia.

Adelina Comas-Herrera, *Care Policy and Evaluation Centre, London School of Economics and Political Science*

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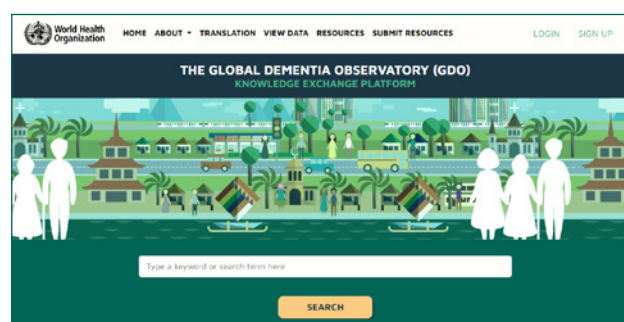
The Global Dementia Observatory: Monitoring the global dementia response and knowledge sharing

Collecting quality and standardised data on national dementia responses is critically important for strengthening health and social care systems for dementia, and for communities to respond to the growing needs of people living with dementia, their family members, and carers. To track international efforts towards achieving the targets of the Global dementia action plan and to support member states in formulating comprehensive national responses to dementia, WHO developed the **Global Dementia Observatory (GDO), a web-based data portal¹ and knowledge exchange (KE) platform.²**

The GDO consists of 35 key dementia indicators that are accompanied by a repository of relevant curated resources and good practice examples from around the world that provide countries with potential solutions to address identified country needs.

After a first round of GDO data collection between 2018 and 2020 that informed the development of the 2021 Global status report on the public health response to dementia,³ WHO is currently conducting a second round of GDO data collection. Ministerial focal points are being appointed by member states to coordinate data collection across government agencies, national and subnational stakeholders. Updated GDO data will be shared via the GDO data portal and inform future reporting to WHO governing bodies. In addition, updated country profiles will assist countries in identifying priority areas for action and support policymakers and programme implementers in enhancing their countries' response to dementia.

The GDO KE Platform plays an integral role in supporting policy makers and programme implementers in their efforts. The platform contains relevant, free of charge, high-quality resources that can be used to inform evidence-based national and local dementia responses. The platform currently features 132 good practice examples from 18 countries, covering all seven action areas of the global dementia action plan.



Through streamlined links between GDO data collection on the one hand and resource submissions to the GDO KE platform on the other, information sharing across regions and countries will be greatly improved. Going forward, it will be easier for stakeholders to identify relevant resources and good practice examples on the GDO KE platform that could be used to address the needs that they have identified based on their respective GDO data and country profile.

How can you contribute to the Global Dementia Observatory?

WHO continuously welcomes **submissions of resources** for the platform. We are looking for a wide range of geographical, language, cultural, and contextual diversity and encourage all stakeholders to share their resources by completing this submission form.⁴

Resources in all languages and from all regions are submitted to the Platform. To support the review process, we need more language diversity among peer-reviewers and focus groups of people with lived experience of dementia. We encourage anyone who is interested in **joining the peer-review network** to express their interest by completing this registration form.⁵

WHO Brain Health Unit

¹ [https://www.who.int/data/gho/data/themes/theme-details/GHO/global-dementia-observatory-\(gdo\)](https://www.who.int/data/gho/data/themes/theme-details/GHO/global-dementia-observatory-(gdo))

² <https://globaldementia.org/en>

³ <https://www.who.int/publications/i/item/9789240033245>

⁴ <https://extranet.who.int/dataformv3/895286?lang=en>

⁵ <https://extranet.who.int/dataformv3/456967?lang=en>

The 10/66 Dementia Research Project: Wave 3 insights and implications for Latin America

The 10/66 Dementia Research Project, established to address the underrepresentation of dementia research in lower- and middle-income countries, has emerged as a pivotal initiative in understanding dementia globally.^{1,2} Named to signify that only 10 percent of global dementia research focused on the 66 percent of people with dementia living in less affluent nations, this project has been instrumental in shedding light on the prevalence, risk factors, and progression of dementia in these regions. Initiated to fill a critical gap in dementia research, the 10/66 project primarily focuses on countries often overlooked in global dementia studies. It aims to provide comprehensive data on dementia's prevalence and impact in these regions, thereby contributing to a more nuanced understanding of dementia as a global health issue.³ After more than 20 years of data collection using the same study protocols, the study has concluded its third wave of assessment, and emerging findings will be shared with the scientific community.

The contrasting trends in dementia prevalence between Latin America and the Caribbean and other regions like North America and Europe underscore the importance of contextualised health interventions.

The third wave of the 10/66 project, covering the period from 2016 to 2019, offers a comprehensive analysis of dementia in Latin America and the Caribbean (LAC). Comparing the first wave (2003–2006) with the third wave (2016–2019) in four Latin American countries – Cuba, the Dominican Republic, Mexico, and Peru – reveals significant trends in dementia prevalence. Preliminary data suggest an increase in the Dominican Republic, Mexico, and Peru, while Cuba slightly declined, from 12.4 percent in Wave 1 to 10.1

percent in Wave 3. In contrast, the Dominican Republic's age-adjusted prevalence rose from 11.5 percent to 13.6 percent, Peru from 9.2 percent to 16.8 percent, and Mexico from 8.3 percent to 17.1 percent. These trends are particularly striking given the global context, where North America and Europe are witnessing a decrease in dementia rates,^{3,4} possibly due to improved management of cardiovascular health and higher educational levels.⁵

This contrast in trends raises critical questions about the underlying causes in LAC. According to the 10/66 study, the rise in dementia prevalence coincides with an increase in known risk factors for dementia (e.g., hypertension and Type 2 diabetes), including poor cardiovascular health, with less than 20 percent of the study's population in these countries exhibiting ideal cardiovascular health. This highlights the importance of addressing lifestyle and health factors, specifically in LAC countries, to mitigate dementia risk. Modifiable risk factors contribute to a significant proportion of dementia cases globally, but the impact is even more pronounced in LAC.⁶

The findings from the 10/66 project's third wave have profound implications for public health in Latin America. The increasing prevalence of dementia in LAC underscores the urgent need for targeted health interventions. Prevention strategies should emerge as a key focus in the battle against dementia in Latin America. Addressing modifiable risk factors can significantly impact the incidence and prevalence of dementia.⁷ For instance, improving cardiovascular health through better detection and treatment of diabetes and hypertension and promoting healthier lifestyles can mitigate the risk of dementia. Public health interventions aimed at these factors will also benefit the wider health system, given their role in other chronic diseases.

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- 2 Prina AM, Acosta D, Acostas I, et al. Cohort Profile: The 10/66 study. *Int J Epidemiol*. 2016;46(2):dyw056. doi:10.1093/ije/dyw056
- 3 Nichols E, Steinmetz JD, Vollset SE, 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(2):e105-e125. doi:10.1016/S2468-2667(21)00249-8
- 4 Tom SE, Phadke M, Hubbard RA, Crane PK, Stern Y, Larson EB. Association of Demographic and Early-Life Socioeconomic Factors by Birth Cohort With Dementia Incidence Among US Adults Born Between 1893 and 1949. *JAMA Netw Open*. 2020;3(7):e2011094. doi:10.1001/jamanetworkopen.2020.11094
- 5 Grodstein F, Leurgans SE, Capuano AW, Schneider JA, Bennett DA. Trends in Postmortem Neurodegenerative and Cerebrovascular Neuropathologies Over 25 Years. *JAMA Neurol*. 2023;80(4):370-376. doi:10.1001/JAMANEUROL.2022.5416
- 6 Mukadam N, Sommerlad A, Huntley J, Livingston G. Population attributable fractions for risk factors for dementia in low-income and middle-income countries: an analysis using cross-sectional survey data. *Lancet Glob Health*. 2019;7(5):e596-e603. doi:10.1016/S2214-109X(19)30074-9
- 7 Calandri IL, Crivelli L, Caramelli P, et al. LatAm FINGERS: Overcoming Barriers for a Dementia Prevention Trial Startup. *Alzheimer's & Dementia*. 2022;18(S11):e065869. doi:10.1002/ALZ.065869

As the 10/66 study continues and prepares for Wave 4, it will continue its commitment to data sharing. Data from the 10/66 study are now accessible through platforms like the Global Alzheimer's Association Interactive Network (GAAIN), and Alzheimer's Disease Data Initiative (ADDI), which is a testament to this commitment. This initiative enables researchers worldwide to access this rich dataset, fostering global collaboration and potentially leading to innovative strategies for dementia prevention and treatment.

In summary, the preliminary insights from the 10/66 project's third wave highlight the need for a comprehensive approach to understanding and tackling dementia, especially in Latin America. The contrasting trends in dementia prevalence between LAC and other regions like North America and Europe underscore the importance of contextualised health interventions. Prevention strategies are crucial in addressing dementia in LAC. The project's data-sharing initiative not only democratises access to valuable research data, but also fosters a collaborative environment for addressing

dementia as a global public health challenge. As the project moves forward, it remains a critical source of knowledge and hope for better managing and preventing dementia worldwide, with a focus on the most affected regions.

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The 10/66 Dementia Research Group extends our deepest gratitude to the individuals and communities whose dedication and involvement have been pivotal in advancing dementia research. We extend special thanks to our principal investigators in Latin America for their leadership and dedication: Juan Llibre Rodriguez (Cuba), Daisy Acosta (Dominican Republic), Mariella Guerra (Peru), Aquiles Salas (Venezuela), Ana Luisa Sosa (Mexico) and Ivonne Jimenez (Puerto Rico).

Key points



Countless researchers, advocates, and others around the world committed to addressing dementia are producing knowledge and data every day. If this information remains in narrow silos, however, then we may be missing on incredibly valuable opportunities to connect the dots and advance our collective understanding of the condition. Data harmonisation and sharing will be key to greater understanding. Information systems are therefore a priceless resource to move us all forward in a cooperative way.

Chapter 7

Dementia research and innovation



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

In the past year, the narrative used to describe the complex field of dementia research has started to shift. Thought leaders in the dementia research space have begun to let words of cautious optimism slip into their dialogue. There is still realism: we don't have the magic bullet yet; dementia is a complex condition; no one solution will fit all. However, multiple strands of research are dovetailing, creating a synergy around how we can detect dementia in a more timely and accurate way and treat it using more precise measures.

We are entering a new era of detection, treatment, and care of dementia. New disease-modifying treatments, while still not available for all people nor appropriate for all types of dementia, can offer some individuals a new post-diagnosis trajectory of treatment. Novel projects such as AD-RIDDLE (see essay in Chapter 3) will use implementation science to gather real-world evidence around the use, efficacy, and efficiency of biomarkers in detecting preclinical and prodromal Alzheimer's disease, enabling more personalised interventions that fit the needs of each individual.

These exciting advancements in dementia research help build confidence and momentum to explore new and better ways to combat this complex condition, and encourage us to look broadly at the challenge, investing in research and investigating all potential avenues with open minds. In his essay, Professor Christian Behl posits that, although there have been recent breakthroughs, we need to explore AD as a multifactorial, multigenetic, and highly complex age-associated disorder.

Meanwhile, Dr Howard Fillit argues that precision medicine and combination therapy are needed to treat individuals in a targeted manner and to open up possibilities for prevention protocols. Recognising that the era of new diagnostic technologies is imminent, the World Health Organization (WHO) describes its new Preferred Product Characteristics (PPC) to ensure safe and appropriate use, efficacy, and global accessibility.

Two essays from South America remind us that dementia research needs implementation, which in turn needs strong health and care systems to ensure sustainability. The IMPACT project team writes about how their work aims to strengthen health care systems in Peru, specifically through community health workers using a technology-enabled intervention to improve health-related quality of life for people living with dementia and their caregivers. From Brazil, Drs Eduardo Zimmer and Wyllys V. Borelli describe how dementia researchers and government can collaborate and reinforce each other's efforts – enabling access to significant clinical information and data on cognition and function combined with an opportunity to raise dementia awareness, promote timely diagnosis, prevention, and management of dementia.

The advances in disease-modifying treatments and new diagnostic methods of the past few years have been hailed as groundbreaking. This progress has reinvigorated the field of dementia research, encouraging scientists to find more answers, explore new possibilities and delve deeper into precision medicine as a whole.

Advancing research through state dementia plans: the Brazil example

Brazil is the largest country in South America by both land area and population. The Brazilian population reaches around 210 million people, making it the seventh most populous country in the world. Notably, it has more than 32 million individuals aged over 60.¹ Healthcare access in Brazil reflects its high inequality levels, characterised by significant income disparities. But while the wealthy predominantly opt for private healthcare, the middle and lower classes rely on the Brazilian Unified Health System (Sistema Único de Saúde, SUS)² the largest government-run public healthcare system in the world, providing universal access to the entire population.³ This makes the SUS well-suited for the development of an unprecedented dementia plan tailored to Brazilian demographics and culture, **and the ideal environment to see in real time the importance of government policy – whether at the national or regional level – in advancing dementia research.**

Due to the considerable ethnic and socioeconomic diversity of Brazilian states, dementia plans in the country must be customised regionally. In 2022, the southernmost state of Brazil, Rio Grande do Sul (RS), approved State Law 15820/22, which established a policy for addressing dementia.⁴ The secretary of health of RS has now assembled a multidisciplinary group of dementia experts to develop a modern state dementia plan aimed at rapidly addressing issues related to education for healthcare professionals, diagnosis, healthcare management, and raising awareness of stakeholders, marking a significant opportunity to develop innovative research strategies, from bench to bedside, to benefit a vast number of public healthcare

users. In 2023, the state of Ceará, which is located in the northeast of Brazil, established a very detailed state policy for addressing dementia.⁵ Dementia policies are currently being discussed in multiple states of Brazil. Furthermore, the National report on Dementia in Brazil (ReNaDe), released at the end of 2023, presented important findings regarding the care, diagnosis, research, and costs associated with dementia in the country.⁶

It is estimated that the SUS collects data from around 25 million older adults per year across the country.⁷ Thus, the implementation of a research framework for collecting a massive amount of clinical information about cognition and function can put the Brazilian SUS in the spotlight in the context of dementia awareness, diagnosis, prevention, and management, **and shows how dementia research can benefit from support and partnership with governmental institutions.** For example, a short and structured data collection strategy can be performed by any primary care healthcare professional in Brazil and retrieve valuable clinical data, while also assisting healthcare patients.⁸ Another strategy is to take full advantage of the SUS remote infrastructure created to face the COVID-19 pandemic.⁹ A brief telephone-based cognitive screening, such as the modified telephone interview for cognitive status (TICS), takes less than 10 minutes and demonstrates important correlation with the Mini-Mental State Examination results.¹⁰ Moreover, telephone interviews also have the potential to identify loss of functional independence through many culturally validated tools,¹¹ increasing the potential for remote screening of dementia.

- 1 IBGE (Instituto Brasileiro de Geografia e Estatística). *Censo demográfico 2022 : população por idade e sexo : resultados do universo*. IBGE; 2023. <https://biblioteca.ibge.gov.br/index.php/biblioteca-catalogo?view=detalhes&id=73102>. Accessed April 1, 2024.
- 2 Silva B, Hens N, Gusso G, Lagaert S, Macinko J, Willems S. Dual Use of Public and Private Health Care Services in Brazil. *Int J Environ Res Public Health*. 2022;19(3). doi:10.3390/ijerph19031829
- 3 Castro MC, Massuda A, Almeida G, et al. Brazil's unified health system: the first 30 years and prospects for the future. *Lancet*. 2019;394(10195):345-356.
- 4 Lei Ordinária 15820 do estado do Rio Grande do Sul. Leis Estaduais. <https://leisestaduais.com.br/rs/lei-ordinaria-n-15820-2022-rio-grande-do-sul-institui-a-politica-estadual-de-enfrentamento-a-doenca-de-alzheimer-e-outras-demencias-no-estado-do-rio-grande-do-sul-e-da-outras-providencias>. Accessed April 1, 2024.
- 5 de Saúde/SEAPS/SESA SE de AP e. P. *Política Estadual de Atenção à Pessoa Com Doença de Alzheimer E Outras Demências*. Governo do Estado do Ceará; 2023. <https://www.saude.ce.gov.br/wp-content/uploads/sites/9/2023/03/RESOLUCAO-144-ANEXO-Politica-de-Aten-a-Saude-da-P-com-Doenca-de-Alzheimer-e-out-Demencias.pdf>. Accessed April 8, 2024.
- 6 Cleusa Pinheiro Ferri, Samantha Lemos Turte-Cavadinha, Simone Nardin Weis, and José Ribamar Souza Duarte Júnior. *Sumário Executivo Relatório Nacional Sobre a Demência No Brasil: Necessidades de Cuidado, Custos, Produção Científica E Investimento Em Pesquisa*. Ministério da Saúde; 2023. <https://static.poder360.com.br/2023/12/pesquisa-cuidados-demencia.pdf>.
- 7 Macinko J, de Andrade FB, de Souza Junior PRB, Lima-Costa MF. Primary care and healthcare utilization among older Brazilians (ELSI-Brazil). *Rev saúde pública*. 2018;52(Suppl 2):65 - 65.
- 8 Sabbagh MN, Boada M, Borson S, et al. Early Detection of Mild Cognitive Impairment (MCI) in Primary Care. *J Prev Alzheimers Dis*. 2020;7(3):165-170.
- 9 Scheffer M, Cassenote A, de Brito E Alves MTSS, Russo G. The multiple uses of telemedicine during the pandemic: the evidence from a cross-sectional survey of medical doctors in Brazil. *Global Health*. 2022;18(1):81.
- 10 Elliott E, Green C, Llewellyn DJ, Quinn TJ. Accuracy of Telephone-Based Cognitive Screening Tests: Systematic Review and Meta-Analysis. *Curr Alzheimer Res*. 2020;17(5):460-471.
- 11 Dauphinaut V, Boublay N, Moutet C, Achi S, Bathsavanis A, Krolak-Salmon P. Comparison of Instrumental Activities of Daily Living assessment by face-to-face or telephone interviews: a randomized, crossover study. *Alzheimers Res Ther*. 2020;12(1):24.

In parallel, this data collection on a large scale may be associated with the use of novel biomarker technologies, such as ultrasensitive biomarkers utilising blood as the biological matrix without the need of non-scalable cerebrospinal fluid (CSF) or positron emission tomography (PET) tests.¹² Considering the persistent diagnostic challenges of dementia in Brazil,¹³ this strategy can be a game-changer. With this in mind, the state of RS acquired ultrasensitive equipment, which will now permit the measurement of Alzheimer's disease (AD) blood biomarkers. In conjunction with SUS, the RS state will be able to estimate the prevalence of AD blood biomarker positivity in the RS population for the first time. Individuals with suspected cognitive decline due to neurodegenerative disorders can also have facilitated access to blood biomarker status to reduce the barriers to diagnosis and management.¹⁴

There is an opportunity in Brazil to embrace the collection of massive clinical and biomarker data about dementia in collaboration with SUS, which will ultimately inform regional patterns of dementia risk and help design regionally tailored public interventions.

SUS presents a unique opportunity for a multidimensional approach aiming at secondary prevention. SUS incorporates a myriad of healthcare professionals from diverse backgrounds, including different medical

specialties, speech therapists, physical therapists, among others. Furthermore, programmes like HIPERDIA, which focuses on prevention, diagnosis, treatment, and control of diabetes and hypertension, are likely to play an important role in preventing dementia.^{14,15} In fact, SUS has the potential to significantly reduce dementia cases by covering most of the risk factors of dementia except for formal education.^{16,17}

These are a few examples of how well-designed national or regional dementia plans can rapidly advance dementia research. There is an opportunity in Brazil to embrace the collection of massive clinical and biomarker data about dementia in collaboration with SUS, which will ultimately inform regional patterns of dementia risk and help design regionally tailored public interventions. Lastly, healthcare users will benefit the most from a structured plan with well-defined guidelines to expand prevention, diagnosis, and treatment of dementia.

Brazilian researchers are playing a leading role in dementia research, and in collaboration with SUS and support from the government, they can make Brazil a role model for the Global South **and the rest of the world.**

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¹² Brum WS, Cullen NC, Janelidze S, et al. A two-step workflow based on plasma p-tau217 to screen for amyloid β positivity with further confirmatory testing only in uncertain cases. *Nat Aging*. 2023;3(9):1079-1090.

¹³ Calil V, Elliott E, Borelli WV, et al. Challenges in the diagnosis of dementia: insights from the United Kingdom-Brazil Dementia Workshop. *Dement Neuropsychol*. 2020;14(3):201-208.

¹⁴ Teunissen CE, Verberk IMW, Thijssen EH, et al. Blood-based biomarkers for Alzheimer's disease: towards clinical implementation. *Lancet Neurol*. 2022;21(1):66-77.

¹⁵ Ferrari-Souza JP, Brum WS, Hauschild LA, et al. Vascular risk burden is a key player in the early progression of Alzheimer's disease. *Neurobiol Aging*. 2024;136:88-98.

¹⁶ Borelli WV, Leotti VB, Strelow MZ, Chaves MLF, Castilhos RM. Preventable risk factors of dementia: Population attributable fractions in a Brazilian population-based study. *The Lancet Regional Health – Americas*. 2022;11. doi:10.1016/j.lana.2022.100256

¹⁷ Suemoto CK, Mukadam N, Brucki SMD, et al. Risk factors for dementia in Brazil: Differences by region and race. *Alzheimers Dement*. 2023;19(5):1849-1857.

Shaping the future: A new era of Alzheimer's research guided by the biology of ageing

Between the United States' FDA approval of anti-amyloid Leqembi (lecanemab) and the anticipated approval of donanemab, we have entered a new era of Alzheimer's research. After decades of learnings, we now have a better understanding of the disease biology, enabling us to develop safe and effective therapeutics. Data from several anti-amyloid drug trials have validated that this pathway is only modestly effective, further supporting the fact that the biology of ageing must become the leading approach for drug development. As we age, biological processes can go awry and contribute to Alzheimer's, which has multiple, interrelated causes like inflammation, vascular dysfunction, and metabolic disturbances that result in a cascade of dysfunction.

The ultimate goal is to treat patients with a combination therapy and precision medicine approach akin to cancer care, and an arsenal of drugs addressing the various ageing pathways will be necessary to eventually stop Alzheimer's in its tracks. The field is on track to deliver, with nearly 75 percent of drugs¹ in the robust and diverse drug pipeline exploring novel pathways, setting the stage for the next generation of clinical trials. We anticipate the next phase of trials will combine amyloid-targeting drugs with other novel drugs to uncover additional clinical benefits for patients.

Biomarkers have proven vital for every phase of the drug discovery and development process, and they must be developed in tandem with novel drugs. With the unique design of Eli Lilly's TRAILBLAZER-ALZ 2 trial that used Amyvid and Tauvid PET scans to screen and enrol patients and measure the drug's target engagement, it is evident that biomarker-powered trials will become an industry standard.

In the past year, there has been considerable momentum in biomarker development – particularly in blood tests – which will be integral to the future of Alzheimer's care. New diagnostics and biomarkers will pave the way for earlier detection and precision care, while also enabling the rollout of new drugs. With one anti-amyloid on the market in the US, Japan, and China, the need for accessible and affordable diagnostic tools becomes even more vital as we look to ensure the right

drugs are delivered to the right patients at the right time. Blood tests like ADDF-funded ALZpath's pTau217 assay and C2N's Precivity AD2 test are proving to be equally as accurate as PET scans and spinal taps, the current gold standard diagnostics for Alzheimer's. We are on track for blood tests to become the standard of care in clinical settings due to their more affordable and non-invasive nature. Accessible and scalable biomarkers will also be pivotal for supporting precision medicine in Alzheimer's care by helping physicians uncover each patient's unique biomarker profile.

Prevention has long been an area of focus for Alzheimer's researchers, and more recent data validates the valuable role lifestyle interventions will play in preventing the disease. If the onset of Alzheimer's can be delayed by up to five years on average, incidence rates would drop by 50 percent,² which is why precision prevention is the next frontier in Alzheimer's research. Thanks to the landmark FINGER study³ led by Professor Miia Kivipelto, MD, PhD, we now know that up to 40 percent of dementia cases can be prevented with lifestyle interventions, highlighting the potential to prevent or delay the onset of Alzheimer's with a multifaceted approach that pairs lifestyle choices with therapeutics. The MET-FINGER study, which is funded by the ADDF, takes prevention studies a step further by combining the diabetes drug metformin with the lifestyle interventions cited in the FINGER study, which may lead to higher prevention rates. This trial is an example of what to expect from the future of combination therapy clinical trials that offer the opportunity to uncover new prevention protocols for patients.

The next phase of Alzheimer's research and treatment will hinge on combination therapy, precision medicine, and prevention. This is harvest time – scientists are on track to leverage the past four decades of research to develop new and novel drugs. In the next five years, we hope to see additional drug approvals, bringing us one step closer to stopping Alzheimer's in its tracks.

Howard Fillit, MD, co-founder and chief science officer of the Alzheimer's Drug Discovery Foundation (ADDF)

- 1 Alzheimer's Drug Discovery Foundation, 2021 Alzheimer's Clinical Trials Report. <https://www.alzdiscovery.org/research-and-grants/clinical-trials-report/2021-report>.
- 2 Wilson D, Peters R, Ritchie K, Ritchie CW. Latest Advances on Interventions that May Prevent, Delay or Ameliorate Dementia. *Ther Adv Chronic Dis*. 2011 May;2(3):161-73. doi: 10.1177/2040622310397636. PMID: 23251748; PMCID: PMC3513883.
- 3 The FINGER Study, *FINGERS Brain Health Institute*. <https://fbhi.se/the-finger-study/>.

Rethinking Alzheimer's disease (research)

In his 1910 textbook *Psychiatrie*, German psychiatrist Emil Kraepelin – then a pivotal advocate of the new movement of “biological psychiatry” – coined the term “Alzheimer’s disease” (AD) based on Alois Alzheimer’s previous case report of a particular form of *presenile* dementia, a patient called Auguste D. For a long time, histopathological descriptions dominated efforts to uncover potential biological causes of AD. The overt abnormalities seen in postmortem brain slices through the microscope, the extracellular amyloid-*plaques*, and the intracellular tau-*tangles*, were used as hallmarks to characterise the disease and to distinguish it from other brain disorders; AD was seen largely as a “plaques-and-tangles-disease”. Since then, this neuropathological definition has dominated, and it is still represented in today’s “biological definition” of the disease (based on the so-called ATN-NIA/AA criteria). From early on, this definition insinuated that amyloid beta (A β), and tau were the central pathogenetic factors, with A β as the upstream trigger of the disease, and tau protein as the downstream executor of the amyloid-driven process.

A deeper understanding of the (individual) neuronal factors and mechanisms of vulnerability would allow us to encounter additional targetable pathways for Alzheimer’s disease therapy and prevention.

Intensive research efforts, especially in the last three decades, on the enzymatic generation of A β as plaque-peptide, its biochemical aggregation, and its deposition in brain tissue, were the basis of the “amyloid-cascade-hypothesis” formulated in 1992 (and refined a few times since then). From there on, larger parts of the AD research field considered A β as the initial trigger of the disease and the prime target in the search for a disease-modifying therapy. However, most experimental therapy approaches of the last 20–30 years focusing on A β failed to stop cognitive decline and disease progression when translated into the clinic. For instance, inhibition of the enzymes that generate A β or tackling the aggregation process was not successful; the removal of amyloid from the brain by *active immunisation* did not work either (or could not be further followed in humans due to severe side effects). Finally, also the infusion of several anti-amyloid antibodies targeting different biophysical forms of amyloid beta (*passive immunisation*) was not beneficial regarding cognition in the clinics for the last 20 years. More recently, however, two monoclonal antibodies targeting and removing A β , lecanemab and donanemab, were reported to have moderate but statistically significant effects in delaying the cognitive decline in individuals

showing early AD. While the clinical meaningfulness of the study effects is under fierce discussion, parts of the Alzheimer’s community welcome these first positive clinical results of amyloid-targeting in 30 years and interpret these results as the conclusive proof of the “amyloid-cascade-hypothesis.” Other parts of the field remain highly sceptical, considering the statistically calculated minimal effects as clinically not relevant and as being very likely not tangible for the patient. In addition to possible severe side effects of these immunotherapies, it is important to note that the group of patients that is eligible to receive such antibodies is highly restricted, the infrastructural needs for their application are challenging, and – last, but not least – the therapy costs are very high.

The AD research field currently appears highly divided while waiting for the results of an extended use of these antibodies to learn if some beneficial results can be sustained or even increased with a prolonged treatment, or if the effects will disappear over time. Putting this all aside, however, there is agreement and consensus in larger parts of the field that this immunotherapy approach is certainly not the long-awaited breakthrough or cure for AD. Considering the plethora of findings contradicting the current biological definition, it needs to be critically considered whether defining AD rather narrowly as a “plaques-and-tangles-disease” was a good idea. In fact, AD is understood today as a multifactorial, multigenetic, and highly complex age-associated disorder. In retrospect, we could speculate that the strong focus on amyloid-driven research strategies has been blinding out additional pathogenetic factors and alternative pathways.

Interestingly, some alternative concepts on how AD could develop beyond amyloid – such as the role of oxidative stress, mitochondrial and metabolic disturbances, infections, and of imbalances of proteostasis/autophagy and lipid metabolism – were introduced many years ago but were not adequately followed. Moreover, the high number of genetic risk factors identified by genome-wide association studies (GWAS) in recent years suggests that AD is highly individual and its onset and course may develop on other grounds, independent of A β . Seeing this high number of AD risks factors, personalised genetic risk configuration may also determine an individual’s resilience and their brain’s capacity to adapt to challenges (e.g. brain trauma, infections, inflammations, metabolic challenges, protein aggregates), thus defining the onset of neurodegeneration during ageing.

All of this needs to be investigated in great detail now to come closer to the causes of AD, which could be a prime candidate for a “personalised medicine” therapy

approach. In addition, a deeper understanding of the (individual) neuronal factors and mechanisms of vulnerability would allow us to encounter additional targetable pathways for AD therapy and prevention. A significant "paradigm shift" in the current AD research and a thinking beyond amyloid is indispensable – a shift that includes the integration of various partly overlooked

alternative disease hypotheses. I am convinced that it is high time to rethink *Alzheimer's Disease* and *Alzheimer' Disease Research*¹ in many aspects.

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¹ Christian Behl. Alzheimer's Disease Research—What Has Guided Research So Far and Why It Is High Time for a Paradigm Shift, Springer Cham 2023; ISBN: 978-3031-31570-1. doi.org/10.1007/978-3-031-31570-1

Forthcoming WHO Preferred Product Characteristics (PPC) for the use of blood-based biomarkers for the diagnosis of Alzheimer's disease

Recent advancements in biomarker research offer the potential to revolutionise the diagnosis of Alzheimer's disease. Although the access and availability of biomarker tests outside the research context is still limited, their widespread use for clinical decision-making is imminent. Addressing key challenges such as global access across different resource and service-delivery settings, as well as their rational and appropriate utilisation, will be essential to ensure health equity and reduce the persisting gaps between high- and lower- and middle-income countries.

The World Health Organization is developing Preferred Product Characteristics (PPC)¹ to provide guidance

to developers and manufacturers on the preferred characteristics for such diagnostic products to ensure safe and appropriate use, efficacy, and global accessibility. This collaborative effort involves diverse experts, individuals with lived experience, and a public consultation to gather comprehensive stakeholder input.

The WHO PPC, scheduled for publication later in 2024, aims to steer developers and manufacturers towards creating diagnostics that are safe, efficient, and universally accessible.

WHO Brain Health Unit

¹ <https://www.who.int/health-topics/dementia>

Innovations using mHealth for People with Dementia and Co-Morbidity and their Caregivers (IMPACT) in Peru

Over 60 percent of people with dementia (PWD) live in lower- and middle-income countries (LMICs), where populations are ageing rapidly and the capacity to provide adequate diagnosis, management, and support is limited and often lacking. In Latin American and Caribbean (LAC) countries, a recent systematic review found an increase in dementia prevalence in older adults (65+) to 11 percent, compared with the 7 percent reported in 2009.¹ In Peru, there were 147,000 people living with dementia in 2010, a number predicted to rise fourfold by 2050 to 748,000.² The high cost of informal care in dementia and in general is not well measured in healthcare systems or by most common macroeconomic indicators. Furthermore, providing informal care for dementia, alongside the multiple other long-term conditions with which dementia often coexists, places a significant toll on the mental and physical health of family members. In return, mental ill health amongst caregivers results in poorer outcomes for PWD.³

The IMPACT project uses dementia as a tracer condition to identify barriers, pain points, and potential solutions in the delivery of chronic care for complex conditions.

The IMPACT project uses dementia as a tracer condition to identify barriers, pain points, and potential solutions in the delivery of chronic care for complex conditions. The project will provide insights and lessons for the strengthening of health systems in Peru, and more widely in LAC, through sustainable, integrated, person-centred, community-delivered, technology-enabled innovation. IMPACT embraces the complexity of dementia and multimorbidity, with particular attention to the challenges of living with these conditions, and of providing care within the household outside traditional healthcare delivery structures.

IMPACT focuses on the physical and mental health of both PWD and caregivers. Our specific objectives are 1) to evaluate the readiness of health systems to provide support for PWD and their caregivers; 2) to develop and implement an mHealth application for dementia case-finding by community health workers (CHWs); 3) to determine the feasibility of a CHW-delivered, technology-enabled intervention to improve health-related quality of life for PWD and their caregivers; and, 4) to assess the socioeconomic burden of dementia. Through these objectives, and in combination with our broad programme of outreach, capacity building, and engagement activities, we will identify barriers to and facilitators for high-quality dementia diagnosis and care in LAC.

The research is being conducted across four sites: Lima, the capital of Peru; Tumbes, a semiurban region on the northern coast of Peru; Huancayo, in the central Andes; and Iquitos, the largest city of the Peruvian jungle. The geographical and sociocultural diversity of Peru allows us to conduct the study in one country yet have a range of scenarios and populations of relevance to many LAC countries. The outputs will therefore be primed for generalisability across the region.

Specific challenges that we have identified in Peru with respect to health system provision for dementia include low levels of dementia diagnosis, lack of support for caregivers, and a highly fragmented and complex health system. There is insufficient public awareness of dementia, with memory loss still being seen as part of normal ageing. People with cognitive impairment have limited access to healthcare, and appropriate training among health professionals is minimal or absent. Dementia assessments from high-income countries (HICs) are generally inappropriate for off-the-shelf use due to cultural biases and because illiteracy rates among adults over 60 years old are high and show regional variation (12.3 percent in urban areas, 41.6 percent in rural areas of Peru).^{4,5}

- 1 Ribeiro F, Teixeira-Santos AC, Caramelli P, Leist AK, et al. Prevalence of dementia in Latin America and Caribbean countries: Systematic review and meta-analyses exploring age, sex, rurality, and education as possible determinants. *Ageing Research Reviews* 81 (2022) 101703 <https://doi.org/10.1016/j.arr.2022.101703>
- 2 Custodio N, Wheelock A, Thumala D, Slachevsky A. Dementia in Latin America: epidemiological evidence and implications for public policy. *Front Aging Neurosci* 2017 9:221. doi: 10.3389/fnagi.2017.00221.
- 3 Alva-Diaz C, Malaga M, Rodriguez-Calienes A, Morán-Mariños C, et al. Costs Related to Frontotemporal Dementia in Latin America: A Scoping Review of Economic Health Studies. *Front. Neurol* 2021; 12:684850. doi: 10.3389/fneur.2021.684850
- 4 Lopera F, Custodio N, Rico-Restrepo M, Allegri RF, et al. A task force for diagnosis and treatment of people with Alzheimer's disease in Latin America. *Front. Neurol* 2023; 14:1198869. doi: 10.3389/fneur.2023.1198869.
- 5 Custodio N, Duque L, Montesinos R, Alva-Diaz C, et al. Systematic review of the diagnostic validity of brief cognitive screenings for early dementia detection in Spanish-speaking adults in Latin America. *Front Aging Neurosci* 2020; 12:12. doi: 10.3389/fnagi.2020.00270.

However, the Peruvian context also provides unique opportunities for innovative scalable health systems innovations for dementia care. IMPACT is developing codesigned, culturally appropriate assessment tools, such as the Peruvian adaptation of the Rowland Universal Dementia Assessment Scale (RUDAS)⁶ and adapting established caregiver support programmes such as the Care Ecosystem⁷ to the Peruvian context to empower CHWs to lead non-pharmacological interventions. Familiarity with and use of mobile technology is widespread and increasing, even in rural areas and amongst older age groups. We are working closely with the Peruvian Ministry of Health (MINSa), which is committed to the development of a national dementia plan and has introduced major mental health reforms with an emphasis on community assessment and care.^{8,9}

The aim of IMPACT is to strengthen health systems for dementia in LAC at different levels of the health system—macro, meso, and micro—through research, capacity building, and communications. We are working with patients, caregivers, and community organisations as well as healthcare workers, providers, and policymakers to understand where current pressure points lie, to promote implementation of appropriate dementia

assessment tools at scale within health services, to improve support systems in the community for caregivers and to provide clinical and economic data for the development of the national dementia plan. Crucially, the project will also raise awareness and tackle stigma about dementia amongst key stakeholders and the general public through targeted educational campaigns across traditional and social media platforms.

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Key points



The dementia research narrative is slowly shifting. The more we learn, the more precise and targeted our therapies can become. The earlier we detect, the greater our chances of reducing risk. The more targeted our dementia policies, the stronger our health and care systems will become. Small shifts can lead to seismic – and sustainable – change.

- 6 Custodio N, Montesinos R, Lira D, Herrera-Perez E, et al. Validation of the RUDAS for the identification of dementia in illiterate and low-educated older adults in Lima, Peru. *Front Neurol* 2020; 11:11. doi: 10.3389/fneur.2020.00374.
- 7 Possin KL, Merrilees JJ, Dulaney S, Bonasera SJ, et al. Effect of collaborative dementia care via telephone and internet on quality of life, caregiver well-being, and health care use. *JAMA Intern Med* 2019; 179(12): 1658-1667. doi: 10.1001/jamainternmed.2019.4101.
- 8 <https://busquedas.elperuano.pe/normaslegales/ley-para-la-prevencion-y-tratamiento-de-la-enfermedad-del-al-ley-n-30795-1660608-13/>
- 9 Miranda J J, Diez-Canseco F, Araya R, Cutipe Y, et al. Transitioning mental health into primary care. *The Lancet Psychiatry* 2017;4: 90–92. doi: 10.1016/S2215-0366(16)30350-9.

Report summary

The implementation of the WHO Global action plan on the public health response to dementia in 2017 marked a momentous turning point – a declaration to and by the world that dementia was a public health issue worth rallying around.

Seven years on, the laudable aspirations of this plan have been eclipsed at the international and national levels by other concerns: a global pandemic, devastating conflicts across the globe, and economic downturns affecting states and citizens alike.

Amid this grim landscape, there are so many reasons to hope.

Yet the scale of the dementia challenge remains just as pressing today. Dementia is the seventh leading cause of death worldwide, with an estimated 139 million people projected to be living with the condition in 2050. Every year that the can is kicked down the road has serious, tangible ramifications for people living with dementia, carers, and societies.

Yet amid this grim landscape, there are so many reasons to hope. Advocates across the world work tirelessly to fill the gaps in awareness raising, support, and services for people living with dementia; scientists are constantly expanding our understanding of Alzheimer's and dementia, with the hopes of finding a cure and improving risk reduction, care, treatment, and support; millions of people around the world devote time and energy to caring for people with dementia, often without recognition or glory, because it is the right thing to do; and countless people live with dementia every day with steadfastness and dignity, challenging society's preconceptions about the condition.

All these individuals are making a difference – and they deserve to be carrying out these incredibly important duties with all available resources. As many of the contributors to this report have made clear, national dementia policies are critical tools to ensure that we face the manifold challenges of dementia as well equipped as possible. The Global action plan on dementia is currently the most powerful tool at our disposal to influence governments to adopt dementia policies in their respective countries.

This is the moment of truth: Will WHO member states renew their commitment to the Global action plan until 2035, and take full advantage of this extension to live up to the solemn promise they made in 2017? Or will they let this opportunity pass them by, despite the clear consequences on the short, medium, and long term for us all?

We hope that, after reading this report, the choice is clear.

Appendix A

ADI member nations that are WHO member states, with dementia plans represented by income group, plan stage, and status as of 30 April 2024

Country	WHO region	WHO status	ADI status	Income group	Plan status	
Argentina	Region of the Americas	WHO	Member	HIC	Stage 1 & 2	No current contact with government or Ministry of Health & No plan
Armenia	European region	WHO	Member	UMIC	Stage 5B	Plan adopted, funded, and monitored (some limited funding)
Australia	Western Pacific region	WHO	Member	HIC	Stage 3A	Not yet launched, but commitment to funding for some of the 7 action areas
Austria	European region	WHO	Member	HIC	Stage 5B	Plan adopted, funded, and monitored
Azerbaijan	European region	WHO	MDP	UMIC	Stage 2A	Initial meetings with governments, but no further progress
Bahamas	Region of the Americas	WHO	Member	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 (i.e., dementia is integrated into a broader health plan which could include older persons, non-communicable disease, neurology, mental health etc.) including dementia under consideration
Barbados	Region of the Americas	WHO	Member	HIC	Stage 2D	Grouped health plan (i.e., dementia is integrated into a broader health plan which could include older persons, non-communicable disease, neurology, mental health etc.) including dementia under consideration
Belgium	European region	WHO	Member	HIC	Stage 2C	Some funding committed to 7 action areas of Global plan, but no expressed intention of launching a plan
Bolivia	Region of the Americas	WHO	Member	LMIC	Stage 2D & 2E	Grouped health plan (i.e., dementia is integrated into a broader health plan which could include older persons, non-communicable disease, neurology, mental health etc.) including dementia under consideration & Dementia referred to in existing grouped health plan, but not as a separate health condition
Bosnia and Herzegovina	European region	WHO	Member	UMIC	Stage 3C	In development, slow progress
Botswana	African region	WHO	MDP	UMIC	Stage 2A	Initial meetings with government, but no further progress
Brazil	Region of the Americas	WHO	Member	UMIC	Stage 4F	Plan adopted, but not implemented
Brunei	Western Pacific region	WHO	Member	HIC	Stage 3D	Grouped health plan including dementia in development
Bulgaria	European region	WHO	Member	UMIC	Stage 2D & 2E	"Grouped health plan (i.e., dementia is integrated into a broader health plan which could include older persons, non-communicable disease, neurology, mental health etc.) including dementia under consideration & Dementia referred to in existing grouped health plan, but not as a separate health condition"
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 2B	Some developments towards a plan, but progress stalled
Canada	Region of the Americas	WHO	Member	HIC	Stage 5B	Plan adopted, funded, and monitored

Country	WHO region	WHO status	ADI status	Income group	Plan status	
Chile	Region of the Americas	WHO	Member	HIC	Stage 5A	Plan adopted but not fully communicated
China	Western Pacific region	WHO	Member	HIC	Stage 5B	Plan adopted, funded, and monitored
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 4A	Inadequate funding
Croatia	European region	WHO	Member	HIC	Stage 3D	Grouped health plan including dementia in development
Cuba	Region of the Americas	WHO	Member	LMIC	Stage 5A	Plan adopted but not fully communicated
Cyprus	European region	WHO	Member	HIC	Stage 4B	No Funding
Czech Republic	European region	WHO	Member	HIC	Stage 4A	Inadequate funding
Denmark	European region	WHO	Member	HIC	Stage 5A	Plan adopted but not fully communicated
Dominica	Region of the Americas	WHO	MDP	UMIC	Stage 3C	In development, slow progress
Dominican Republic	Region of the Americas	WHO	Member	UMIC	Stage 4B & 4F	No funding & Plan adopted, but not implemented
Ecuador	Region of the Americas	WHO	Member	UMIC	Stage 1	No current contact with government or Ministry of Health
Egypt	Eastern Mediterranean region	WHO	Member	LMIC	Stage 2D	Grouped health plan
El Salvador	Region of the Americas	WHO	Member	LMIC	Stage 1	No current contact with government or Ministry of Health
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
Ethiopia	African region	WHO	MDP	LIC	Stage 3C	In development, slow progress
Finland	European region	WHO	Member	HIC	Stage 2C	Some funding committed to 7 action areas of Global plan, but no expressed intention of launching a plan
France	European region	WHO	Member	HIC	Stage 3C	In development, slow progress
Georgia	European region	WHO	Member	LMIC	Stage 3A	Not yet launched, but commitment to funding for some of the 7 action areas
Germany	European region	WHO	Member	HIC	Stage 5B	Plan adopted, funded, and monitored
Ghana	African region	WHO	Member	LMIC	Stage 3C	In development, slow progress
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 & 2E	Initial meetings with government, but no further progress & Dementia referred to in existing grouped health plan, but not as a separate health condition
Honduras	Region of the Americas	WHO	Member	LMIC	Stage 2A	Initial meetings with government, but no further 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 status	
Iran	Eastern Mediterranean region	WHO	Member	UMIC	Stage 4F	Plan adopted, but not implemented
Israel	European region	WHO	Member	HIC	Stage 4A	Inadequate funding
Italy	European region	WHO	Member	HIC	Stage 4A	Inadequate funding
Jamaica	Region of the Americas	WHO	Member	UMIC	Stage 2	
Japan	Western Pacific region	WHO	Member	HIC	Stage 5B	Plan adopted, funded, and monitored
Jordan	Eastern Mediterranean region	WHO	Member	UMIC	Stage 2D & 2E	Grouped health plan (i.e., dementia is integrated into a broader health plan which could include older persons, non-communicable disease, neurology, mental health etc.) including dementia under consideration & Dementia referred to in existing grouped health plan, but not as a separate health condition
Kenya	African region	WHO	Member	LMIC	Stage 3B	In development, good progress
Lebanon	Eastern Mediterranean region	WHO	Member	UMIC	Stage 2B	Some developments towards a plan, but progress stalled
Lesotho	African region	WHO	Member	LMIC	Stage 2E	Dementia referred to in existing grouped health plan, but not as a separate health condition
Lithuania	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
Macedonia (North)	European region	WHO	MDP	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	Dementia referred to in existing grouped health plan, but not as a separate health condition
Malaysia	Western Pacific region	WHO	Member	UMIC	Stage 3D	Grouped health plan including dementia in development
Maldives	South-East Asian Region	WHO	Member	UMIC	Stage 3A	Not yet launched, but commitment to funding for some of the 7 action areas
Mali	African region	WHO	MDP	LIC	Stage 2E	Dementia referred to in existing grouped health plan, but not as a separate health condition
Malta	European region	WHO	Member	HIC	Stage 4A	Inadequate funding
Mauritius	African region	WHO	Member	UMIC	Stage 2B	Some developments towards a plan, but progress stalled
Mexico	Region of the Americas	WHO	Member	UMIC	Stage 4B	No funding
Montenegro	European region	WHO	Member	UMIC	Stage 2E	Dementia referred to in existing grouped health plan, but not as a separate health condition
Morocco	Eastern Mediterranean region	WHO	Member	LMIC	Stage 1	No current contact with government or Ministry of Health
Netherlands	European region	WHO	Member	HIC	Stage 5B	Plan adopted, funded, and monitored
New Zealand	Western Pacific region	WHO	Member	HIC	Stage 4B	No funding
Nicaragua	Region of the Americas	WHO	Member	LMIC	Stage 1	No current contact with government or Ministry of Health
Nigeria	African region	WHO	Member	LMIC	Stage 3D	Grouped health plan including dementia in development

Country	WHO region	WHO status	ADI status	Income group	Plan status	
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 4B	No funding
Panama	Region of the Americas	WHO	Member	HIC	Stage 3A	Not yet launched, but commitment to funding for some of the 7 action areas
Peru	Region of the Americas	WHO	Member	UMIC	Stage 3D	Grouped health plan including dementia in development
Philippines	Western Pacific region	WHO	Member	LMIC	Stage 2D	Grouped health plan
Poland	European region	WHO	Member	HIC	Stage 2A	Initial meetings with government, but no further progress
Portugal	European region	WHO	Member	HIC	Stage 4B	No funding
Qatar	Eastern Mediterranean region	WHO	Member	HIC	Stage 4A	Inadequate funding
Romania	European region	WHO	Member	UMIC	Stage 3C	In development, slow progress
Russian Federation	European region	WHO	Member	UMIC		Plan/Strategy adopted – No further updates
Saint Kitts and Nevis	Region of the Americas	WHO	Member	HIC	Stage 2A	Initial meetings with government, but no further progress
Saint Lucia	Region of the Americas	WHO	MDP	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	MDP	UMIC	Stage 2A	Initial meetings with government, but no further progress
Saudi Arabia	Eastern Mediterranean region	WHO	Member	HIC	Stage 2A & 2B	Initial meetings with government, but no further progress & Some developments towards a plan, but progress stalled
Senegal	African region	WHO	MDP	LIC	stage 2A	Initial meetings with government, but no further progress
Serbia	European region	WHO	MDP	UMIC	Stage 2E	Dementia referred to in existing grouped health plan, but not as a separate health condition
Seychelles	African region	WHO	MDP	LIC	Stage 2B	Some developments towards a plan, but progress slow
Singapore	Western Pacific region	WHO	Member	HIC	Stage 5A	Plan adopted but not fully communicated
Slovak Republic	European region	WHO	Member	HIC	Stage 1	No current contact with government or Ministry of Health
Slovenia	European region	WHO	Member	HIC	Stage 5	Plan/Strategy adopted
South Africa	African region	WHO	Member	UMIC	Stage 2B	Some developments towards a plan, but progress stalled
Spain	European region	WHO	Member	HIC	Stage 3C	In development, slow progress
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 3C	In development, slow progress
Sweden	European region	WHO	Might become a member	HIC	Stage 5B	Plan adopted, funded, and monitored

Country	WHO region	WHO status	ADI status	Income group	Plan status	
Thailand	South-East Asian Region	WHO	Member	UMIC	Stage 5C	Grouped health plan including dementia adopted, with specific targets and funding
Tonga	Western Pacific region	WHO	Member	UMIC	Stage 2A & 2B	Initial meetings with government, but no further progress & Some developments towards a plan, but progress stalled
Trinidad and Tobago	Region of the Americas	WHO	Member	HIC	Stage 3C	In development, slow progress
Tunisia	Eastern Mediterranean region	WHO	Member	LMIC	Stage 2A	Initial meetings with government, but no further progress
Turkey	European region	WHO	Member	UMIC	Stage 3B	In development, good progress
Uganda	African region	WHO	Member	LIC	Stage 2D	Grouped health plan (i.e., dementia is integrated into a broader health plan which could include older persons, non-communicable disease, neurology, mental health etc.) including dementia under consideration
Ukraine	European region	WHO	Member	LMIC	Stage 3B	In development, good progress
United Arab Emirates	Eastern Mediterranean region	WHO	Member	HIC	Stage 2B	Some developments towards a plan, but progress stalled
United Kingdom – England	European region	WHO	Member	HIC	Stage 3D	Grouped health plan including dementia in development
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		
Venezuela	Region of the Americas	WHO	Member	UMIC	Stage 1	No current contact with government or Ministry of Health
Yemen	Eastern Mediterranean region	WHO	Member	LIC	Stage 2D	Grouped health plan (i.e., dementia is integrated into a broader health plan which could include older persons, non-communicable disease, neurology, mental health etc.) including dementia under consideration
Zambia	African region	WHO	MDP	LMIC	Stage 1	No current contact with government or Ministry of Health
Zimbabwe	African region	WHO	Member	LIC	Stage 2A	Initial meetings with government, but no further progress

Appendix B

ADI member nations that are not WHO member states, with dementia plans represented by plan stage and status as of 30 April 2024

Country	ADI member	Plan stage	Plan status
Bermuda	Member	Stage 2A	Initial meetings with government, but no further progress
Bonaire	Member	Stage 4F	Plan adopted, but not implemented
British Virgin Islands	Member	Stage 2	No plan/strategy
Cayman Islands	Member	Stage 2A	Initial meetings with government, but no further progress
Curacao	Member	Stage 4F	Plan adopted, but not implemented
Gibraltar	Member	Stage 5	Plan/Strategy adopted
Hong Kong SAR	Member	Stage 3C	In development, slow progress
Macau SAR	Member	Stage 5A	Plan adopted but not fully communicated
Puerto Rico	Member	Stage 5A	Plan adopted but not fully communicated
United Kingdom – Scotland	Member	Stage 4A/4F	Inadequate funding/Plan adopted, but not implemented
Sint Maarten	Member	Stage 2E	Dementia referred to in existing grouped health plan, but not as a separate health condition
TADA Chinese Taipei	Member	Stage 5B	Plan adopted, funded, and monitored
United Kingdom – Northern Ireland	Member	Stage 4F	Plan adopted, but not implemented
United Kingdom – Wales	Member	Stage 4D	Plan under threat (e.g., is coming to an end and could be terminated or replaced by a general health plan)

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

About ADI

Alzheimer's Disease International (ADI) is the international federation of Alzheimer associations throughout the world. Each of our more than 100 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 carers, 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 the 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.
- Delivering ADI accreditation programme to ensure people living with dementia receive high quality care and support provided by appropriately trained professionals and carers.
- Supporting global advocacy by providing facts and figures about dementia, and monitoring as well as influencing dementia policies.

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

You can find out more about ADI at www.alzint.org

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