



**World Dementia
Council** Leading the Global Action
Against Dementia

Defeating dementia: the road to 2025

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Introduction

Dementia is the 21st century’s biggest health challenge. Today almost 50 million people around the world have the disease and that number is set to triple by 2050.

In 2013, the then Prime Minister David Cameron used the United Kingdom’s presidency of the G8 to host a historic summit in London which focused the international community’s attention on the growing dementia challenge. There, the G8 agreed key commitments, set out in their declaration and communique, on how global action could turn the tide on dementia by 2025.

Five years on there is much to be proud of. The London summit has helped propel forward international efforts to find disease-modifying therapies, improve care, raise awareness and understand how we can reduce the risk of dementia. Progress has been made but the challenge remains immense.

From understanding the basic biology of dementia, through to tackling the still too prevalent perception that it is a natural part of ageing, there is no part of this agenda where the job is done. It is vast. And no single report can cover the successes since 2013 nor the challenges of realising the 2025 ambitions.

No individual, no organisation and no country can defeat dementia alone. The G8 summit aimed to harness the strength of international collaboration to improve the lives of people with the disease. In this report we set out four areas where greater international cooperation through the G7 and G20, along with organisations like the European Union, Organisation for Economic Co-ordination and Development (OECD) and World Health Organization (WHO).

These four areas are:

- the search for a disease modifying therapy;
- the challenge of living well;
- the need for better care;
- reducing the impact of dementia.

It is not to say that there are issues that lie outside these areas that are not significant. Since 2013 the dementia movement has grown and grown. From grassroots activism to advocacy at the United Nations, individuals and organisations are pushing for change. This report shines a spotlight on a small number of areas where greater international collaboration can help drive this.

In addition to these chapters, this report hears from individuals and organisations who five years ago and since have done so much to help the cause.

Alongside these voices we hear the words of the most important people of all – those affected by dementia. They are the reason we are fighting for this cause.

The 2013 summit marked a turning point in the international effort to meet the dementia challenge. The job is not done. The job is far from done. But we can collectively look back at the last five years and be proud of the advances that have been made since the G8 met in London. And with that sense of pride redouble our efforts to deliver on the 2025 goals.



Harry Johns
Chair, WDC
President and CEO,
Alzheimer’s Association



Lenny Shallcross
Executive Director, WDC



David Cameron

Five years ago, I hosted the G8 summit in Lough Erne. As the leaders of the world arrived in Northern Ireland, I had an urgent message for them. It was about dementia. I warned them that this health crisis had the world in its grip. That it was the only major cause of death we couldn't prevent or slow down or cure.

As part of the UK's G8 presidency we convened the first ever G8 dementia summit in London. Some ambitious goals were set for the international community to meet by 2025, including the aim to identify a cure or a disease-modifying therapy for dementia. It was also here that we agreed the foundation of the World Dementia Council.

Why was it so important to bring world leaders together on this issue? Because this is a great global challenge of our time. 50 million people around the world have dementia; by 2050 that will have more than trebled to over 150 million. No individual, organisation or country is going to be able to solve it alone. It doesn't affect one country or some countries; it affects us all. It is too big and too complex to tackle without each other. And it will grow and grow if we don't do more, and do so now.

As this report shows, we have made much progress towards our goals in the last five years.

First, on awareness. Countries across the world are raising awareness through programmes such as Dementia Friends. In fact, I made sure all my ministers took part in the programme – and now in the UK over two million people have followed suit.

Second, on care. More people than ever are living in dementia-friendly communities and more people are receiving good quality care. The world is a better place for people living with dementia than it was five years ago.

Third, on risk. We are discovering more about how lifestyle and other factors can contribute towards a person's risk of developing dementia.

Fourth, on research. Across the world we are investing more in dementia research. In Britain, we established the UK Dementia Research Institute with government funding and additional funding from the charitable sector. There's the Dementia Discovery Fund, which will help to turn research breakthroughs into potential new treatments. And I am proud to be President of Alzheimer's Research UK, the charity which is backing new research and playing a leading role in the early diagnosis of dementia, with an overall ambition to detect the condition 10–15 years earlier than we do today.

This is the groundwork that will make breakthroughs possible. But there is much further to go.

Funding is vital. In the UK, between 2012 and 2015, government funding for dementia research doubled to over £60 million a year. Yet dementia research still receives less funding than other major disease areas, despite it being the biggest killer in our country.

Technology is also key. It has the potential to transform everything, from how we manage risk, to how we deliver care. Big data can rapidly accelerate dementia research – not just biomedical research, but care research as well. The World Health Organization's Global Dementia Observatory is a great way of pooling information. We need more of that.

Five years ago, I was daunted when I explained the scale of the challenge to those leaders. But now, reading reports like this, I feel a deep sense of confidence. Because there is light at the end of a very long tunnel. We are going in the right direction. And if we keep up the pressure, take all the steps we've said we would, there's no reason the diseases that cause dementia cannot be defeated.



A handwritten signature of David Cameron in black ink.

The Rt Hon David Cameron

President, Alzheimer's Research UK and Former Prime Minister of the United Kingdom, 2010–2016

Shinzo Abe

I would like to extend my heartfelt congratulations to the World Dementia Council (WDC) upon your fifth anniversary as well as the publishing of this five-year progress report. The WDC was established under the United Kingdom's leadership following the G8 London Summit in 2013. In the five years since then, many people around the world have come to the realization that we have a significant responsibility to act on the issues of dementia.

In addition to the adoption of the "G7 Ise-Shima Vision for Global Health" at the 42nd G7 Summit (the G7 Ise-Shima Summit), which was held in Japan in 2016, the "Kobe Communiqué," including global dementia initiatives based on Summit agreements, was adopted at the G7 Health Ministers' Meeting held in Kobe that same year. Japan will continue efforts to maintain a leading role within the international community in the fight against dementia.

With approximately 7 million elderly people projected to be living with dementia in Japan by 2025, in 2015, the Government established a "Comprehensive Strategy to Accelerate Dementia Measures," also known as the "New Orange Plan." This plan promotes the creation of age- and dementia-friendly communities not only by the Ministry of Health, Labour and Welfare (MHLW), but also through the joint efforts of other relevant ministries and agencies. For instance, the number of Dementia Supporters, people who have proper knowledge and understanding of dementia and are able to provide a certain level of support to people living with dementia and their families, has already exceeded 10 million across the country, and we aim to foster 12 million Supporters by 2020.

To further advance research on dementia, in FY2016, it was suggested at the Japan Agency for Medical Research and Development (AMED) that a system of international, multi-sectoral cooperation be established for the effective and efficient promotion of dementia research. A research project was thus started on the construction of a concrete framework to that end. Since this fiscal year, discussion has been underway at expert meetings toward the creation of a real-world test field for new dementia-friendly products and services as part of this "Public-Private Joint Demonstration Platform for Dementia Patients" project.

G20 meetings will be held in Japan in 2019, and we are considering the organization of discussions on themes related to the aging of society. Japan has achieved the longest healthy life expectancy in the world, and it is expected that our healthy life expectancy will increase even further in the future. In preparation for the emergence of a "100-year life society," Japan is currently working to create society in which people of all ages can continue to meaningfully participate and live healthy, active lives with peace of mind. It is my hope that, as populations around the world continue to age, we will be able to share Japan's initiatives on aging far and wide, thereby contributing to the resolution of international issues. In closing, I would like to express my sincere wishes for the continued health and success of everyone involved with the WDC.



Shinzo Abe

Shinzo Abe

Prime Minister of Japan

Angel Gurría

The 2013 G8 Dementia Summit focused the attention of the international community on the condition. It could not have come at a more pressing time. In the OECD today, 19 million people live with dementia. With no clinical breakthroughs, and the share of people aged 80 and over set to more than double by 2050, millions more will develop dementia in the coming years.

Since the Summit, the OECD has worked with countries, the World Dementia Council, the WHO and other global stakeholders to address the challenges of dementia. But despite ambitious commitments, progress has been slow. This important report prepared by the WDC, takes stock of the progress achieved and, more importantly, the challenges that we continue to face. We need to accelerate action in three main areas.

First, the quality of care for people living with dementia is unacceptable. Our recent OECD report, *Care Needed: Improving the Lives of People with Dementia*, draws attention to many of the gaps in care that persist today. More than half of people in the OECD remain undiagnosed and do not receive the care they deserve. Even once a diagnosis is made, too many people find the care they receive inadequate. Specialised care pathways for people with dementia are available in just a handful of countries. Even fewer have developed dementia-friendly design guidelines for care facilities. And financial incentives for training care workers in dementia are rare. Nearly one in twenty people aged 65 and over across the OECD are prescribed antipsychotics, despite much evidence that this is often unnecessary. Families and carers are poorly supported, with patchy counselling and respite services, and up to three-fifths of carers experience anxiety or depression as a result. Women, who make up three-fifths of family carers in the OECD, are disproportionately affected. This must change. Countries should set clear targets around diagnosing people with dementia. Raising standards for the quality of care can no longer be delayed. More transparency and monitoring of the effectiveness, safety and patient-centredness of care is possible.

Second, health systems still do not take full advantage of the rich data available across health care settings to improve research and the quality of life of people affected by dementia. We must harness the statistical power of analysing deep and broad data, and do this globally. New efforts in the past two years, such as the EU General Data Protection Regulation, and the OECD Council Recommendation on Health Data Governance, have laid the foundation for how countries can harmonise approaches to the safe use of health data across borders. New EU and global initiatives have been launched to promote standards for data, data sharing, data security and governance that will support brain research. These efforts are a good start, but significant

obstacles to collaboration remain that require policy action. Developing harmonised governance frameworks, improving data security and interoperability, and developing sound approaches to public engagement and transparency are within reach and would be game changers for both research and care providers.

Third, in spite of all efforts, innovation for dementia is slow. Five years ago, less than 0.5% of the health research budget in OECD countries was devoted to dementia. Since then, some progress has been made but many problems in the innovation model remain. The complexity of the diseases that cause dementia have contributed to many failures, making R&D investment risky. Promoting public-private partnerships and more public investment in upstream research is critical. Collaboration between the many disparate stakeholder groups, including industry, regulators, academia, and patient and payers' organisations must improve.

Global leaders have once again come together in recognition of the challenges we continue to face, and with a strong commitment to work together to overcome them. Governments, businesses, advocates, and other stakeholders must continue to commit the attention and resources needed to improve the quality of care for people living with dementia today, while also strengthening the data and innovation landscape to generate the clinical breakthroughs for the future. It is my sincere hope that when we come together again, five years from today, we will be able to recount our accomplishments, rather than hope for future success. The OECD is committed to helping countries achieve these changes. Count on us!



Angel Gurría
Secretary-General, OECD



Tedros Adhanom Ghebreyesus

Fifty million people around the world now have dementia, a number that is projected to triple by 2050. Someone develops dementia every three seconds. This is not just a problem for high-income countries; most people with dementia live in low and middle-income countries.

Dementia affects not only the person with the condition, but also the lives of family members, who may experience psychological or physical distress, or financial hardship. Dementia takes a heavy economic toll on societies because of the high costs of care and loss of productivity. In addition, lack of awareness of dementia and the common misconception that it is a natural part of ageing leads to stigma, and delays in diagnosis.

Five years after the seminal G8 UK dementia summit, this report highlights achievements since 2013, yet clearly shows that much remains to be done. The adoption of the Global action plan on the public health response to dementia 2017-2025 by the World Health Assembly in May 2017 signaled the international community's commitment to address the challenges posed by dementia, and to improve the lives of people with dementia, their families and others who care for them. It represents a roadmap for global action to enhance our collective response to dementia and urges Member States to develop ambitious national responses.

Successfully addressing dementia requires a collaborative, multisectoral response from all partners, grounded in public health. It also needs an enhanced health information and monitoring system to inform policy making, care planning, and service delivery. It obliges all of us to respect and promote the human rights, dignity and autonomy of people with dementia. A person with dementia is a person who deserves to be treated with respect like everybody else. We all have a responsibility to work towards a society that is more dementia-friendly and inclusive. The best way to do this is to involve people with dementia and their carers in all issues that affect them.

The World Health Organization, together with our partners, is working on the implementation of the global dementia action plan at global, regional and national levels. In 2017, WHO launched the Global Dementia Observatory, a web-based data and knowledge exchange platform covering such topics as dementia policies, service planning, and health and social care systems. The observatory allows us to measure progress and helps us to identify areas where efforts are most needed. For example, the global dementia action plan aims for 75% of countries to have a dementia plan by 2025, either as a standalone item or integrated into other policies. But less than 20% of countries currently have such a plan. To close this gap, we have recently launched "Towards a dementia plan: a WHO guide" to provide countries with step-by-step guidance to enhance their policy response to dementia.

While we are working to find a cure for dementia and ways to reduce the risk of developing dementia for future generations, we must also alleviate the burden of dementia for those living with it, and their carers. Research and investment is required, not only to develop better treatments, but also for more accurate diagnostic tools, new technologies for disease monitoring and assessment, assistive technologies and new models of care.

It's vital that services for dementia are provided in an integrated way as part of a strong health system built on primary health care and aimed at delivering universal health coverage.

WHO looks forward to working alongside Member States, civil society and the private sector to improve the health and wellbeing of those affected by dementia, both for present and future generations. We commit to fulfilling the ambitious targets in the global dementia action plan and ensuring that we leave no one behind.



A handwritten signature in black ink, which appears to read "Tedros Adhanom Ghebreyesus".

Tedros Adhanom Ghebreyesus
Director-General, WHO

Marty Reiswig

Alzheimer's disease is the specter haunting our aging generations. But for me, it's not a distant possibility. There's a strong chance it's my destiny. And the clock is ticking.

My grandfather was one of fourteen siblings. Ten of them developed symptoms of Alzheimer's disease in their forties and early fifties. All ten died of the disease. The mutated gene they carried had a one in two chance of being passed to each of their children. My grandfather passed that faulty gene to my father. My dad showed signs of Alzheimer's at age fifty-two. My mom cared for him at home as long as she could, but now, at age sixty-six, my dad resides in a nursing home. He resides there, but he doesn't *live* there. He spends his days in his bed or wheelchair, completely dependent on caregivers to feed him, bathe him, clothe him, and move him. He can't speak. He can't read. He can't even watch television, because focusing on anything for more than a few seconds is impossible. This isn't living. This isn't life. My dad should be cheering at his grandkids' soccer games. Looking forward to retirement. Traveling with his wife. This isn't how things are supposed to be.

Visiting my dad is a wrenching, emotionally draining experience. Alzheimer's has stripped away virtually all of who he was. That's hard enough on its own. But every time I look at him, I know there is a fifty-fifty chance I'm looking into my own future. And if it's my future, then it could be my daughter's future. It could be my son's future.

I don't want my children to watch me deteriorate. I don't want them to go through what I'm going through with my dad.

I don't want them to lie awake at night wondering if it will happen to them.

Thanks to the DIAN study, I've met some of the rare families like mine from around the world who carry a gene that guarantees early-onset Alzheimer's disease. We all have different ways of dealing with the hand we've been dealt. Some choose to learn their gene status, while others, like myself, don't want to know. Some decide not to marry, or not to have biological children, to avoid passing on their gene to another generation. Some spend much of their time and resources preparing for the day they'll be symptomatic; others try to live life to the fullest while they still can.

But we do have two things in common. We have all watched people we love suffer and die from this disease while they were "too young" to have it. And we are all desperate for a cure.

We jokingly call ourselves the X-Men, because we are mutants trying to save the world. We endure injections, blood draws, lumbar punctures, endless scans, and grueling cognitive tests because we believe we can make a difference. We need a treatment, a prevention, a miracle, for ourselves and for our children. But we also want one for the rest of humanity. Because Alzheimer's disease is not a natural part of aging. The identity thief that stole our parents and brothers and sisters long before they died shouldn't be permitted to take the grandparents of the world. Their minds should last as long as their bodies. Imagine the wealth of knowledge we all would inherit if every grandparent could impart their wisdom and share their stories all the days of their lives.

We X-Men will continue to do everything asked of us, but we're not superhuman. Most of us are ordinary people. That's where you come in. Researchers. Drug developers. Elected officials. Leaders and influencers. We need you. *We need you.* Wield your influence with urgency. Slice through the red tape. Plow through every obstacle. Fight forward daily. Our time is running out.

Together, we can save the world from Alzheimer's.

Stand with us.



A handwritten signature in black ink that reads "Marty Reiswig".

Marty Reiswig

Person affected by dementia
living in the United States

Nishi Pulugurtha

Amma had wandered off one November day, exactly eight years ago. We found her after 48 hours. The diagnosis came in a few days later after a series of doctor visits, clinical tests and neurological testing – it was Alzheimer’s disease. I had heard of dementia and Alzheimer’s and knew it involved memory loss.

As I began caring for my mother, I realized that it involved a whole lot of other things and that memory loss was just one aspect of it. Amma could not be left alone at home, I went off for work in the mornings and got back in the evenings. I needed to get help to look after her, to keep her safe so that she did not wander off again. The caregiver who came was completely illiterate and could not even tell the time. She had no idea whatsoever about Amma’s condition. Amma looked absolutely fit and healthy. It took me a long time to train and convince the caregiver of the condition that Amma had and the kind of care she needed. The caregiver came in everyday at 8am and stayed for twelve hours. Amma did not like her presence as she had the keys to the house. She often got angry with her, but the anger abated very soon and Amma would become her jovial self, talking to her, enquiring about her children, telling her stories about her grandson Adi.

After two months, the care agency sent in a replacement. I had to begin the training and explanation all over again. The new caregiver was a much younger girl, and Amma took an immediate liking to her. She soon understood Amma’s condition and started doing things that Amma liked and approved of. They went out for walks in our compound, spent time tending to her plants, sat on the step outside and talked. However, after two months a new caregiver came in. Each time a new caregiver came, the difficulties of training and explaining began again. Many of them did not understand, some were keen to learn, most were not. One thing was common to them all; they were all untrained and clueless about Amma’s condition.

It has been over two years now that Amma has stopped talking. I know her likes and dislikes, her preferences, I understand her body language, I know what will comfort her, her tastes and all. Caring for her all these years has taught me much. It is however, still difficult gauging what is troubling her. More so when she is unwell. However, I can’t be with her all the time. Better awareness and training is urgently needed for those caring for people with dementia to ensure that they are kept safe when their families can’t be with them.

There are also too few clinicians who understand dementia and how it affects people. A year into Alzheimer’s Amma needed dental care as her tooth had broken off. The local dentist prescribed tooth extraction. I told him of Amma’s condition and also warned him that it would be difficult for Amma to follow instructions. My presence during the extraction would be needed. He decided against it and I heard him tell her to do stuff which she obviously did not. She just kept smiling and trying to talk. I had to intervene as getting impatient with Amma would just aggravate matters. It is imperative that quality care be made available for anyone who has Alzheimer’s and that they are treated with respect and dignity.

Learning to deal with Alzheimer’s has been a very difficult task for us at home. I read almost everything about the disease and through my personal experiences of caring for Amma, now have practical knowledge of what needs to be done and how to care for her. There is no way one can be prepared, one keeps on learning each day. I take each day as it comes. Amma’s smiles keep me going. The smiles are muted these days, but she does gaze and peer at me, responds to my call and very slowly smiles at me, not an ebullient one as before, much muted, but it is there nevertheless.



Nishi Pulugurtha

Nishi Pulugurtha

Caregiver living in India

Dennis Gillings

Society's immense challenge of aging populations driving increases in dementia is just beginning to respond to solutions that promise progress during the coming decade. Awareness of dementia and its implications at all levels of the political spectrum is so much greater than it was five years ago. The resulting attention has also become global, as illustrated by the increased geographical membership of the World Dementia Council.

Research funding for dementia by governments, particularly the United States, has increased substantially. This will close gaps in our understanding of molecular mechanisms within the brain that lead to disease and impairment. Early-onset subjects provide an enormous opportunity to expand clinical research into dementia as those unfortunately affected are highly motivated to participate in innovative therapeutic studies and trials.

Demand for dementia care as a result of aging is increasing at about double the rate of economic growth. This is a budgetary time bomb waiting to explode. It is why the huge increase in funding for basic research is so important. Unless we make progress on a cure, the prevalence of dementia will continue to increase and overwhelm society. Moreover, dementia is not just one disease, but many. Analogous to recent progress towards a fuller understanding of cancers and their more effective treatments, the scope and breadth of diseases that can be labelled dementia are undergoing intensive assessment and definition. This will enable targeted therapy for specific forms of dementia to be developed more quickly because of our ever improving understanding of the brain and the way it works.

At the same time behavioral, lifestyle and other individual characteristics are available for systematic analysis in big data sets so that there is greater understanding about what can be done to prevent or delay onset. Lifestyle changes may help compensate in a small way for dementia increases through aging until adequate curative therapy is developed by medical researchers and the biopharmaceutical industry.

Prevention is important. The public at large is beginning to fear dementia as much, if not more, than cancer. Although frightening, it does increase the political pressure to make it a priority to find more solutions to dementia and the related negative trends. The care required by subjects who develop dementia increases in scope and intensity as disease progression takes place. This puts enormous demands on families, communities, caregivers and other resources, particularly financial, necessary to maintain dignity and quality of life.

There has been little progress on improving the affordability of dementia care. Increasingly this will demand sufficient attention if we are to prevent wide differentiation in quality of life between the "haves" and "have nots" who develop dementia and related syndromes. Effective and affordable care models for individuals, families, and communities will require much more research funding, particularly into the role that technology, including robotics, can play in enabling families to care for elderly members with minimum impediment to their busy lives that need to be fulfilled.

It is possible to look at all this as a glass half empty or a glass half full. I prefer the latter; and it is rising! It is rising because of the myriad of initiatives that are now underway, many as a direct result of the 2013 London Dementia Summit. The pages of the report which follows will help understand where we are, how much must be accomplished, and, most importantly, how we are going to get there. Dementia is one of the most critical long-term health issues we face. Failure to overcome dementia is not acceptable. It would mean that gains in life expectancy and quality of life through extraordinary science, innovation and human endeavor in other branches of medicine will, in large part, be lost to the ravages of brain dysfunction as we age. Let us work relentlessly together to fulfill a better promise for current generations and generations to come. Surely such a goal is within our grasp; we will reach it soon.



A handwritten signature in black ink, appearing to read 'Dennis Gillings'.

Dennis Gillings CBE

Former World Dementia Envoy
and Founding Chairman, WDC

Acknowledgements and terminology

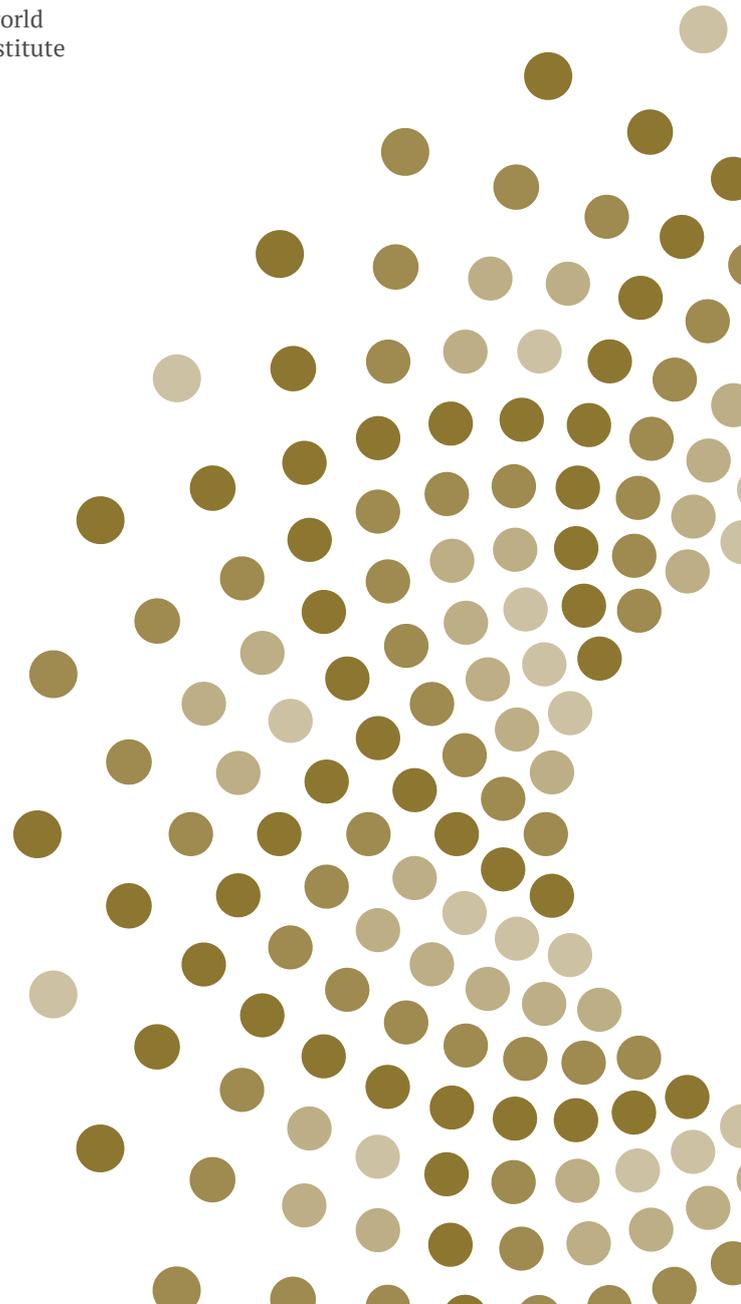
The World Dementia Council was established by the G8 following the London dementia summit in December 2013 with the aim of supporting and challenging the international community to deliver on the 2025 goals.

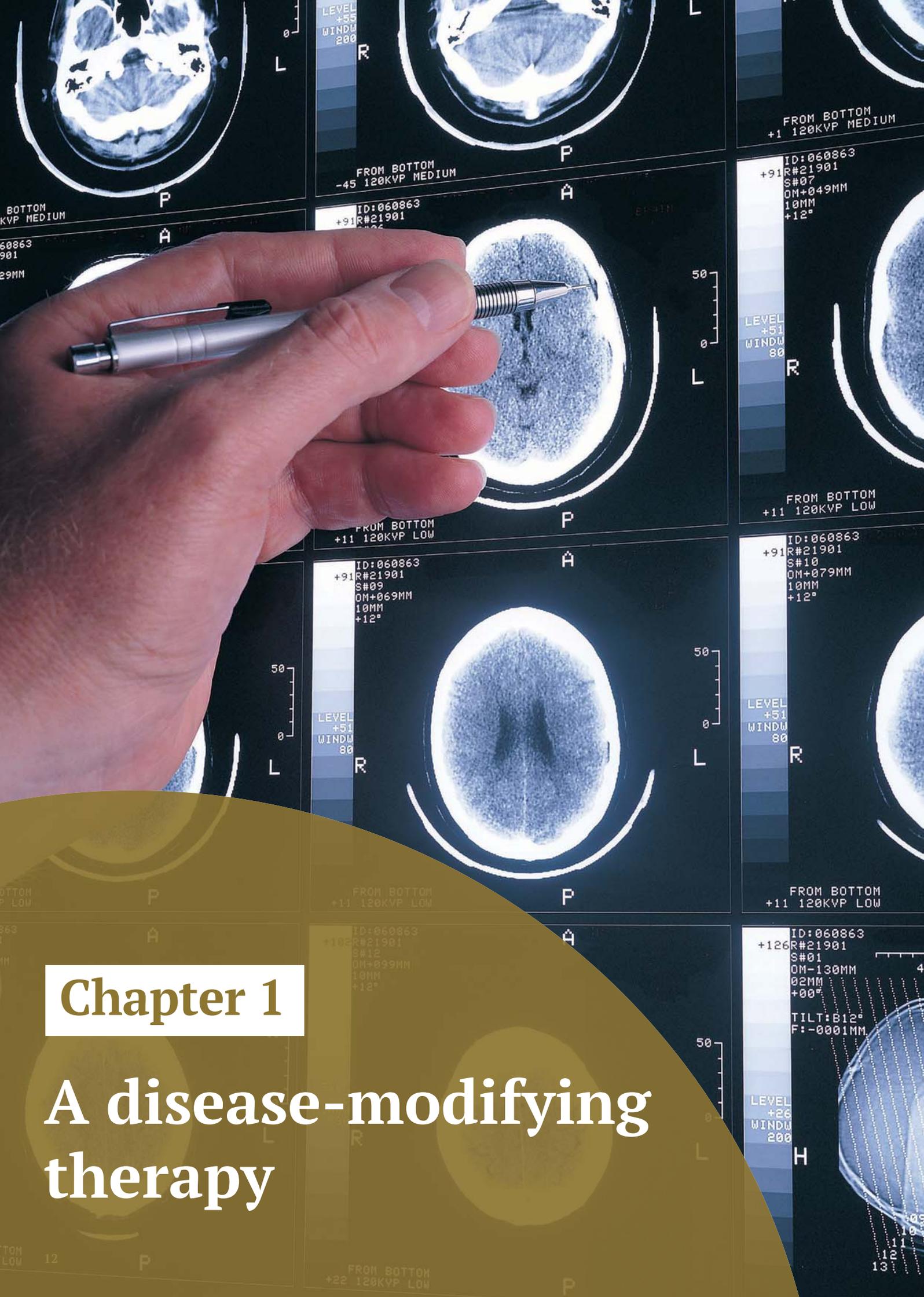
Alongside an Executive Team, the Council is made up of individuals and organisations who have leadership roles around the world. The content of the report and the calls to action do not represent the views of any one individual or organisation represented on the board.

This report benefits greatly from citing statistics from Alzheimer's Disease International reports, in particular successive World Alzheimer's Reports. It also benefits from reports produced by the Organization for Economic Co-ordination and Development and the World Health Organization.

Dementia describes a range of conditions the most common of which is Alzheimer's. Around the world different terms are used with some countries using the term disease and others condition. For the purposes of this report the phrase disease is used. Similarly, the report uses the phrase "person with dementia" and "caregiver". A range of different terms are used around the world and the use of one is for editorial purposes and does not constitute a recommendation on appropriate terminology.

For the purpose of comparative figures US dollars are used throughout the report.





Chapter 1

A disease-modifying therapy

One hundred and twelve years after Alois Alzheimer gave his famous lecture on “an unusual disease of the cerebral cortex”, dementia remains a disease that cannot be prevented or effectively treated. A key commitment made by the G8 summit was to find a disease-modifying therapy by 2025. The international community has stepped up to the challenge.

The funding landscape for dementia research has dramatically changed for the better. The increased funding provided by some governments and organisations provides hope that the G8 summit’s goal of a cure or disease-modifying therapy can be realised.

The five years since the summit have been characterised by several headline-grabbing scientific discoveries. For example, researchers have come to understand that in some forms of dementia, such as Alzheimer’s disease, the associated brain changes begin 20 years or more before symptoms are apparent. This represents a 20-year window of opportunity for intervening with therapies that slow or stop dementia, making increased government investment in research ever more critical. In addition, we have a much better understanding about these brain changes as a result of imaging scans and radiotracers that show protein accumulation, brain atrophy, and more. Without a doubt, this is an exciting time in the field of dementia research.

Unfortunately, the last five years have also been characterised by more headline-grabbing failures in trials of pharmaceutical therapies to treat Alzheimer’s disease or other dementias. So, five years after the G8 summit, there remains an obvious gap: a therapy that prevents, slows, or stops the brain changes associated with dementia. Continuing to ramp up basic scientific research into the biology of dementia is an absolutely essential element to developing a treatment that will prevent, slow, or stop dementia, something that none of the current medications accomplish.

While there are many important areas to address with regard to advancing towards treatments, there are three things where improvements could help bring it closer: continued increases in research funding on the biology of dementia; the sharing and use of data; and recruitment for clinical trials.

There is an urgent need to continue to increase government funding across all G20 countries (and beyond).

Funding

Since the G8 summit, several significant steps have been taken by both governments and non-governmental organisations to increase funding in the dementia research pipeline. For example, the US Government’s funding for Alzheimer’s and related research has increased from \$562 million in the year of the summit to \$2.3 billion for fiscal year 2019. Other countries have increased their funding, although not to this scale. But even with these increased investments, dementia remains a globally underfunded area of medicine.

One of the consequences of a lack of governmental investment in basic science on dementia has been pharmaceutical companies, including the world’s third largest drug maker, dropping any further efforts in developing Alzheimer’s therapies. It is time for all G7 countries to live up to the collective commitment made in 2013 to increase “significantly the amount of funding for dementia research.” And that commitment must expand to include all G20 governments and beyond. The Health and Global Policy Institute, among others, has called upon the G20 to lead a global response to dementia and to make it a focus of the next G20 summit. A commitment to rapidly accelerating dementia research funding by the G20 countries is vitally necessary, not only to safeguard the health of their own citizens but to utilise their resources to protect the health of citizens around the globe.

Alongside increased government funding, since 2013 there has been increased funding from organisations, civil society, philanthropy and others. In 2015, the United Kingdom was one of the key contributors to the new Dementia Discovery Fund (DDF), a specialist venture capital fund that invests in projects and companies to discover and develop novel, effective treatments for dementia. What began with a collective investment of \$100 million from the UK Department of Health, Alzheimer’s Research UK, and several pharmaceutical companies, today has raised a total of \$350 million, including a \$50 million contribution from Bill Gates, co-founder of Microsoft, and a \$60 million donation from AARP, a US-based organisation focused on the needs of older individuals.

In addition, Gates and other donors announced in July 2018 that they are committing more than \$30 million over the next three years to collaborate with the Alzheimer's Drug Discovery Foundation (ADDF) for the new Diagnostics Accelerator programme, which is aimed at developing new, accessible, and affordable biomarkers for early detection of Alzheimer's disease. The Cure Alzheimer's Fund raised more than \$20 million for the development of new therapies in 2017. An initial investment of \$320 million by the UK Medical Research Council, Alzheimer's Society and Alzheimer's Research UK has established a new UK Dementia Research Institute. And, the US Alzheimer's Association is on a path to doubling its own investment in research by 2023. Currently the Association has over \$165 million in committed or active funding in 25 countries.

Although there has been progress, dementia is historically an underfunded area of research and remains underfunded compared to other disease areas. It is vital that government funding continues to increase across the globe and that the international community builds on innovative models of collaborative, cross-sector investment that have emerged since 2013.

Since the G8 summit, the United States Government has taken dramatic steps toward fulfilling the commitment to significantly increase funding for dementia research – a necessary condition to finding preventions and treatments by 2025.

Prior to the Summit, in 2012, the United States released the US National Plan to Address Alzheimer's Disease, which initially established the 2025 goal. Under the auspices of the National Plan, the US National Institutes of Health (NIH) subsequently developed a timeline and series of milestones on the research needed to reach the 2025 goal. But funding for that research lagged. So, the US Congress passed the Alzheimer's Accountability Act, which required the NIH to annually submit a dementia-only research budget directly to Congress. This allowed scientists, not civil servants from the budget office, to publicly spell out the amount of funding needed to meet the milestones.

The results have been dramatic. At the time of the G8 summit in 2013, the US Government was providing \$562 million for dementia research. In the last four funding cycles – after enactment of the Alzheimer's Accountability Act – annual increases in dementia research funding have been \$350 million, \$400 million, \$414 million, and \$425 million. These increases bring the total research for Alzheimer's and related conditions at the US NIH to \$2.3 billion in fiscal year 2019, more than quadrupling since the G8 summit.

Data sharing



As was recognised in the G8 communique, data sharing and open science are critically important if we are to accelerate dementia treatment discovery and ultimately find a cure. An example of the potential of widespread data sharing is the open science model for data from the US Alzheimer's Disease Neuroimaging Initiative (ADNI). Launched in 2004 by the National Institutes of Health (US), ADNI is a longitudinal multi-centre study (with a cohort of 1,900 individuals) designed to develop clinical, imaging, genetic, and biochemical biomarkers for the early detection and tracking of Alzheimer's disease. Its data-access policy was unique: provide all data without embargo to all scientists in the world. As a result, this landmark public-private partnership has made contributions to Alzheimer's disease research far beyond its original expectations, including more than 1,700 publications, many of which were written by scientists not directly involved in ADNI. This data sharing model has been embraced by the research community and points to the astonishing possibilities of scientific discoveries when data is shared.

Data sharing and open science are critically important to accelerating process to treatments and a cure.

The opportunity is widely recognised. However, the challenges to data sharing are substantial. Among these challenges – and a major obstacle in advancing dementia research – are national laws on the subject that differ considerably. This has been compounded by the confusion that exists surrounding the interpretation of the European General Data Protection Regulations (GDPR). It is possible GDPR could unintentionally create obstacles to the sharing of health data.

Furthermore, there are limited incentives for researchers to share their data, and there are varying levels of trust among data owners as to whether their data will be used in an ethical manner, especially with respect to data from patient encounters. To address these issues, the OECD is working with the governments of its 36 member countries to build better health data governance that maximises patient and societal benefit while reducing privacy and security-related risks.

This is not just a challenge for governments; data sharing and open science, commitments that were made in 2013, will only advance dementia research if there is an appreciation among data owners that the potential risks of not sharing data are greater than those of sharing it.

The power of data sharing platforms for research has long been demonstrated by individual studies. New platforms offer researchers access to data from hundreds of studies carried out across multiple continents by thousands of researchers.

The Global Alzheimer's Association Interactive Network (GAAIN) aims to advance global cooperation among the Alzheimer's research community by providing access to a vast collection of Alzheimer's disease research data, sophisticated analytics tools, and computational resources. Similarly, the Dementias Platform UK (DPUK) is a single, secure data repository that allows users to bring data from multiple cohorts into a single and secure environment, thus reducing the need to transfer increasingly large and complex data files between multiple research groups.

GAAIN and DPUK have demonstrated the capacity to change the way researchers work together to advance research on and understanding of dementia. For example, with GAAIN, researchers can look at summary information from various study cohorts, including data on such factors as cognitive status, imaging, fluid biomarkers, and genotyping. In one of the world's largest big-data studies, scientists used the tool to counter long-held beliefs about who is at greatest risk for Alzheimer's disease and when. The researchers examined data from 27 different studies that assessed participants' ApoE gene variation as well as characteristics such as sex, race, ethnicity, dementia type and age at diagnosis.

With the sharing of big data, GAAIN and DPUK show what can be accomplished in harnessing big data in a single platform. This can only help accelerate our understanding of what causes dementia and bring us closer to the day when dementia and other neurodegenerative diseases can be prevented and treated.

Recruitment for clinical trials

A significant benefit of data sharing and open science is that it can help ensure the most appropriate individuals are recruited into clinical trials, thus expediting the development of treatments for dementia. Unfortunately, insufficient numbers of individuals are recruited initially. The slow pace of clinical trial recruitment is, after research funding levels, the largest impediment to finding dementia treatments.

Since the G8 summit in 2013, there have been some steps in the right direction, including an increase in the number of clinical trial registries that help match registrants to clinical trials for which they are eligible and that stay in communication with registrants as new clinical trials open for recruitment. The UK's Join Dementia Research and the Alzheimer's Association TrialMatch are examples of registries focused on citizen education and engagement around clinical trials. There are many others including the Global Alzheimer's Platform, European Prevent Alzheimer's Disease platform, Joint Prevention of Neurodegenerative Disease and the Canadian Consortium of Neurodegenerative Diseases and Ageing and the Brain Health Registry.

The number of clinical trials has more than doubled since 2013.

In addition, despite the number of pharmaceutical companies dropping their Alzheimer's research programmes, there has been a slow but steady increase in the number of Alzheimer's disease clinical trials since 2013 – from 82 to 178. But delays in meeting volunteer recruitment targets persist, and these delays lead to delays in completing clinical trials and delays in the development of new therapies.

For comparison purposes, a recent search in clinicaltrials.gov of three search terms (oncology, dementia, and Alzheimer's disease) over an identical range of trials (active, recruiting, not yet recruiting, and enrolling by invitation) shows 22,892 oncology trials, but only 859 dementia trials (3.7% of the number of oncology trials) and 576 Alzheimer's trials (2.5% of the number of oncology trials). Similarly, as highlighted by an Alzheimer's Disease International report, the global ratio of publications on neurodegenerative disorders to cancer is 1:12.

1:12

the global ratio of publications on neurodegenerative disorders to cancer.

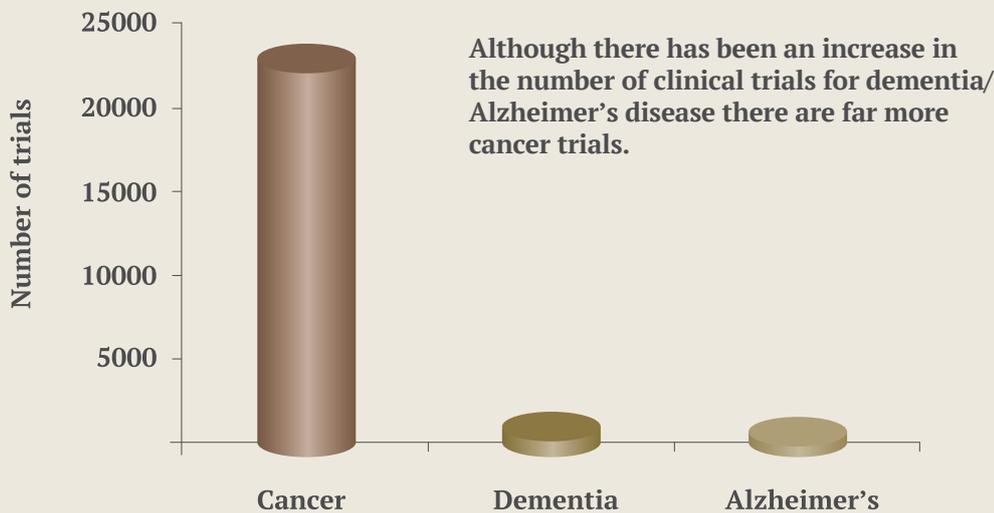
Today we understand much more about the barriers to clinical trial recruitment into dementia studies than we knew even five years ago. Dementia clinical trials are unusual in that they typically require not only a study volunteer, but also a study partner who may be needed as an informant on the volunteer's cognitive function and ability to perform activities of daily living. That eliminates many potential volunteers who do not have a study partner able or willing to participate. Furthermore, being a study partner is not easy, especially if you are also the volunteer's caregiver, which is often the case. Being a study partner can add to the burden of being a caregiver, requiring the caregiver to devote even more time to the activities of his or her loved one with dementia.

For some caregivers, being a study partner results in the loss of income, either directly from having to take more time off work or indirectly from having to pay for transportation to bring the volunteer to the study site. The financial strain of participating as a study volunteer or study partner is especially felt by those with lower incomes. Yet, the majority of people with dementia live in low and middle-income countries (LMICs), making clinical trial recruitment in LMICs even more difficult than in higher-income countries – and in turn creating an additional barrier to increasing the number of clinical trials conducted in LMICs.

Being a study partner is not easy, especially if you are also the volunteer's caregiver, which is often the case.

The importance of developing treatments that prevent, slow, or stop the progression of dementia makes it incumbent on nations to take concrete steps to help ensure people with dementia are encouraged to enrol in clinical trials. And also that they and their study partners are supported throughout the clinical trial process.

Clinical Trials

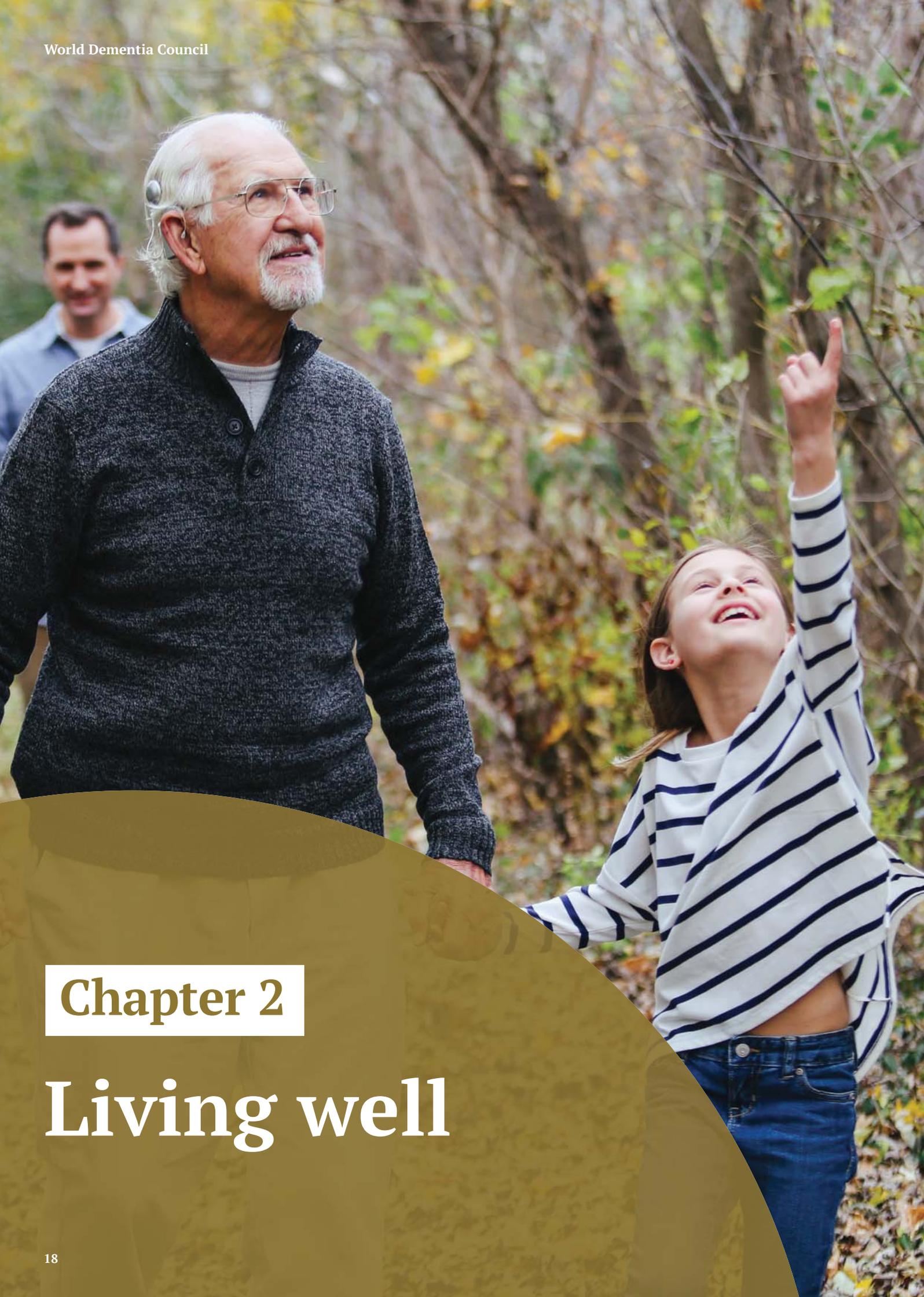


Source: clinicaltrials.gov

Calls to action:

- G7 countries should mobilise funding for dementia research, and task independent organisations to publish regular research funding statistics for each country. A commitment to increase research funding needs to be taken up by the G20.
- G7 and G20 countries should establish agreed rules on cross-border data sharing to foster health research and innovation, such as in the case of dementia. Countries committing to common health data standards that ensure the interoperability of health data and protect patients' privacy, in line with the OECD Council Recommendation on Data Governance.
- The European Commission should review the impact of GDPR to ensure that it is not an unintended barrier to dementia research.
- National governments should undertake a concerted effort to recruit for clinical trials, including setting a recruitment number target and supporting the work of WHO and others to include patients in LMICs in trials.
- International organisations such as WHO should facilitate global coordination of research efforts to reduce fragmentation, promote good practice exchange, optimise resource utilisation and open access to data, build capacity to translate existing findings into action, and strengthen research in LMICs.





Chapter 2

Living well

Dementia awareness is an essential first step in the creation of successful strategies for greater understanding of the disease, to better care and quality of life, and ultimately to lessening the stigma associated with it. And at the most basic level, without knowledge and understanding about dementia – among governments, policy makers, scientists, health care professionals, and the general public – there is no impetus to take action.

Since the G8 summit, dementia has come out of the shadows across the globe. There has been action to raise awareness and tackle stigma in many countries. Alongside that there is much more collaboration internationally, sharing knowledge and best practice. Nevertheless, significant challenges remain. Dementia is viewed by too many people around the world not as the medical condition it is, but as something that just naturally happens when you get older. This is a barrier to individuals getting a diagnosis, getting the health and care support they are entitled to and living in communities that support them.

In 2017 the World Health Organization produced the Global Action Plan on the public health response to Dementia 2017–2025. This was an important milestone and will help to drive change internationally. Many of the seven areas for action lie outside the scope of this chapter, but the Global Action Plan rightly recognises the central importance of raising awareness and tackling stigma.

There are three key areas we would highlight where accelerated international progress would help deliver the ambitions set out by the London summit: national dementia plans; diagnosis rates and prevalence; and support in the community.

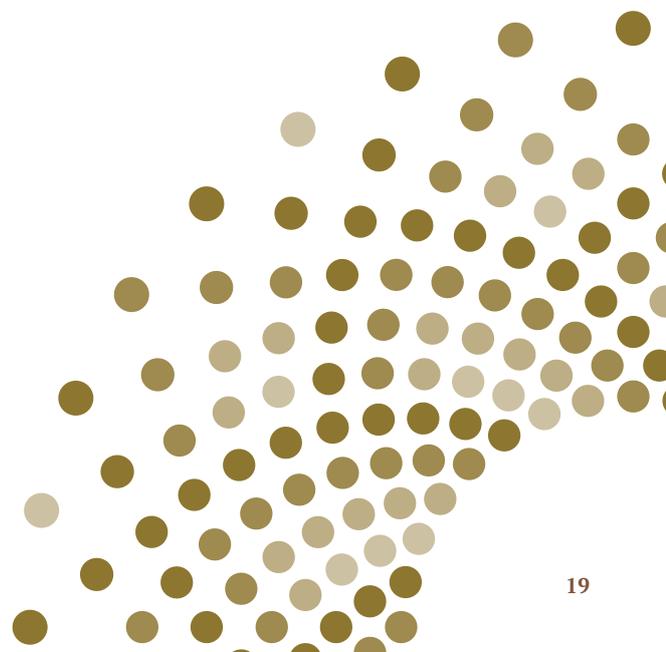
Today there are

50 million people



in the world with dementia
and that number is set to

triple by 2050



National dementia plans

A national dementia plan examines the gaps and needs related to dementia in a particular country and identifies policy solutions to address them, tailored to the unique culture and demographics of that country.

Plans are an important means of promoting awareness and understanding of dementia and of reducing stigma, particularly when people living with dementia and their caregivers provide input on, and are significantly involved in the process of writing, the plan. Of course, good national dementia plans cover more than awareness. They create a vehicle to consider a range of issues from improving the quality of health and social care to expanding support provided to caregivers to increasing research funding. When issued by the government, national dementia plans establish an infrastructure and accountability that can ultimately lead to the creation or enhancement of dementia-capable programmes and services.

However, awareness and understanding are the starting points to a dementia plan. All sections of society have a role in raising awareness and this should be reflected in dementia plans. The media in particular can help increase awareness and understanding; the World Dementia Council worked with the World Federation of Science Journalists to help develop a toolkit on awareness for LMIC journalists.

The World Health Organization has produced resources to help member states develop dementia plans and set a target that 75% of member states will have developed or updated plans by 2025. This is a commendable ambition, but it does mean, even if successful, eight years from now a quarter of countries in the world will still not have a dementia plan. According to Alzheimer's Disease International (ADI), 32 countries and territories have adopted a national dementia plan, with many more plans existing on a sub-national basis. In some federated structures (for example the United States) the varied health and social care systems may mean sub-national plans are needed in addition to national plans.

The G7 and G20 should play a leadership role in developing national plans; every country should commit to prioritising dementia.

A national dementia plan should never be a tick box exercise, nor should it be a one-off. In the UK the first dementia plan was published in 2009 and under the Government of David Cameron, who writes for this report, the Prime Minister's Challenge on Dementia was launched in 2012 and revised in 2015. This requires the continued assessment and evaluation of progress on, and outcomes of, the plans. To ensure that not only the 75% ambition is delivered but has meaningful impact on people with dementia and their caregivers, there should be more standardised tools for the assessment and measuring of outcomes of national plans. Shared effectively through a mechanism such as the WHO Dementia Observatory, this will ensure accelerated progress towards the 2025 goal of improving awareness and reducing stigma.

Building on the G8 summit and the UK Government's work on addressing the global issue of dementia following it, the World Health Organization (WHO) hosted the first ministerial conference on dementia in 2015. Two years later, the 194 member states comprising the World Health Assembly approved the first-ever WHO Global action plan on the public health response to dementia 2017–2025.

The goal of the plan is to achieve physical, mental, and social wellbeing for people living with dementia, their caregivers, and their families. It sets a series of ambitious global targets for 2025 in seven areas: increasing prioritisation; increasing awareness of dementia; reducing the risk of dementia; diagnosis, treatment and care; support for dementia caregivers; strengthening information systems for dementia; and research and innovation. Those targets include at least 75% of Member States (147 countries) having a national dementia plan by 2025. To support Member States in implementing the Global Action Plan, WHO is carrying out a range of activities across the plan's seven action areas.

WHO is supporting and tracking the worldwide response to dementia with the launch of the Global Dementia Observatory (GDO). The GDO is a data and knowledge exchange platform that offers easy access to key dementia data from countries around the world. By tracking data in three domains – policies, service delivery, and information and research – the GDO helps countries measure their progress on the action plan and assists them in strengthening dementia policies, service planning, and health and social care systems.

The G7 and G20 should play a leadership role in developing national plans.

Diagnostic rates and prevalence

While there is, at this time, no effective medical treatment that would change the underlying course of dementia, having a diagnosis is still critical to individuals living with dementia and their families. Diagnosis – especially a timely one – gives individuals the opportunity to make future plans, become educated about the disease, learn about helpful care strategies, access support services, and participate in clinical trials. Above all, individuals living with dementia have a right to know their own medical status. All of these critical activities are not possible without having an accurate and timely diagnosis. Evidence shows that when individuals living with dementia receive a diagnosis and when they and their families have access to information, education, and support, quality of life is dramatically improved.

Furthermore, as our understanding of the underlying pathology of dementia improves it has become clear that in most cases the process of diseases starts many years before symptoms of dementia. It is clear that as new diagnosis technology is developed we will not only need to increase diagnosis rates but need to start detecting much earlier.

The stark reality is that globally, dementia is grossly underdiagnosed. In some countries, such as the United Kingdom and Denmark, there have been dedicated efforts, including by governments, to determine diagnosis rates, set standards around diagnosis, and/or undertake campaigns to promote discussions about memory problems with a health care provider and to encourage physicians to diagnose dementia. Such efforts have led to significant improvements in diagnostic rates, although even where countries have significantly increased diagnosis rates there are significant sub-populations, particularly ethnic minority or socially excluded populations, where under diagnosis remains a challenge. However, in many higher-income countries, diagnostic rates can still be mired in the range of 50% or less. In LMICs, where it has been possible to obtain data, the diagnosis rate is even lower.

Ultimately, there are many barriers to improving diagnostic rates. From the perspective of a healthcare provider, dementia is often not diagnosed because of the lack of definitive diagnostic tools, effective treatments, confidence in delivering an accurate diagnosis, and time and resources. From the general public's perspective, there are many who still believe dementia is a normal part of ageing – or that the stigma associated with a diagnosis is so great – that they are unlikely to share their cognitive concerns with their doctors. As highlighted by the OECD, even collecting accurate dementia diagnosis rates is a challenge; in countries where the healthcare system is fragmented, collecting and communicating data about diagnosis is challenging at best.

These are challenges that lie outside the scope of this report and will often require nation specific solutions. But it is important to recognise the collective international need to raise diagnosis rates. As acknowledged above diagnosis is important in itself, someone with dementia has the right to know. But diagnosis is key to finding people to participate in clinical trials. As the first medical interventions are developed, especially given the likelihood they will benefit people in the early stages, timely diagnosis will be important. The international community cannot wait until treatments are developed before beginning to step up diagnosis rates.

The stark reality is that globally, dementia is grossly underdiagnosed.

WHO has set an ambition that half of countries have a diagnosis rate of 50% by 2025. While this goal is important, leadership from the G7, G20 and European Union, could help drive international efforts to not only meet it but exceed it. Furthermore it is important to ensure that LMICs are not left behind and a diagnosis gap means potentially large populations that would benefit from new treatments are unable to access them through not having received a formal diagnosis.

Knowing the rate of diagnosis first requires having an understanding of the prevalence of dementia, or the number of people living with the disease at a given point in time. Without understanding how many people in a particular country may be affected by the disease, it is not possible to say what proportion has been diagnosed, in turn making it difficult to develop strategies to increase diagnosis rates. Dementia prevalence estimates are determined through epidemiological studies, usually longitudinal cohort or representative-sample studies that are then extrapolated to the population as a whole. In some higher-income countries with multiple studies providing prevalence estimates, those figures can vary widely. In LMICs, there are fewer studies and in some cases, none at all. A thorough understanding of the scope of the problem – that is, the prevalence – is critical to understanding and planning for the resources necessary to address the problem of underdiagnosis. Efforts need to be made in all countries to determine the prevalence of dementia and then to determine the diagnostic rate so that the whole of the problem is known, strategies can be developed and implemented, and progress can be measured.

Support in the community

Dementia is a condition that often lasts for many years, depending on an individual's other co-morbidities.

Maintaining quality of life throughout the disease process can be challenging due to stigma, lack of awareness about the disease, lack of disease education, and lack of resources and support. As the diagnostic process improves, more individuals are being diagnosed in the early stage of dementia. While life-changing, a diagnosis of dementia, particularly one in the early stage, does not mean the person's life has ended. Individuals with the disease continue to live their lives, engaging with family and friends in the activities they have always pursued. Through the progression of dementia, with some assistance and adaptation, people living with dementia can continue to participate in their lives in a meaningful manner.

Globally, most individuals living with dementia do so in the community. Even in countries where residential options, such as assisted living facilities and nursing homes, are widely available, it is more common for individuals to live in the community with family or friends. Helping individuals with dementia and their families access available care and support locally is critically important.

Globally most individuals living with dementia do so in the community.

The years since the G8 summit have seen the emergence of initiatives aimed mainly at raising awareness and reducing stigma in local, regional, and municipal communities. Some have been grassroots initiatives, some led by civil society, some by governments and in many cases a combination of all three. At the heart of these initiatives is a belief that people with dementia and their caregiver can be helped to live well, even as the disease progresses, through being included in the community and supported by their friends and neighbours.

These dementia-friendly programmes or initiatives have focused on such things as providing education and raising awareness among businesses, health care providers, first responders, providers of long-term care services, faith communities, transportation systems, and financial institutions. Many initiatives have rightly highlighted the key role businesses have to play in supporting their customers and employees.

These initiatives are not confined to high-income countries. Dementia Friends, developed first in Japan by the Ninchisho (dementia) Supporter Caravan and then taken up by Alzheimer's Society in the UK, has now been rolled out in 41 countries including 17 LMICs. This is an example of the important role volunteers can play in improving the lives of people living with dementia and their caregivers. The grassroots demand that drives many of these initiatives is a reflection of the wishes of people with dementia and their caregivers.

WHO is creating a toolkit (to be launched in 2019) to support the development of dementia-friendly initiatives and set an ambition that 50% of countries by 2025 have at least one dementia-friendly initiative. Anecdotally, these dementia-friendly initiatives appear to raise awareness and make life in the community easier for people with dementia. However, it is imperative that a rigorous, scientifically-sound evidence base be created. Not only will evidence of effectiveness help spread the initiatives, it will help highlight which elements and strategies are most effective and increase the likelihood of local funding to provide ongoing sustainability.

The stigma surrounding dementia can be devastating to patients and their families. It depresses diagnosis rates, hinders the provision of good quality care, and often isolates those with dementia from their communities.

Back in 2005, Japan was one of the first countries to address the stigma issue head-on, launching the Nationwide Caravan to train Ninchisho (dementia) Supporters. The programme takes a three-tiered approach. First, medical professionals specialising in dementia train Caravan-Mates in a six hour workshop. The Caravan-Mates then train Ninchisho Supporters. And finally, Ninchisho Supporters conduct a 90-minute seminar for the public held at schools and offices and for community groups across the country, with the goal of educating people about dementia, reducing prejudice, and creating dementia advocates. As of 2014, 5.5 million people in Japan were Ninchisho Supporters. This programme was the model for the Alzheimer's Society's Dementia Friends programme in the UK. As in Japan, the Dementia Friends programme provides face-to-face information sessions focused on transforming the way we think, act, and talk about dementia. Similar efforts are now underway in Australia, Canada, India, Indonesia, Ireland, the Netherlands, Scotland, and Sri Lanka.

Also, as part of Japan's National Dementia Policy Plan in 2015, dementia-friendly communities are being established around the country. These are communities that undertake specific efforts to increase awareness, achieve social inclusion of those with dementia, challenge stigma, and improve care and services throughout their community. Nearly all local governments in Japan have pledged to develop dementia-friendly communities, and the idea is expanding in many other countries.



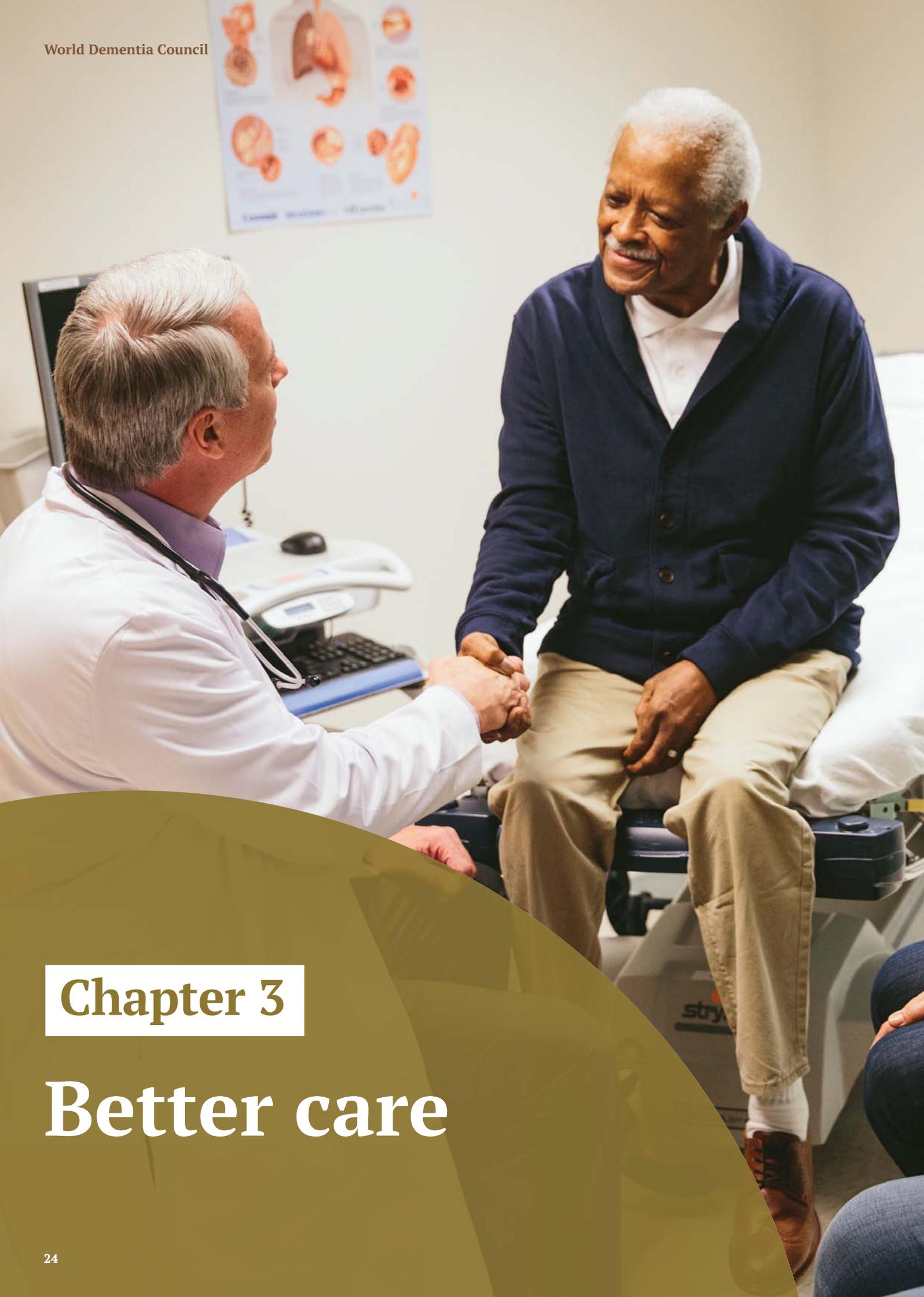
Dementia Friends has now been rolled out in

41 countries
including 17 LMICs



Calls to action:

- All countries should prioritise dementia through developing standalone national dementia plans. WHO should continue to monitor progress and outcomes of national plans through the Global Dementia Observatory.
- WHO should continue to promote a coordinated effort to improve prevalence data in order to inform dementia diagnostic rates, with an emphasis on LMICs with little or no data.
- Governments should fund research on living well initiatives, including assessments of interventions and their effectiveness; support the dissemination of best practices to communities; and fund the roll-out and sustainability of living well initiatives that have been proven effective. It is important to recognise the key role of businesses in supporting people to live well in the community.



Chapter 3

Better care

While there has been significant progress in biomedical research, millions of people globally will continue to need care throughout the progression of the disease without effective treatments. And even if clinical breakthroughs are made, millions of people living with dementia are still likely to need care at some point.

As highlighted in an earlier chapter in this report, too many people with dementia never receive a formal diagnosis while many are diagnosed at a late stage. A timely diagnosis allows the individual and their family to plan their care wishes and is the key to the delivery of good quality care. In the early stages of dementia, individuals will have limited care needs beyond support and information, but as the disease progresses people will usually have increasingly complex care needs. Frequently people with dementia have co-morbidities (one population study estimated as high as 70%) that makes individual care needs more complex.

Informal care costs are a significant proportion of the total cost of dementia faced by a nation state. But there isn't just an economic cost; the provision of informal care often impacts on the health and wellbeing of the caregiver. In both high and LMIC countries it is often the family that provide the majority of care. Although in this report we do not address it, support for caregivers is critical. Although there are resources, such as the WHO iSupport for caregivers, globally support for caregivers is a major challenge.

Countries around the world are grappling with the challenge posed by increasing numbers of people with dementia and the cost and strain this puts on care systems. As a recent OECD report identifies, countries have enhanced their efforts to provide high quality dementia care. Many of the solutions to good quality care are nation state specific, because of the complex interaction of the welfare, care and health systems.

The G8 summit in 2013 recognised the importance of improving care and support and the potential for international action to help drive change by 2025. There are areas for international action that would help accelerate progress.

At the heart of a well-designed care system is the voice of people with dementia.

Quality care

Principles of quality care have been identified and defined by many organisations in many countries around the globe, including a statement on quality care issued by the World Dementia Council in 2017. It is largely agreed that quality care is defined by person-centred approaches that call for the individualisation of care strategies; deliver safe, effective and timely care; include care partners and caregivers; and ensure ongoing, meaningful engagement of the person living with dementia. Person-centred approaches to care have been well-researched, and the evidence demonstrates positive outcomes on quality of life for both individuals living with dementia and their caregivers – and for both family-based caregivers and professional care providers. While many high-income countries have committed to adopting quality care standards, this is much less common in LMICs. And quality standards in high-income countries may not be easily translatable to LMICs. Even in high-income countries, significant challenges and gaps exist.

There are also important steps that could be taken today to improve quality care for people with dementia. Post-diagnostic follow-up support, including the development of person-centred care plans, can help people with dementia and their families better navigate complex health and social care systems. Care workers are too often poorly prepared to handle the additional challenges of caring for someone with dementia. Better training for professional care workers and incentives to upskill workers would help ensure they have the tools to respond effectively, including those exhibiting behavioural and psychological symptoms of dementia (BPSD). Health systems should also minimise the use of antipsychotics, restraints, and other approaches that run contrary to a person-centred care approach. Regular measurement is critical to ensuring such practices are reduced.

Although many of the solutions will be nation state specific, one of the common shared challenges is the lack of research on the implementation of care standards. Too often care research is underfunded. To create a fully realised standard of care, research needs to focus on how care is delivered in practical, everyday settings. For both high-income countries and LMICs, access to affordable and practical interventions is lacking.



Conducting psychosocial research can be difficult. Randomised clinical trials with control groups may not be appropriate as any psychosocial study design has to consider the ethics of withholding an intervention for the control group, fidelity to the intervention itself when it is being delivered by different individuals – in some cases, by family caregivers – and sample size. It should also be recognised that randomised control trials are not always the most appropriate approach to psychosocial research, and the demand or requirement for such trials can hinder the ability to make positive interventions more widely available more quickly. There is a particular need for understanding what good quality care looks like in the later stages of dementia care and at end of life.

At the heart of a well-designed care system is the voice of someone with dementia and their caregiver. The importance of empowering people with dementia and their caregivers is widely recognised; increasingly there has been a focus on taking a human rights approach. This human rights approach has helped empower people with dementia.

Both WHO and OECD have supported nation states to develop better care systems through the gathering and dissemination of evidence. But for millions around the world improving care is of critical importance.

Collecting data

One of the keys to improving care quality is the better gathering of care data across the dementia pathway.

The collection of comparable data can help drive research and identify interventions that will improve quality of life. Data can help us understand the breadth of the problem, track progress, inform public policy, and evaluate outcomes. When data can be collected and aggregated, it can uncover critical information such as the risk for developing dementia, the risk for falls, the success of interventions, and determining when more help may be necessary prior to a crisis situation.

However, there are many barriers inherent to collecting dementia data. As highlighted by a recent OECD report, and throughout this report, one of the fundamental barriers is under diagnosis. Even in countries where physicians are more actively diagnosing dementia, there are still challenges with ensuring the diagnosis is recorded in the medical record.

Another challenge to collecting and sharing data is that health – and also social care – data are rarely brought together to support better monitoring of quality of care, research, and improvement in clinical standards. Many countries lack data governance that would enable the use of data while also protecting privacy of personal and sensitive data. A further issue is the disparate systems used to document data among the myriad of providers, health systems, residential care, community services, and payers that exist globally and sometimes even within countries. Even among countries that have more centralised data collection systems, no mechanism exists to compare data across countries.

Too often care research is underfunded.

WHO's Global Dementia Observatory (GDO) enhances data availability and country capacity to monitor service delivery and dementia diagnostic rates. Alongside this, many countries are seeking to improve data collection by linking different data sets but as the OECD has highlighted, too often important data sets are omitted.

Since the G8 summit there has been significant progress towards the commitment to find treatments; even though no intervention has been successful developed to date. This attention is right; drug interventions have the potential over time to radically change the impact of dementia on the individual and society. But millions need care today and will continue to need care in the years ahead. Biomedical research and better data sharing to drive research is critically important; but so is delivering good quality care through better care research and the better collection of care data.

Technology

The communique issued after the London summit in 2013 identified the importance of innovation in driving improvements in care and support for people with dementia and their caregivers.

Today, most people on the planet carry in their pockets a computer of such power that was near unimaginable 30 years ago. It will not be long before our refrigerators and vacuum cleaners are digitally enabled, as many cars already are. This is a rapidly changing technological world and artificial intelligence and robotics will transform the way we lead our lives in the years ahead.

New technology will impact across every issue highlighted in this report (not least the potential benefits of wearable devices), but it has great potential to improve care and reduce the burden on caregivers. Already there have been substantial developments in technology to support individuals living with dementia and their caregivers, including calendar apps, video-conferencing, voice-activated assistants, online communities, location devices, and medication reminders. For those living with dementia, particularly those in the early stage, this type of personal technology can be helpful for time orientation, reminders, and location assistance. Once the disease progresses, this type of technology has sometimes been less helpful; however, even in such cases, caregivers may find technology useful in providing them with access to support, education, and a way to connect with others.

New technology will impact across every issue highlighted in this report.

While technology has the potential to expand access to support, there are challenges and barriers. Technology based interventions should be evidence based. Although there has been much innovation over the last few years, these are not always underpinned by evidence of impact on quality of life. This makes it harder for the consumer (whether someone with dementia or a health and social care practitioner) to choose between different options. Equally where technological interventions have been shown to have impact in the health and social care system, it is important that different regulatory practices in different countries do not form an unnecessary barrier to seeing technology benefit people with dementia.

Modern technology has the potential to significantly improve the care and support – and the quality of life – of people with dementia and their families. While the field is in its nascent stages, one of the earliest uses of technology has been in research, where modern technologies are helping researchers explore new avenues for discovery.

One of the most exciting is GameChanger. Launched by the University of Oxford and Alzheimer's Society UK, GameChanger is an application that takes advantage of the ubiquity of smartphones. The free app, downloaded to your phone, contains a collection of memory and thinking games that test specific parts of the brain as well as the memory and thinking abilities that are believed to be affected during the early stages of Alzheimer's disease.

Each time someone plays one of these games, that information is entered into a secure database on healthy brain activity. The more people who download the app and play the games, the larger the dataset will become and the greater the potential insights the data could help uncover. Examples of the exciting and promising uses of this data in dementia research include tracking healthy brain function as people age, and identifying and developing better cognitive tests. It even has the potential to change the way we diagnose dementia.

Calls to action:

- WHO and OECD should establish a global standard of person-centred quality care supported by consistent outcome measures and data collection. The WHO Global Observatory could facilitate these efforts.
- Governments should increase investment in care research and ensure research funding is effectively coordinated.
- Governments should support the development of technology and ensure unnecessary regulatory barriers do not exist to its deployment in health and social care systems.



Chapter 4

Reducing the impact of dementia

The best approach to dealing with dementia is not having to deal with it at all. We now know – in a way we did not at the time of the G8 summit in 2013 – that individuals can take steps to reduce their risk of cognitive decline, and a growing body of evidence shows great progress in understanding ways in which individuals may be able to reduce their risk of dementia.

Prevention is a term that covers a range of interventions including reducing the risk of developing neurodegenerative disease that will cause dementia and reducing the risk of neurodegenerative disease resulting in cognitive decline. In this chapter we use the term to cover all interventions.

Prevention of disease is the utmost public health priority. The lack of a treatment that changes the underlying course of dementia – and the increasing number of deaths caused by dementia around the world – makes finding ways to reduce the risk of developing dementia in the first place, and educating the public about those risks, an even greater public health imperative.

There is another risk associated with dementia: the risk of financial ruin. As WHO has highlighted, dementia has the potential to undermine social and economic growth globally and overwhelm health and social care systems. The global cost of dementia will double by 2030 to \$2 trillion according to research commissioned by Alzheimer's Disease International. A significant portion of the costs of caring for people with dementia – and the overwhelming majority of costs in low-income countries – is borne by the individuals affected themselves and by their families, primarily from the informal care provided by family caregivers and friends.

To reduce the risk of dementia, global action is needed: to reduce the risk of developing dementia through brain health; to help individuals and nation states manage the financial costs; and specifically to support women, who are disproportionately impacted by dementia.



The global cost of dementia will
double by 2030 to
\$2 trillion

Source ADI

Global brain health

Since the G8 summit, data from several longitudinal studies have shown a decline in dementia prevalence and/or incidence rates among certain population cohorts over the last few decades.

Speculation on the reasons why has focused on increased levels of education, and substantial improvements in cardiovascular risk factors and management of cardiovascular conditions, among the study populations. In other words, these studies suggest that medical and public health interventions on heart health might also be beneficial to brain health by reducing the risk of cognitive decline and dementia. In addition, separate evidence reviews published since the G8 summit by the National Academies of Science, Engineering and Medicine in the United States, the US Alzheimer's Association, American Association of Retired Persons with Age UK, and the Lancet Commission on Dementia Prevention, Intervention and Care, reached similar conclusions about the biggest risk factors for cognitive decline and/or dementia, and about ways evidence now shows individuals can reduce their risk for cognitive decline and possibly dementia.

Two recent randomised controlled trials have begun to confirm these conclusions. In 2015, the first results of the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER) were published. The study found overall cognitive performance as well as executive function improved significantly with a multi-component lifestyle intervention involving physical activity, nutritional guidance, cognitive training, social activities, and management of cardiovascular risk factors. The results were so positive that Worldwide FINGERS (WW-FINGERS) has been formed to test similar multi-component interventions in 14 countries to date.

The second recent randomised controlled trial was the Systolic Blood Pressure Intervention Trial-Memory and Cognition in Decreased Hypertension (SPRINT-MIND) study. Results presented at the 2018 Alzheimer's Association International Conference showed that efforts to aggressively lower systolic blood pressure below 120 reduced the risk of developing mild cognitive impairment and dementia.

This exciting evidence and positive information on dementia risk reduction, however, may not be reaching a broad population. Public health risk reduction awareness campaigns throughout the world have focused predominantly on diseases of the body not the brain. While there has been a broad-based bias toward conventional physical health, the primary reason brain health public awareness efforts have been virtually non-existent is the lack of a strong evidence base. Governments must invest in more prevention research to ensure stronger and more definitive evidence on risk reduction. But, we cannot let the perfect be the enemy of the good. We now know enough about certain aspects of cognitive decline and dementia risk reduction that messages on brain health must be incorporated into public health policies, campaigns, and strategies. The upcoming WHO guidelines on risk reduction of cognitive decline and dementia will provide evidence-based recommendations for a public health response to dementia.

Governments must invest in more preventative research to ensure stronger and more definitive evidence on risk reduction.

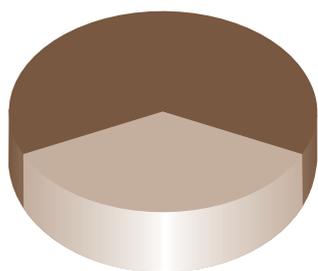
As noted above, the potential promise of risk reduction has been suggested by several longitudinal cohort studies showing reductions in dementia prevalence and/or incidence over time. Unfortunately, such studies have been limited to Western Europe and North America, and the cohorts have been predominantly white. The World Dementia Council has co-sponsored an effort with the Global Brain Health Institute to bring training to physicians in Indonesia to help raise awareness about the benefit of risk reduction in LMICs. More research is needed to see if the positive trends around risk reduction persist across races, ethnicities, and cultures – both in higher-income countries and LMICs. Furthermore, it is important that studies on dementia risk reduction follow the WW-FINGER model. That is, they should occur in a variety of countries around the world – including in LMICs – to identify the most appropriate risk reduction interventions for various cultures.

Studies on interventions to reduce the risk of dementia often focus on a single risk factor, such as diet or exercise, or a single activity, such as cognitive training. But what if the key to risk reduction is not with any one risk factor but with “all of the above”?

In 2015, the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER) showed that, in nearly 1,200 cognitively normal older adults age 60–77 who were at elevated risk of dementia, a multi-domain intervention could improve or maintain cognitive function and reduce the risk of cognitive decline. A large, long-term, randomised controlled trial, FINGER included nutritional guidance, physical exercise, cognitive training, social activities, and management of vascular and metabolic risk factors. A control group received general health advice. Over two years, improvement in overall cognition was 25% higher in the intervention group, with especially strong improvements in executive function and processing speed. This was seen regardless of sociodemographic and socioeconomic factors or baseline characteristics, suggesting that a multi-domain intervention could improve or maintain cognitive functioning in at-risk elderly individuals.

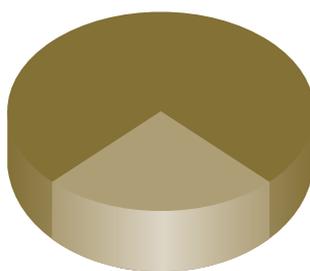
Building on the promising results of this study, FINGER is going global. Worldwide FINGERS (WW-FINGERS) will link and align studies from countries around the world that are evaluating multi-domain lifestyle interventions similar to that used in the original FINGER trial. In 2018, WW-FINGERS trials have been planned in Australia, China, Finland, Singapore, the United Kingdom and the United States; initial planning for additional trials is underway in Argentina, Canada, Germany, India, Italy, Japan, Mexico and Spain. WW-FINGERS has the potential to show a path forward to cognitive improvement and perhaps, ultimately, dementia prevention among those at elevated risk.

Global costs, 2015



Informal Care
Formal Health and Social Care

Costs in low-income countries, 2015



Informal Care
Formal Health and Social Care

Economic risk

In 2015, the global costs of dementia were an estimated \$818 billion.

The health and social care systems – and the governments that fund them – bear a large portion of the costs, and those costs will only escalate in the years ahead. But few realise that 40% of the total costs of dementia (\$331 billion in 2015) represent the costs of informal care – the value of unpaid care provided by family members and others in the community. In low-income countries, informal care represents an even greater proportion of the total costs – 69% – meaning families are bearing the overwhelming majority of the financial burden. If these trends continue, informal care costs in 2030 will reach around \$800 billion.

While none of these costs show up in the economic data of a country, they certainly represent real costs to families. The financial impact of lost jobs, lost income, and out-of-pocket spending in order to care for someone with dementia can bankrupt a family. Even long after a caregiver's responsibilities are over, the financial effects will continue as pension and retirement income will be lower due to the fewer number of years the caregiver spent in the work force. The overarching labour market effects of – and the economic disruption that can result from – large numbers of dementia caregivers reducing their hours or completely leaving the workforce should be of significant interest and concern to governments.

Informal care costs in 2030 will reach around \$800 billion.

And yet, governments do very little to support unpaid caregivers. This must change. Strategies must be developed that would reduce the financial risk as well as the non-financial burden that families face when someone develops dementia. This includes implementing programmes that lessen the out-of-pocket costs associated with caring and enable caregivers to remain in the workforce and initiatives to provide respite care, counselling and training.

The international community is rightly giving attention to the impact of ageing on economies. Dementia represents a significant fiscal challenge and any strategy to mitigate the cost of ageing must include the development of strategies to support countries to reduce the cost of dementia. This includes not only supporting caregivers but also many of the other issues highlighted in this report such as improving care and ensuring the uptake of new technology.

Impact of dementia on women

A central component of reducing the financial risk of dementia is to recognise and better understand the role of women in providing dementia care. Overwhelmingly, across nations and cultures, women are far more likely to serve as caregivers for people – their husbands, parents, parents-in-law, and grandparents – who are living with dementia. Often, women take on this role “by default” – there is no one else to do it or willing to do it. Studies also show that female caregivers provide more intense care for longer periods of time than male caregivers.

Bearing the biggest burden of providing dementia care also means bearing the brunt of the financial impact of dementia, particularly – but not solely – in experiencing adverse consequences in the workforce. In order to provide care, many women must reduce their hours of work or quit their jobs entirely. This affects both their immediate income and future pension income as well as their career paths and opportunities for advancement. A 2014 poll in the United States found that among female dementia caregivers who continued to work while providing care, 1 in 6 felt they had been penalised at work because of their caregiving duties.

Inevitably, this issue affects not just women but society more broadly. It speaks to the roles women are too often just expected to play. And it speaks to the willingness to recognise the larger societal responsibility and burden women are bearing – and whether they will in turn be supported by society.

Calls to action:

- Governments should act on evidence on brain health, including evidence on the link between heart and brain health, and share emerging learnings about successful public health strategies.
- WHO should support/facilitate integration of dementia risk reduction in NCD programmes.
- OECD should undertake an assessment of the effectiveness of strategies to reduce the cost of dementia for health and care systems. This should include supporting people who are caregivers, and where possible people who have dementia, to remain active in the labour market.

Bill Gates

Innovation improves lives. Just look back at history: innovation is the reason HIV isn't a death sentence anymore. It's how we've cut the under-five death rate by more than half since 1990, and why we're closer than ever before to eradicating polio.

I believe innovation can do something similar for dementia.

Dementia – and Alzheimer's disease in particular – is a budding health crisis. The fact that people are living longer lives should be good news. But as life expectancies continue to increase around the world, more people will live long enough to suffer the devastating effects of dementia and to require special care from both doctors and their families and friends for years. If we're going to make sure people can enjoy their later years and keep rising healthcare costs in check, we will need lots of scientific breakthroughs to help stop the disease.

The goal of achieving a disease-modifying treatment for Alzheimer's disease by 2025 is within reach. The world is investing more into important research. We're starting to understand more about the disease, and we're exploring diverse approaches to stopping it. The data we're collecting in the process is a tremendously powerful tool that I believe can be better harnessed to advance innovations and drive progress across all of the priority areas in this report.

One of the best ways we could accelerate the discovery of scientific breakthroughs is by facilitating more and better access to data. This would make it easier for researchers to look for patterns, develop new hypotheses, and find new pathways for treatment. To start, we should expand the ability of researchers to analyse multiple data sets at once and leverage cutting-edge analytical tools to broaden our understanding of the disease.

There are already several efforts underway that have changed the way researchers work together to answer questions, but we need even more data sharing. We need to commit to bringing together more and better data – from both industry and academia – and we need to make the platforms that already exist to access that data talk to each other more efficiently.

To truly unlock the transformative power of this data, it won't be enough just to get the technical solution right. We also need to understand the challenges holding researchers back from sharing their data with one another. Whether it be policy barriers, access to technical and funding resources, or other issues, we need to remove unnecessary roadblocks and build a more supportive ecosystem.

With so many new tools and theories in development, I believe we are at a turning point. An interoperable data ecosystem would take us further faster and move us closer to our goal of achieving a disease-modifying treatment by 2025.

I hope this report leaves you as optimistic about progress as I am, and that it inspires you to keep working towards our goal. Since I got involved with the Alzheimer's community one year ago, I've been blown away by the incredible work being done. Alzheimer's and other dementias are particularly difficult diseases to take on, but the amazing coalition of experts, doctors, families, advocates, and governments working to move us forward makes me hopeful for the future.



Bill Gates

Bill Gates

Co-chair,
Bill & Melinda Gates Foundation

Gabriela Michetti

For Argentina as for so many countries dementia is a huge health challenge and an increasing one.

Argentina has an estimated 500,000 people with dementia, and by 2050 it is expected to have more than doubled to 1.2 million. The overall cost of dementia is enormous – a particular challenge when governments around the world, such as ours, face huge public spending pressures. Dementia costs Argentina \$3.25 billion each year, a per capital cost of \$7,774. But beyond the economic costs there is the cost to the family. It is the family that is often the main care provider for someone with dementia, and it is especially girls and women who provide over 90% of informal care.

As a middle-income country in Latin America, Argentina shares with its neighbours many similar barriers to advancing public health: aging and heterogeneous populations; limited resources; and high levels of poverty and disability. These barriers, in the context of a disease that is progressive and without an effective treatment or cure, create immense health policy battles for governments like my own. But despair should not and cannot triumph. There are things we can be doing now to strengthen preventative interventions to reduce risk, raise awareness, and improve care for our citizens.

Argentina does not have a national dementia plan but offers several advantages in the way of caring for older adults. The National Institute for retired people (INSSJP) created in 1971 includes 91% of the Argentinean Elderly People, approximately 4,000,000. This Institute has a Program for Medical Assistance (PAMI) that provides health care, tourism, entertainment and social clubs for all its affiliated members around the country.

In 2016 the Strategic National Plan for Healthy Brain was launched in PAMI including five proposals:

1. Create awareness about the importance of dementia
2. Provide training for general practitioners
3. Facilitate access to diagnosis and treatment
4. Promote prevention and reduction of risk factors
5. Encourage the scientific research

The national disability law includes dementia and requires for the social security and the health system, the coverage of all the medical care costs related to dementia.

Dementia is too often still regarded as primarily affecting high-income nations, but the fight we face is truly global. There are 3.4 million cases of dementia in Latin America and the Caribbean right now. Within three years that will increase eight-fold to more than 16 million. By just 2030, Latin America and the Caribbean will have more people with dementia than in North America. This is not a challenge we can ignore.

And what is true for Latin America and the Caribbean is true for so many low and middle-income countries. Today most people living with dementia already live in LMICs. And over the next few decades that proportion will increase and increase.

We, as low and middle-income countries should be aware and prepared. We must work together to deepen the research and development of new technologies applied to the prevention and early detection of this condition. The promotion of biomedicine is fundamental and it must not be forgotten that the approach must be interdisciplinary, reaching new ways to support not only the individuals but their families. Through new technology and specialized professionals and through our growing university and research sector, we can change the lives of those who suffer from dementia and also of the society in general.

Low and middle-income countries have demonstrated -in different sectors- that we can both be innovative and drivers of change, not just followers. In the public health politics around dementia, we must be drivers of change with creativity, investigation and always searching for a more equitable society.



Gabriela Michetti
Vice President of Argentina

Maria Shriver

Dementia is a mind-blowing condition I am all too familiar with.

As a daughter of Alzheimer's, I have seen first-hand how it devastates millions of families across the globe. I know we are still without a treatment or a cure, but I simply refuse to believe that there is nothing we can do to prevent, reverse or end this disease.

Alzheimer's is one of the biggest health crises of our time. That's why the moment to respond swiftly and smartly is now. No matter our location, no matter our background, we must all come together and make it our mission to defeat this disease.

This is especially true if we care about our female population, since women are at an increased risk for Alzheimer's. In my mind, Alzheimer's is actually the biggest women's empowerment issue of our time. Women work so hard to be recognized for our minds. The last thing we want to do is lose them.

These statistics, in particular, really stop me cold in my tracks:

- Two-thirds of the brains affected by Alzheimer's belong to women.
- A woman in her 60s is twice as likely to develop dementia over the course of her lifetime than breast cancer.
- Women are also half the work force and predominately raise our children and care for elderly relatives – many of whom have dementia.

In 2010, I partnered with the Alzheimer's Association to release "The Shriver Report: A Woman's Nation Takes on Alzheimer's." This groundbreaking project was the first to publicly report the disproportionate impact that Alzheimer's has on women. Since that time, we have advanced gender-based research and learned more about the unique factors affecting women's cognitive health. But to this day, we still do not fully understand why women are getting Alzheimer's more often than men.

In several countries such as the UK, dementia is now the leading cause of death amongst women. This must be an international rallying call for governments and civil society to step up to support women's needs.

I started the nonprofit The Women's Alzheimer's Movement because I was frustrated that answers weren't coming fast enough. I was also frustrated that practically no one was studying why this disease affects women differently. The Women's Alzheimer's Movement's mission is to change the game. We urge scientists to consider sex and gender in their Alzheimer's research. We also fund groundbreaking research and work to educate the public about caring for their cognitive health. We need everyone on board to help make these efforts successful.

Some progress has been made since the London dementia summit in 2013. But there is much to be done. Unpaid family caregivers across the world are on the frontlines of the battle against dementia. In my own country, 16.1 million Americans provide billions of hours of unpaid care to people with Alzheimer's and other dementias. Many women report stepping up to become the caregiver in their families, and that often means stepping down from careers and salaries. Forty per cent of them say they have no choice but to do so. What's more, these figures are significantly higher in the developing world, areas which will account for 71% of the global prevalence of dementia by 2050.

In our recent Shriver Report Snapshot poll, one in two Americans said they worry they won't have someone to care for them as they age. They also worry they won't be able to care for someone else. Additionally, a majority admitted that they fear Alzheimer's, but said their doctors aren't talking to them about the disease or their cognitive health.

Reflecting on the five years since that original G8 summit, we are at a fitting moment to reaffirm our commitment to meeting the 2025 goals. A breakthrough moment for dementia is possible in our lifetime. We cannot afford not to believe it. As patients, caregivers, researchers, advocates, corporate leaders and policymakers across the world push forward together on this extraordinary mission, let's remember that women are at the epicentre of the dementia crisis. That's why we must be at the heart of the solution.



A handwritten signature of Maria Shriver in black ink.

Maria Shriver

Award-Winning Journalist
and Founder of The Women's
Alzheimer's Movement

G8 Declaration 11 December 2013

We, the G8 Health Ministers, met at the G8 Dementia Summit in London on 11 December 2013 to discuss how to shape an effective international response to dementia.

We acknowledge the on-going work occurring in our countries and globally to identify dementia as a major disease burden and to address issues related to ageing and mental health, including the World Health Organization's 2012 report, *Dementia – A Public Health Priority*. Building upon the significant research collaborations that exist between our countries and our multilateral partners will strengthen our efforts and allow us to better meet the challenges that dementia presents society.

We recognise that dementia is not a normal part of ageing. It is a condition that impairs the cognitive brain functions of memory, language, perception and thought and which interferes significantly with the ability to maintain the activities of daily living. We also acknowledge that dementia affects more than 35 million people worldwide, a number that is expected to almost double every 20 years.

We note the socio-economic impact of dementia globally. 70% of the estimated annual worldwide cost of US\$604 billion is spent on informal, social and direct medical care. Yet nearly 60% of people with dementia live in low and middle income countries so the economic challenge will intensify as life expectancy increases across the globe.

These costs are expected to increase significantly if therapies to prevent dementia and improve care and treatment are not developed and implemented. We recognise the need to strengthen efforts to stimulate and harness innovation and to catalyse investment at the global level.

Therefore, and in accordance with national, sub-national and local responsibilities, we commit ourselves to:

1. Call for greater innovation to improve the quality of life for people with dementia and their carers while reducing emotional and financial burden. We therefore welcome the UK's decision to appoint a global Dementia Innovation Envoy to draw together international expertise to stimulate innovation and to co-ordinate international efforts to attract new sources of finance, including exploring the possibility of developing a private and philanthropic fund to support global dementia innovation;
2. The ambition to identify a cure or a disease-modifying therapy for dementia by 2025 and to increase collectively and significantly the amount of funding for dementia research to reach that goal. We will report biennially on expenditure on publicly funded national dementia research and related research infrastructure; and we will increase the number of people in dementia related research studies;
3. Work together, share information about the research we fund, and identify strategic priority areas, including sharing initiatives for big data, for collaboration and cooperation;
4. Develop a co-ordinated international research action plan which accounts for the current state of the science, identifies gaps and opportunities, and lays out a plan for working together to address them;
5. Encourage open access, where possible to all publicly funded dementia research and to make the research data and results available for further research as quickly as possible, while protecting the privacy of individuals and respecting the political and legal frameworks of the countries in which the research is conducted;
6. Take stock of our current national incentive structure for research, working in partnership with the Organisation for Economic Co-operation and Development (OECD), and consider what changes could be made to promote and accelerate discovery and research and its transformation into innovative and efficient care and services;
7. Hold a series of high-level fora throughout 2014, in partnership with the OECD, WHO, the European Commission, the EU Joint Programme on Neurodegenerative Disease (JPND), and civil society, to develop cross sector partnerships and innovation, focused on:
 - Social impact investment – UK-led
 - New care and prevention models – Japan-led
 - Academia-industry partnerships – Canada and France co-led
8. Call upon the WHO and OECD to identify dementia as an increasing threat to global health and support countries to strengthen health and social care systems to improve care and services for people with dementia;
9. Call upon the UN Independent Expert on the enjoyment of all human rights by older persons to integrate the perspective of older people affected by dementia into their work;
10. Call upon all sectors to treat people affected by dementia with dignity and respect, and to enhance their contribution to dementia prevention, care and treatment where they can; and
11. Call upon civil society to continue and to enhance global efforts to reduce stigma, exclusion and fear.
12. We will meet again in the United States in February 2015 with other global experts, including WHO and OECD, to review the progress that has been made on our research agenda.



World Dementia Council

Leading the Global Action
Against Dementia

The World Dementia Council is a charitable incorporated organisation registered in England and Wales, registration number 1170743.

Registered address Tavis House, 1-6 Tavistock Square,
London WC1H 9NA, United Kingdom
E info@worlddementiacouncil.com