



Global action against dementia

Progress Report

December 2013- March 2015



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Cover photos: Top Left: Alzheimer's Disease International: Adela Hernandez, Federacion Mexicana de Alzheimer (FEDMA); Top Right: UKDH; Bottom Right: UKDH; Bottom Left: Alzheimer's Disease International: Alzheimer Society of Bangladesh.

March 16, 2015

Secretary of State Foreword

In the UK, the Prime Minister has made fighting dementia and helping those living with the condition a personal priority.

Dementia has a devastating impact on the lives of those with the condition as well as their families and friends. Too often a diagnosis brings with it fear and uncertainty for the individual and those closest to them. The scale of this growing health and social care challenge also places a burden on national health and care systems and budgets.

The number of people living with dementia worldwide in 2015 is estimated to be 47.47 million, reaching 75.63 million in 2030, and 135.46 million in 2050. Estimated costs of dementia in 2010 were \$604 billion.

It was a seminal moment in December 2013, when the G8 countries all agreed to work together to address dementia on a global scale. Leaders from around the world made commitments to innovate, invest and collaborate towards finding a cure. The G8 signed up to a shared vision to identify a cure or disease modifying therapy by 2025 and to embrace international collaboration on dementia through a series of high level actions set out in a Declaration and Communique.¹

The challenge was, and remains, great. But the (now) G7 countries have shown that, in a short space of time, big steps can be taken and momentum on a global scale can be created with leadership, commitment and collaboration.

For example:

- Countries have showcased and shared areas of focus, expertise and progress. These include prevention and care in Japan, research in the US, industry-academia collaboration in France and Canada and finance in the UK.
- Global organisations have embraced the work, WHO and Organisation for Economic Co-operation and Development (OECD) have led the way.
- Private sector and Non-Governmental Organisations (NGO) stakeholders have worked together with governments to establish new ways to accelerate drug development and improved systems of prevention and care.
- The finance sector has created new mechanisms for investment in dementia research.

It is testament to progress since the Summit that all G7 countries now have effective frameworks to address dementia within their national jurisdictions.

Since the G8 Dementia Summit in December 2013, exciting new momentum has developed around global action against dementia. People, countries and organisations from across the

¹ <https://www.gov.uk/government/publications/g8-dementia-summit-agreements>.

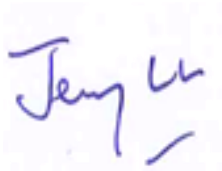
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world have united with a new energy to work towards a common vision and agreed priorities.

The WHO's first Ministerial conference for Global Action Against Dementia (GAAD) will provide a forum to celebrate all that is being achieved. But more importantly it will be a launch-pad to extend and advance a broader global commitment and plan of action. It will provide the opportunity to engage more widely with countries from across regions and from all economies.

This report provides an overview on progress of all that is being achieved since the Summit in 2013, resulting from work across the G7 and beyond.

Dementia is a global challenge. We all have a part to play and together we can make the world a better place for people with dementia, their carers and families.



The Rt Hon Jeremy Hunt, UK Secretary of State for Health



March 16, 2015

1. Introduction

In December 2013, the G8 Countries made a commitment to work together to improve the quality of life for people with dementia and their carers, with an ambition to identify a cure or a disease modifying therapy by 2025. Implicit in this (now) G7 action was a commitment to progress their own dementia strategies and to accelerate the science, innovation and research that each had underway.

The Global Action Against Dementia programme has provided an orchestration for change across, between and within nations. It has created new mechanisms for working together as well as with the private and NGO sectors. This unified network has already led to innovations in therapy, emerging changes in regulatory paradigms and plans for integration of care and social support systems, taking us closer to finding a cure and improving the quality of life for those with the condition.

Within countries, health ministers have pushed for new strategies, new funding, and new commitments. All G7 countries now have effective frameworks to address dementia within their national jurisdictions. Individually, countries have celebrated some positive successes.

This report celebrates all that is being achieved and highlights how the Summit has provided a springboard for new action at both an individual government/organisational level as well as in new collaborative relationships. This report seeks to provide a flavour of the breadth of work that is underway. It demonstrates the commitment that has been built among the G7 countries to work together, to share what they know and what they find out about dementia and to join with a wide range of stakeholders to advance the work. It shows that countries and sectors can work together when presented with a health and care challenge on such a scale.

2. Why Dementia is a global challenge

What is dementia?

The term 'dementia' describes a set of symptoms that include decline in memory, reasoning, communication skills and the ability to carry out daily activities. Alongside this decline, individuals may develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering. These cause problems in themselves, which complicate care, and can occur at any stage of the illness. These symptoms occur when the brain is damaged by certain diseases, such as Alzheimer's Disease. Around 60 per cent of people with dementia have Alzheimer's Disease, which is the most common type of dementia, around 20 per cent have vascular dementia, which results from problems with the blood supply to the brain and many people have a mixture of the two. There are other less common forms of dementia, for example dementia with Lewy bodies and frontotemporal dementia.

The Global Challenge

The world's population is ageing. Improvements in health care in the past century have contributed to people living longer and healthier lives. However, this has also resulted in an increase in the number of people with non-communicable diseases, including dementia. As a result, Alzheimer's Disease and other dementias are becoming a growing, global challenge. WHO has recently

estimated that the number of people living with dementia worldwide in 2015 was 47.47 million, reaching 75.63 million in 2030, and 135.46 million in 2050.² The World Health Organization (WHO) estimated the global cost of dementia care in 2010 was US\$604 billion – 1.0% of global GDP – around 70% of which is spent on informal, social and direct medical care. By 2030, it is estimated that the cost of caring for people living with dementia could be a staggering US\$1.2 trillion or more.³ This is unsustainable.



² 'The epidemiology, and impact of dementia. Current state and future trends', Background Paper Prepared for the World Health Organization Ministerial Conference on Global Action Against Dementia, March 2015, Professor Martin Prince, Dr Maelenn Guerchet, Dr Matthew Prina.

³ Ibid.

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Table 1: No. of people with dementia, and increases from 2015-2050, by continent and country development status:⁴

Region Year	People with dementia millions (% of world total)			Proportionate increase (%)	
	2015	2030	2050	2015-2030	2015-2050
World	47.47	75.63	135.46	59	185
By continent	2015	2030	2050	2015-2030	2015-2050
Asia	23.55 (50%)	39.79 (53%)	71.84 (53%)	69	205
Europe	11.44 (24%)	14.80 (20%)	20.75 (15%)	29	81
Latin America/ Caribbean	4.66 (10%)	8.52 (11%)	18.78 (14%)	83	303
North America	4.78 (10%)	7.28 (10%)	11.74 (9%)	52	145
Africa	3.04 (6%)	5.24 (7%)	12.35 (9%)	73	307
By development status	2015	2030	2050	2015-2030	2015-2050
G7	13.28 (28%)	19.01 (25%)	27.22 (20%)	43	105
G20	34.52 (73%)	55.03 (73%)	94.92 (70%)	59	175
OECD	18.95 (40%)	27.98 (37%)	43.65 (32%)	48	130
High Income countries	17.75 (37%)	25.86 (34%)	39.19 (29%)	46	121
Low or middle income countries	29.71 (63%)	49.76 (66%)	96.27 (71%)	67	224

These updated estimates are higher than the original estimates reported in the 2009 World Alzheimer's Report, by 15 per cent in 2030, and by 17 per cent in 2050. Population ageing is the main driver of projected increases. Since population ageing is occurring at an unprecedented fast rate in low and, in particularly, middle income countries, the bulk of the increase in numbers through to 2050 will occur in those countries.

From 2015 to 2050, the numbers of people with dementia will have increased slightly less than two fold in Europe, somewhat more than twofold in North America, threefold in Asia, and fourfold in Latin America and Africa. While 28 per cent of people with dementia live in G7 countries and 37 per cent in high income countries, 63 per cent live in low and middle income countries. By 2050, the proportion living in G7 countries will have shrunk to 20 per cent, while the proportion living in what are currently low and middle income countries will have increased to 71 per cent.⁵

Dementia, including Alzheimer's Disease, is one of the biggest global public health challenges facing our generation. Newly available data suggests that the current burden and future impact of the dementia epidemic has been underestimated, particularly for the Asia East and Sub-Saharan African regions. This is a global epidemic – although cases are

⁴ Ibid.

⁵ Ibid.

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disproportionately concentrated in the world's richest and most demographically aged countries, already the clear majority (63 per cent) of people with dementia live in low and middle income countries where access to social protection, services, support and care are very limited. In the next few decades, the global burden of dementia will shift inexorably to poorer countries, particularly rapidly developing middle income countries that are members of the G20, but not the G7.⁶



⁶ Ibid.

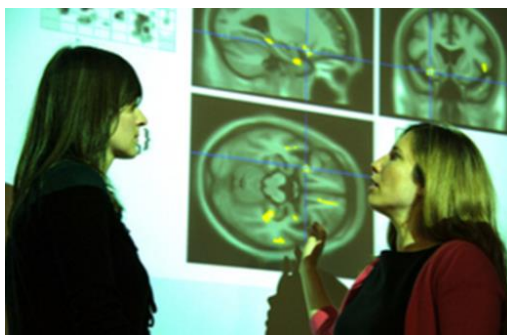
⁷ World Health Organization, March 2015.

3. Innovations for dementia treatment and investment

The central goal of Global Action Against Dementia is to identify a cure or disease-modifying treatment by 2025 in order to dramatically change the trajectory of the condition. Achievement of that goal requires greater investment in innovations in basic, translational and clinical research. Commitments 1, 2 and 6 of the G8 Declaration refer to finding a cure or disease-modifying therapy for dementias. In order to achieve this goal, innovative drug development strategies in the changing regulatory context are needed.

The Challenge

Dementia is one of our greatest medical challenges. It places a heavy burden on the individuals with the disease, their relatives and society as a whole, a problem that will only get worse as the world's population inexorably ages. The pharmaceutical industry estimates that a new drug that delays onset of dementia by five years could reduce expected numbers of people with the disease by as much as 50 per cent and save around \$450 billion a year by 2050.⁸



Dementia prevalence is expanding and by 2050 will increase globally by a further 205 per cent, with a shift in burden to low and middle income countries.⁹ Many important and potentially cutting edge approaches to dementia drugs never enter the innovation cycle beyond theory, particularly in the early stages of research, because of gaps in knowledge, regulatory hurdles, lack of incentives or investments. From 1998 to 2011, there have been 101 unsuccessful drugs and only three new approvals.¹⁰ At the global level, public sector Research and Development spending levels remain inadequate, despite recent increases among a number of the G7 nations. As a result and due to the potential missed savings opportunity, the worldwide cost of dementia is due to increase dramatically. However, in order to achieve a scaling up of the global resources for dementia innovation as set out by

⁸ 'Researching Alzheimer's Disease: Setbacks and Stepping Stones' PhMRA, 2012, p. 3.

⁹ 'The epidemiology, and impact of dementia. Current state and future trends', Background Paper Prepared for the World Health Organization Ministerial Conference on Global Action Against Dementia, Professor Martin Prince, Dr Maelenn Guerchet, Dr Matthew Prina.

¹⁰ 'Researching Alzheimer's Disease: Setbacks and Stepping Stones' PhMRA, 2012, p. 13.

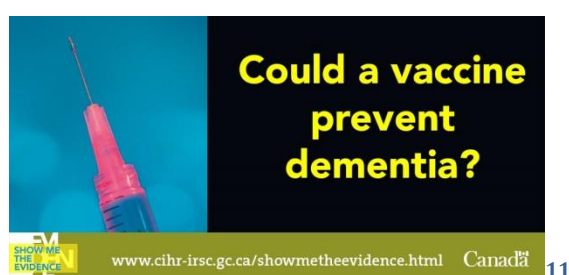
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the UK Prime Minister David Cameron at the G8 Dementia Summit, a more multidisciplinary and multi government approach will be required.

What has been achieved

Research science

The 2013 G8 Dementia Summit has generated unprecedented interest in dementia treatment and investment and has resulted in a number of exciting global collaborations and initiatives that will take us closer to the commitment of a cure or disease-modifying therapy by 2025.



A range of projects from across the G7 are outlined at the end of this section of the report, demonstrating the breadth of activity and potential for discovery.

One innovative example is the Innovative Medicines Initiative (IMI) project European Prevention of Alzheimer's Dementia (EPAD) that was launched in Paris on 15 January 2015.

It is a novel collaboration between academic and private sectors to test innovative treatments for the prevention of Alzheimer's dementia. The EPAD initiative is being closely coordinated with a similar Global Alzheimer's Platform (GAP) initiative in the US as well as parallel initiatives emerging in Canada and other countries. The international collaboration will, when operational, create a global clinical trial platform that will reduce the time, cost and risk of testing innovative drug candidates or drug combinations.

The EPAD initiative aims to develop an infrastructure that efficiently enables the undertaking of adaptive, multi-arm Proof of Concept studies for early and accurate decisions on the ongoing development of drug candidates or drug combinations. This includes evaluating patients' reactions to a drug early in a clinical trial and modifying the trial according to these reactions. The EPAD project will initially run for five years.

The platform will draw European participants, whose records are already part of existing national/regional cohorts or register studies, into an EPAD register of approximately 24,000

¹¹ Canadian Institute of Health Research

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people. From this group, 6,000 people will be asked to join a pan-European EPAD Cohort for consistent, longitudinal follow-up, and approximately 1,500 of them will eventually be invited to enter the standing EPAD Proof of Concept Trial. This approach aims to ensure EPAD has access to an at-risk population showing biomarker evidence of Alzheimer's Disease prior to the development of dementia.

All data collected from the cohort and trial will become publically available for analysis to improve disease models in the pre-dementia phase of Alzheimer's Disease.

“EPAD is part of a global initiative that will make a fundamental difference to the understanding and management of Alzheimer's Disease in people with very early or no symptoms at all. This could be a game-changer. It is only possible because of the absolute commitment of academics, industry, policy makers and the public to work hand in hand to defeat this global threat”, Prof Craig Ritchie, EPAD Co-coordinator, Professor of the Psychiatry of Ageing at the University of Edinburgh.

Integrated Development

A mandate for Global Integrated Development is being led by Raj Long, Senior Regulatory Officer at the Bill and Melinda Gates Foundation and World Dementia Council member. She was asked by the UK Department of Health to develop a strategy and to facilitate engagement with the regulators as an Independent Expert. On 10 November 2014, the UK Government brought together for the first time in Geneva, 11 drug regulators from the European Union, the United States, Canada, Japan and Switzerland, supported by a clinical working group, WHO and Office of ECD. The meeting examined the relationship of the current state of dementia research to regulatory science. Industry input received from the group of companies that belong to the Global CEOi Initiative on Alzheimer's Disease and dementias was also considered alongside an initial assessment of attrition over the last 15 years.



“The one thing that we can't have is business as usual if we want to make a real difference for people with dementia and their families. Regulators must now come together as a group and look at dementia, and see what can be done to find innovative solutions to the problem ”
Raj Long Senior Regulatory Officer, Bill and Melinda Gates Foundation, Director Dementia Integrated Development UK HMG, World Dementia Council Member.

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A closed workshop followed, enabling the regulators to collectively and collaboratively discuss in a “safe harbour”, how best to shape dementia drug development in light of current Research and Development gaps, and the possible steps to enable better understanding of the research and development science within existing laws and regulations.

As a result, six areas of priority action were identified by the regulators including an appetite to widen multilateral cooperation internationally, underpinned by series of regulator-led projects including:

- **Attrition analysis** to assemble and analyse a relevant sample of data and examine the factors-features of terminated development.
- **Clinical trial efficiency** to draw together transferable insights from oncology, rheumatology and antimicrobial resistance, including adoption of master protocol designs, consent forms and data mining in order to improve efficiency of clinical trials for drug development.
- **Modelling and extrapolation** to elaborate on which evidence exists to inform extrapolation of data collected in rare genetic forms of Alzheimer’s disease into late onset sporadic dementia. Moreover theoretical models and approaches taken from other psychiatric disorders will also be elaborated upon.
- **Composite end points** to advance the state of the art various cognitive measures that could be in a composite end point for the early stages of AD (not mild to moderate or severe AD).
- **Risk-benefit balance** to consider strategically how best to balance possible benefits given the high level of uncertainty about the disease.

In March 2015, Raj Long provided the G7 with an independent assessment of the global approach to the development of safe, effective and affordable medicines for dementia by 2025 and included a set of recommendations for governments, regulators and industry.

Finance

A range of efforts are being taken forward to bring together public and private finances in different ways. Building on these, and in response to the relatively low investment into dementia drug development, the UK Department of Health commissioned work to review the options for a new type of financial product which could lead to accelerated innovation in dementia drug development. It was decided that a pre-clinical fund should be developed, a proposal that was fully endorsed by the World Dementia Council. The focus of the fund will be to explore new molecule hypotheses and support innovative asset development. This will

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help progress the 2013, G8 Summit commitment to the ambition of finding a cure or disease modifying treatment by 2025.

On 2 December 2014, the UK Government's Autumn Statement announced plans to invest £15 million to the fund to encourage greater investment from the international health community and to re-energise the drug development pipeline. The new Fund will be a unique collaboration that will bring together the combined expertise of public, private and charitable sectors. Organisations involved will be working closely together over the coming months to ensure the fund will identify and finance research that, in time, could generate new treatments for dementia and improve outcomes for people living with the disease.

“The government will commit £15 million to help kick-start a fund...to help drive forward the search for new drugs to beat dementia... and attract the private sector investment needed for this crucial work, dementia is one of the greatest enemies of humanity and we must all play our part defeating it.” David Cameron, UK Prime Minister.

G7 Key Achievements:

Canada: A partnership between the Parkinson Society of Canada and the Institut universitaire de gériatrie de Montréal undertook a longitudinal study on Parkinson's and dementia - the first of its kind - to explore the possibility of identifying individuals with early stage Parkinson's who will go on to develop dementia. Their results, demonstrating that people with Parkinson's are six times more likely to develop dementia than someone in the general public, further the idea that early intervention (e.g. medication, cognitive training, and transcranial magnetic stimulation) may help to slow cognitive deterioration.¹²

By studying the prescription records of nearly 9000 older people living in Quebec, Canadian and French scientists suggest a link between the use of benzodiazepine drugs and increased risk of developing Alzheimer's disease. 1796 of the people studied had a diagnosis of Alzheimer's Disease, and of these, nearly 50 per cent had been given benzodiazepines in the last five to 10 years prior to their diagnosis. This study demonstrates a link between benzodiazepines, which are commonly prescribed to treat anxiety and sleep disturbance, and Alzheimer's Disease – although a limitation of this study is that benzodiazepines treat symptoms such as anxiety and sleep disturbance, which may also be early indicators of Alzheimer's disease.¹³

Germany: A study published in September 2014 found that aromatic turmerone, a compound found in the plant turmeric, can boost the generation of stem cells in the brains of rats. Researchers at the Institute of Neuroscience and Medicine in Jülich, Germany, looked at the effect of turmerone on cells within the brain that can become nerve cells. These neural stem cells generate the growth of new nerve cells, so can play a role in helping the brain to repair damage. Brain scans were given to rats that had been injected with the compound, and the result showed that growth of new cells was boosted in two regions of the brain. This treatment is now being explored to determine whether it has any potential for neurodegenerative diseases.¹⁴

Another important German study looked at drugs used for type-2 diabetes to stave off symptoms for Alzheimer's Disease. Researchers used data from German healthcare plans from 2004-2010 to track a database of 146,000 patients over the age of 60 without evidence of dementia. Early results of the study show that those taking the pioglitazone medication for diabetes were at less risk of developing dementia. Findings were presented at the

¹² Hanganu, A., et al. "Mild cognitive impairment is linked with faster rate of cortical thinning in patients with Parkinson's disease longitudinally," *Brain* 137, 4 (2014): 1120–1129. doi:10.1093/brain/awu036.

¹³ *British Medical Journal*, September 2014.

¹⁴ Aromatic-turmerone induces neural stem cell proliferation in vitro and in vivo *Stem Cell Research & Therapy* 2014, 5:100 doi:10.1186/scrt500

Alzheimer's Association International Conference (AAIC) in July 2014.

France: A major breakthrough in the understanding of Alzheimer's Disease has been published in Nature Genetics: 11. New genetic susceptibility factors for Alzheimer's Disease have been discovered through the largest study ever conducted, the I-GAP (International Genomics Alzheimer's Project) consortium including eleven countries from G7 and beyond, led by France. The findings reinforce pathways previously implicated in Alzheimer's Disease pathology, including immune response, inflammation, cell migration and lipid transport pathways. The new candidate genes and pathways identified pave the way for a better understanding of the pathophysiology of dementia and demonstrate the added value of international collaboration and data sharing. Following this publication the I-GAP has released the summary results data in order to enable other researchers to examine particular variants or loci along the whole human genome for their evidence of association. The files include p-values and direction of effect at over 7 million directly genotyped or imputed single nucleotide polymorphisms (SNPs).¹⁵

Scientists led by a team at the University of Caen (Basse, Normandy) have designed a new drug that is being investigated as a potential treatment for Alzheimer's Disease. By synthesising a compound which combines the effects of two drugs currently used in Alzheimer's Disease treatment (RS67333, which has been shown to have beneficial effects on memory, and donepezil, which helps relieve some of the symptoms of the disease by helping communication between nerve cells) this research has taken a different approach to drug development, by producing a compound with two biological targets. Mice treated with this new compound, donecopride, did better in memory tests than those that were not treated with the drug.¹⁶

Italy: The Sleep Study Group of the Italian Dementia Research Association (SINDem) has published recommendations on clinical assessment and management of sleep disorders in individuals with mild cognitive impairment and dementia. A clinical review demonstrated that sleep disturbances show high prevalence in mild cognitive impairment and dementia patients, and they are often associated to each other. This study reached clear consensus and good practice guidelines were provided, which are important as poor sleep results in an increased risk of morbidities and mortality in dementia patients.¹⁷

Researchers led by the Fatebenefratelli Hospital in Rome have found that levels of copper in the bloodstream may be able to indicate Alzheimer's Disease in its earliest stages. A study tested blood samples from 141 older people with mild cognitive impairment, and compared

¹⁵ http://www.pasteur-lille.fr/en/recherche/u744/igap/igap_download.php

¹⁶ Proceedings of the National Academy of Sciences, August 2014.

¹⁷ Neurol Sci. 2014 Sep;35(9):1329-48. doi: 10.1007/s10072-014-1873-7. Epub 2014 Jul 19.

levels of copper to results from memory tests conducted every six months. After four years, researchers found that 50 per cent of those people with the highest level of free copper in their blood had developed Alzheimer's Disease. Conversely, less than 20 per cent of those with the lowest levels of free copper had developed the disease four years later, which suggests that lowering copper intake could help reduce risk.¹⁸

Japan: Joint research between the Kyoto University Centre for iPS Cell Research and Application and the Fujifilm Group is accelerating the development of T-817MA. This drug hopes to protect neurons and promote neurite outgrowth, and has demonstrated strong efficacy in animal models. Phase II clinical trials were launched in June 2014 in collaboration with the US therapeutic research consortium and the Alzheimer's Disease Cooperative Study.

The result of a study funded by the FIRST (Funding Program for World-Leading Innovative R&D on Science and Technology) was published from the NCGG (National Center for Geriatrics and Gerontology). The results revealed a plasma biomarker for Alzheimer's Disease by using novel, high sensitive immunoprecipitation-mass spectrometry. The ratio of APP669-711 to AB1-42 potentially could be a precise surrogate for cerebral amyloid depositions.¹⁹

United States: Researchers continue to develop and refine biomarkers—brain imaging and tests of blood and other body fluids—as well as non-invasive measures to detect the onset and progression of Alzheimer's Disease. Currently, these measures are primarily used in clinical trials to test the effectiveness of test interventions. In 2014, advances in biomarkers shed new light on the complexities of the disease and how it evolves over time, and offered the promise of a blood test that could identify those at risk for dementia. We also learned more about effective ways to measure memory complaints and other markers for those who may be at risk.

In a 2014 study of volunteers with the rare, familial early-onset form of Alzheimer's participating in the NIA-supported Dominantly Inherited Alzheimer's Network (DIAN), previously identified biomarkers showed an unexpected pattern of change over time. The goal of the study, led by researchers at Washington University in St. Louis, MO, was to understand how cerebrospinal fluid (CSF) biomarkers change as the disease progressed.

The researchers first analyzed CSF biomarkers, beta-amyloid levels, and the cognitive status of DIAN volunteers: 146 carried the mutant gene for early-onset Alzheimer's and 96 were non-carriers. As had been found in previous studies, among the younger participants, those

¹⁸ Journal of Annals of Neurology, April 2014.

¹⁹ 'Novel plasma biomarker surrogating cerebral amyloid deposition in disease' Kaneko N. et al, Proc Jpn Acad Ser B Phys Biol Sci. 2014;90(9): 363-64.

with the mutation had biomarkers that indicated disease onset some 10 to 20 years before symptoms are expected to show. These markers included reduced CSF beta-amyloid 42 levels (associated with increased amyloid plaques), increased levels of CSF tau (associated with tau tangles), and other markers associated with damaged neurons, including a new marker called visinin-like protein-1 (VILIP-1).

They then looked at CSF biomarkers and cognitive test data collected over 2 to 3 years in 37 older volunteers with an average age of 40. Among the 26 mutation carriers in the group, biomarkers of neuronal death and injury increased up to the expected year of onset of cognitive symptoms—but then began to decrease.

These results suggest that neuronal death slows down during the later stages of Alzheimer's Disease, and that the use of neuronal death markers should be used with caution in tracking disease progression in clinical trials.²⁰

Researchers have also made progress in using blood from young mice to reverse age-related changes in the brains of old mice, according to studies that have used a technique called parabiosis, in which the circulatory systems of two mice are joined together to allow blood to flow between them.

One team from the University of California studied the effects of young blood on the production of new neurons, or neurogenesis, in the brains of older mice. Neurogenesis normally tapers off during aging, as does blood flow to brain regions where new neurons are born. They found blood from young mice stimulated blood vessel growth in these brain regions of aged mice, doubling blood flow to the area. The mice exposed to young blood had significant growth in cells involved in the sense of smell; they performed better on olfaction tests than did old mice exposed to the blood of old mice. The researchers were able to partially mimic the effects of young blood on vascular growth and neurogenesis by treating aged mice with GDF11, a blood protein that promotes the growth of several cell types.²¹ Many molecules are present at higher levels in the blood of young people compared to older people, and this and other related studies suggest that some of those molecules could be useful therapeutic targets.

²⁰ Fagan AM, Xiong C, Jasielec MS, Bateman RJ, Goate AM, Benzinger TL, Ghetti B, Martins RN, Masters CL, Mayeux R, Ringman JM, Rossor MN, Salloway S, Schofield PR, Sperling RA, Marcus D, Cairns NJ, Buckles VD, Ladenson JH, Morris JC, Holtzman DM. Longitudinal change in CSF biomarkers in autosomal-dominant Alzheimer's disease. *Science Translational Medicine* 2014;6(226):226ra30.

²¹ Villeda SA, Plambeck KE, Middeldorp J, Castellano JM, Mosher KI, Luo J, Smith LK, Bieri G, Lin K, Berdnik D, Wabl R, Udeochu J, Wheatley EG, Zou B, Simmons DA, Xie XS, Longo FM, Wyss-Coray T. Young blood reverses age-related impairments in cognitive function and synaptic plasticity in mice. *Nature Medicine* 2014;20(6):659-63.

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United Kingdom: In 2014, UK Prime Minister David Cameron articulated his hopes for the future of dementia drugs in a letter calling fellow leaders: 'To give patients earlier access to new drugs, ensure new dementia medicines are affordable across the globe and encourage a move for greater innovation and collaboration between government, industry, regulators and the scientific community'

Results of a study "Plasma proteins predict conversion to dementia from prodromal disease", were published on 8th July 2014 in *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*. This research could eventually lead to a blood test for early stage dementia. The international collaboration was led by King's College London and Proteome Sciences plc, and was funded by Alzheimer's Research UK, the UK Medical Research Council (MRC), the NIHR Maudsley Biomedical Research Centre and Proteome Sciences.

In January 2015 the MRC Toxicology Unit provided evidence that neurodegenerative diseases can be halted in animal models by subverting mechanisms that have a normal function in hibernation, offering an entirely new therapeutic target for Alzheimer's. The study received widespread publicity²². The research team discovered that a "cold-shock" chemical called RBM3 could be used these to prevent brain cells dying in animals, providing a potential new drug target. The study suggested that RBM3 was key to the formation of new neuronal connections and in a series of tests showed the brain cell deaths from prion disease and Alzheimer's could be prevented by artificially boosting RBM3 levels.

Europe: From 2014, the "Health, demographic change and wellbeing" societal challenge of Horizon 2020, the EU Framework Programme for Research and Innovation, supports collaborative research for developing personalised medicine approaches for prevention, treatment and care of chronic diseases, including dementia and neurodegenerative diseases. It also contributes to the coordination of EU Member States through the Joint Programming Initiative on Neurodegenerative Diseases Research (JPND). In particular, the JPND called in January 2015 for collaborative research proposals on longitudinal cohort approaches, advanced experimental models, and risk and protective factors in neurodegenerative diseases for a total value of EUR 40 million (including a European Commission contribution of EUR 10 million). Horizon 2020 also co-funds the Innovative Medicines Initiative 2, Europe's largest public-private partnership with the European pharmaceutical industry, aiming to speed up the development of, and patient access to, innovative medicines, particularly in areas where there is an unmet medical or social need such as Alzheimer's Disease (e.g. the 5-year European Prevention of Alzheimer's dementia EPAD project, a collaborative research initiative that started in January 2015 to improve the chance of successfully preventing Alzheimer's dementia and to better understand early aspects of Alzheimer's Disease before dementia develops).

²² <http://www.bbc.co.uk/news/health-30812438>

4. Improving collaboration in dementia research

There is a growing momentum around improving the way that countries and organisations work together to get the best out of research into dementia. Commitments 2, 3, 4 and 5 of the G8 Declaration highlight the importance of this work. Collectively, they outline an ambition to gain a better understanding of the current levels and types of research that is funded for dementia, with the ambition of using this information more collaboratively, and to establish an approach to take the coordination of international research efforts to a new level.

The Challenge

In order to make a breakthrough in dementia research, there is a need to improve the way that research and research data is disclosed and shared.

There has been limited access to information about the research that is undertaken around the world. There are also relatively few people engaged in dementia research studies and there are shortcomings in the systems needed to track, share and coordinate research and link researchers pursuing related efforts. Improving the sharing of research information and offering the opportunity to participate in research to an increasing number of people (patients and healthy populations) will not only help to diversify and accelerate the pace of scientific discovery but may also help to improve the quality of life of people directly affected by dementia.

Various barriers in the methods by which research is disclosed, shared and linked mean that the limited amount of research funding that is invested may not have been applied as productively as possible and that the research that has been carried out is often effectively inaccessible to other researchers. Some of these barriers are of a technical nature, for example related to interoperability and standards, storage or the technical infrastructure to allow for data sharing. The most significant challenges, however, are cultural and ethical. Currently there is not a culture of data sharing in dementia research, and there are often large disincentives for researchers to disclose and share research data. As a result, public policy plays a crucial role in setting the conditions to promote data sharing and in developing robust framework conditions for trust and partnerships.

What has been achieved

In order to take forward the research commitments from the G8 Dementia Summit, WHO, OECD and others have worked closely with the G7 countries and others partners to build a

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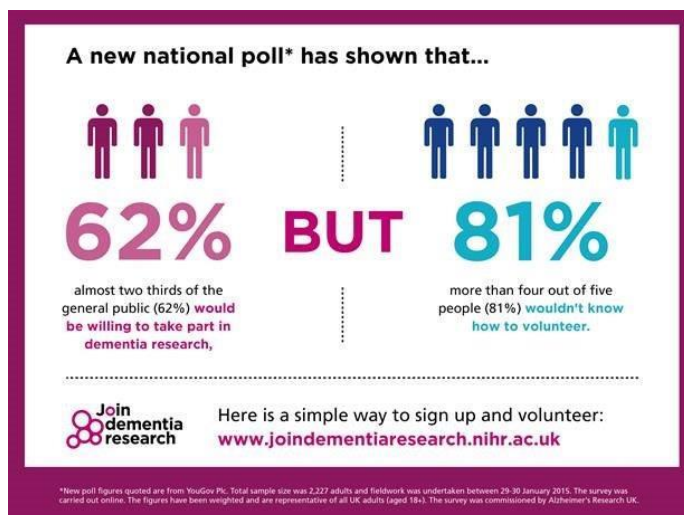
better understanding of the current levels of research investment and the challenges and opportunities for change.²³

Spending on dementia research

OECD has produced a new compilation of data on public funding of dementia research at the level of specific health research areas, conditions and diseases. They have estimated that across the G7, \$781 million is spent on dementia Research and Development, with \$2,115 million on Neuro Degenerative Disease, from a total health Research and Development budget of \$43,854 million, in the last year for which data are available. OECD will continue to provide, through its working party of National Experts on Science and Technology (NESTI) a forum for discussion and decision on statistical standards. IMI2, which identifies discovering new therapies for Alzheimer's Disease as a priority, has a total budget of €3.276 billion. The programme began in 2014 and will run for 10 years. In December 2013 UK Prime Minister David Cameron committed to doubling funding for dementia research from £66 million in 2015 to £122 million in 2025.

Involving people in dementia research

The National Institute for Health Research (NIHR) has collated data on the number of people participating in dementia research studies. A number of the G7 countries have taken significant steps in the past year to increase the number of people in studies, for example,



the UK Prime Minister's Challenge on Dementia included the ambition to recruit 10 per cent of people with dementia into trials by 2020. This is nearly halfway achieved, with 4.5 per cent currently engaged in research and nearly 5,000 individuals registered on Join Dementia Research, an initiative for matching potential research participants to studies.²⁴

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In addition, the U.S. National Institute on Aging (NIA) at the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), and the Administration for Community Living (ACL) are collaborating on the Recruiting Older Adults into Research (ROAR) project to encourage older adults and their family caregivers, including

²³ 'Strategic Approaches for Prioritising Dementia Research', Background Paper Prepared for the World Health Organization Ministerial Conference on Global Action Against Dementia, March 2015.

²⁴ <https://www.joindementiaresearch.nihr.ac.uk>

²⁵ National Institute of Health Research and Alzheimer's Research UK

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underrepresented populations, to consider participating in research. The project is starting with Alzheimer's research, through leveraging of state and local Aging Services and Public Health networks.

A dementia citizen science platform has been developed as an innovative platform for crowd sourcing new knowledge about dementia care. This is a pilot which will enable people with dementia and their carers to actively participate in dementia research in a meaningful way. The aim is to launch the project by Summer 2015.

Reviewing and prioritising research portfolios

WHO has led the effort to map the landscape of dementia research by reviewing existing methods of priority setting and carrying out a survey of research projects that are being led by public/governmental agencies. WHO intends to continue collating this data, and from a wider breadth of individuals, organisations and countries. At a later stage, the analysis might also be expanded to private agencies or foundations.

Building on this, WHO has coordinated a research prioritisation exercise, inviting contributions from over 2000 experts from around the world and eliciting more than 700 individual research questions that have been formulated into representative Thematic Research Avenues which relate to three areas (Basic, Clinical-Translational, Implementation Research). A survey has been sent to stakeholders to score each of the 59 proposed Thematic Research Avenues according to the following five criteria: (1) Potential For Success, (2) Impact on Burden Reduction, (3) Potential for Conceptual Breakthrough, (4) Potential For Translation, and (5) Equity.

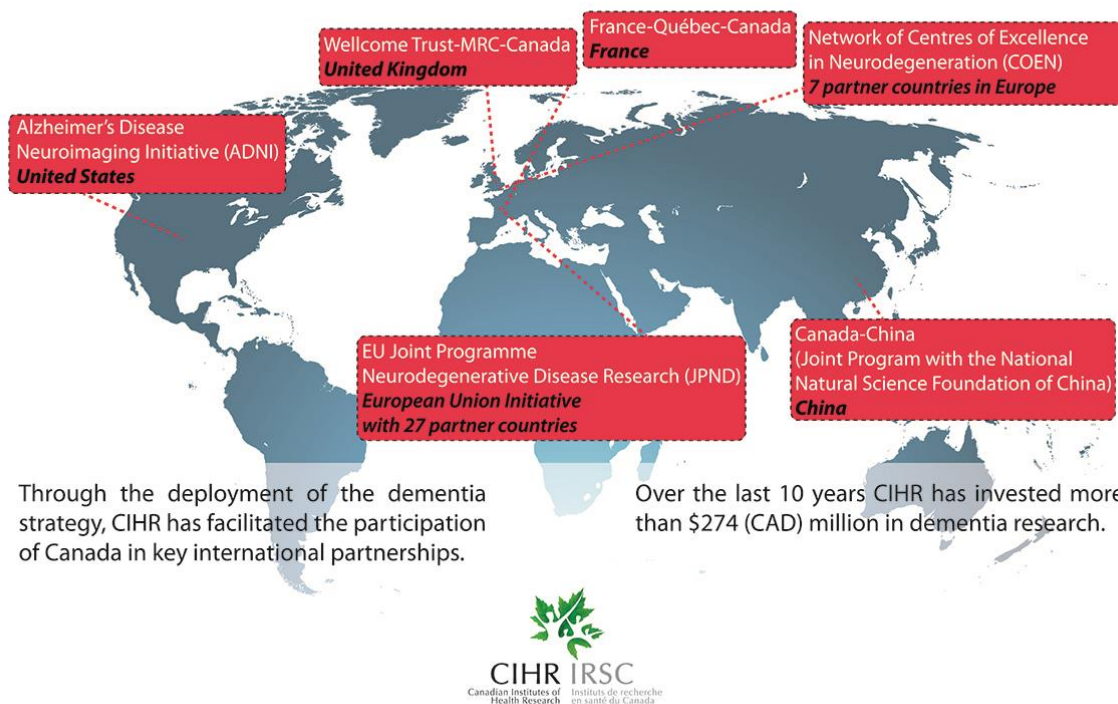
Open science

The OECD has set out an approach to tackle the issue of open access to data focused around developing good practice on data governance, principles aimed at policy makers, funding agencies and researchers and actions to strengthen cooperation. There is a consensus that data sharing can be accelerated and a strategy will be taken forward in 2015 based upon a review of four case studies that highlight best practice and barriers to progress.

Collaborations already exist for dementia research. Horizon 2020, the EU Framework Programme for Research and Innovation, supports collaborative research and innovation actions and is open for participation from across the world. The EU Joint Programme Programming Initiative on Neurodegenerative Diseases Research (JPND) provides a mechanism for coordinated research, reaching beyond the G7. Other collaborations have also emerged or gained momentum in the wake of the Summit, including the EU level action and the Canadian Consortium on Neurodegeneration in Aging (CCNA).

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International component of the CIHR Dementia Research Strategy



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In addition, the U.S. Government has made substantial advances in encouragement of data sharing. In February 2013, the Director of the White House Office of Science and Technology Policy issued a memorandum to all agency and department heads entitled, “Increasing Access to the Results of Federally Funded Scientific Research.” The memo directed federal agencies with more than \$100 million in annual conduct of research and development to develop plans for increasing public access to peer-reviewed scientific publications and digital data resulting from federally funded research investments. As a result, the NIH and its sister agencies developed policies that aligned their work through a common set of guiding principles and a framework around which they could develop implementation plans tailored to the needs of their research communities, taking into account their unique missions and legal authorities.

‘France is now firmly committed to the Global Action Against Dementia with countries from over the world to accelerate research and find a cure. In the context of the new French plan on Neurodegenerative disorders France has now joined the Center of Excellence in Neurodegeneration initiative allowing networks between the best centres across Europe and Canada to combat neurodegenerative disorders.’ Marisol Touraine, Minister of Social Affairs and Health, France.

²⁶ Canadian Institute of Health Research

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Big Data

Advances in dementia research will undoubtedly rely on harnessing the increasing volume and richness of data available through biomedical research, medical and healthcare systems, social media and lifestyle sources. OECD has undertaken a series of meetings to bring together key players in the big data area to explore practical steps to provide international join-up across initiatives. As a result, two concrete examples of global data sharing have been created in the context of the G7 action against dementia – one focussed on providing a wealth of open-source biomedical data for the community, the other focussed on linking big data approaches at the population level. The first builds upon GAAIN, the Global Alzheimer’s Association Interactive Network that links eleven international partners from four continents through a federated network of data resources. The capability of this network is being extended significantly through connections with the French National Alzheimer’s Database, the European Medicines Informatics Framework (EMIF), and the Canadian based Longitudinal Online Research and Imaging System (LORIS). The second exemplar is a complementary collaboration between the CCNA and the Dementias Platform (DPUK) which will create an integrated system to share and analyse large-scale complex cohort-based datasets encompassing both broad and deep data from up to 2 million individuals, including imaging, genomics and health data. As a result, these collaborations will enable the aggregation of an unprecedented volume of individual and population-level data, offering an open science solution to help research to more efficiently tackle Alzheimer’s Disease and related disorders.

Following the G7 Research meeting held in Washington in February 2015, the UK Medical Research Council, working under the banner of the EU joint research programme agreed to develop a single global inventory of population studies and disease-focused cohorts so that researchers have access through one portal to the information they need. At the same time, the United States of America and the International Alzheimer’s Disease Research Portfolio will provide a comprehensive and up to date registry of all clinical research including clinical trials. Both these initiatives will build and coordinate the global effort to advance dementia research.

G7 Key Achievements:

Canada: The Canadian Consortium on Neurodegeneration in Aging (CCNA) was launched on 10 September 2014. The CCNA brings together 20 research teams (and over 300 of the best Canadian researchers in this field) from across Canada to focus efforts on preventing and delaying the onset of dementia, as well as improving the lives of people already affected. It represents an investment of \$ 32 million CAD and is becoming the privilege Canadian hub for international collaborative efforts on dementia research.

France: The new national plan on neurodegenerative diseases 2014-2019 ensures the involvement of France in the Global Action Against Dementia, with the aim of coordinating national efforts with G7 and other countries initiatives. It also confirms participation of the country to the Joint Programming Initiative on Neurodegenerative diseases, alignment of national research priorities with its strategic research agenda, and contribution to its funding program. Most importantly, the plan allows France to participate to the Center of Excellence in Neurodegeneration initiative by identifying such structures in the country.

Germany: As part of the “Local Alliance for People with Dementia” initiated by the German Alzheimer Association and that has been supported by the German Federal Government, the novel project “EinBlickDemenz” was launched in autumn 2014. In cooperation with the Munich Cluster for Systems Neurology (SyNergy) and the German Center for Neurodegenerative Diseases (DZNE) scientific findings in dementia research are written in easy-to-understand language and made available to the public. New articles are added to this “knowledge portal” on a weekly basis. Everybody is invited to comment on these articles. In this way Alzheimer’s patients and their relatives as well as other interested parties gain access to the latest findings and can better assess current dementia-related topics which are discussed in the media.

In addition, the Federal Ministry of Health installed a health care research programme “future-workshop dementia”, in which projects are funded that concentrate on the support of caring relatives and on regional dementia networks. The aim is to identify success factors in the build-up of regional dementia networks und to implement such networks on a permanent basis.

Japan: The Japanese Government has launched a “Comprehensive Strategy to Accelerate Dementia measures” (new Orange plan) in January 2015. This plan sets research and development as one of the seven pillars. Japan will promote a nationwide prospective cohort study with high quality and high efficacy focusing on genomics, international cooperation etc and will start the framework for clinical research as a registration system of

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persons with dementia.

United Kingdom: A website for patients and public to register their interest in being contacted for relevant studies was launched on 24 July 2014. 'Join dementia research', will help to increase the number of people in studies, and seek to enroll 10 per cent of patients, as well as healthy people, into studies by 2020, and to provide a nationally consistent system to enable them to do so.

The Dementia Platform UK (DPUK) was announced on 19th June 2014, and is a £53 million industry-partnered programme, funded by Medical Research Council with £4 million provided through from six industry partners from the biopharma sector, along with eight universities. The partners collectively will deliver the world's largest research cohort, of two million study participants who have supplied detailed biological, clinical and lifestyle information for research, supplemented by the creation of three national technology networks, spanning neuroimaging, disease modelling and informatics.

United States: Alzheimer's research in the United States has benefited from the provision of additional funds over the past several years. In FY2012, as part of a Presidential initiative, Dr. Francis Collins, Director of the National Institutes of Health (NIH), redirected \$50 million to expand Alzheimer's Disease research, and in FY2013, he provided \$40 million for this purpose from unallocated funds in the NIH budget. Additional Federal appropriations of \$100 million in FY2014 and \$25 million in FY2015 were provided with the expectation that a significant portion of these increases would be directed towards Alzheimer's Disease research. Spending at the NIH on Alzheimer's Disease research increased 25% from FY2011-FY2014.

The NIH-led Accelerating Medicines Partnership (AMP) (designed to transform and accelerate drug development) achieved a significant milestone in March 2014 with the launch of a new Alzheimer's Big Data portal—including delivery of the first wave of data—for use by the research community. AMP is an unprecedented venture bringing together NIH, the U.S. Food and Drug Administration, industry and academic scientists from a variety of disciplines to translate knowledge faster and more successfully into new therapies. The opening of the AMP-AD Knowledge Portal and release of the first wave of data will enable sharing and analyses of large and complex biomedical datasets. Researchers believe this approach will ramp up the development of predictive models of AD and enable the selection of novel targets that drive the changes in molecular networks leading to the clinical signs and symptoms of the disease.

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European Union: The European Union are supporting research in 4 main areas:

- (i)** Horizon 2020 (H2020), the EU Framework Programme for Research and Innovation (2014-2020)²⁷: opportunities for research on dementia/neurodegenerative diseases in all three priorities of H2020, and in particular within the societal challenge 1 '*Health, demographic change and well-being*';
- (ii)** Public-private partnership: the Innovative Medicines Initiative 2 (IMI2)²⁸ expands the scope of the initiative to cover the entire medical research and innovation value chain. IMI2 strategic research agenda identifies neurodegenerative diseases as a priority to be addressed in the years to come;
- (iii)** Member States coordination: the Joint Programming Initiative on Neurodegenerative Diseases Research, in particular Alzheimer (JPND) gathers 28 countries (including non-EU countries such as Canada) and aims at de-fragmentation through a common research strategy and alignment of national programmes. Further H2020 support is envisaged to extend the JPND capacities towards new members, including outside Europe, and explore scenarios for its long-term sustainability;
- (iv)** International cooperation: the Global Alliance for Chronic Diseases (GACD)²⁹ is considering mental health as a potential future topic amongst other priorities.

²⁷ http://ec.europa.eu/research/participants/data/ref/h2020/legal_basis/fp/h2020-eu-establact_en.pdf

²⁸ http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=uriserv:OJ.L_.2014.169.01.0054.01.ENG

²⁹ <http://www.gacd.org/>

4. Living well with dementia

The person with dementia – alongside their carer and family – should be at the heart of everything we do. Every person, from all backgrounds, walks of life and in all parts of the world - people of different ages, gender, sexual orientation, ability or ethnicity - should receive high quality, compassionate care from diagnosis through to end of life care.

Commitments 9, 10 and 11 of the G8 Declaration all reflect the ambition to improve the quality of life of those living with dementia their carers and families. They call upon all sectors of society to uphold the human rights of older persons living with dementia and to enhance global efforts to reduce stigma, exclusion and fear. They include an ambition to improve dementia care and risk reduction strategies.

The Challenge

There are 47.47 million people living with dementia and their quality of care varies greatly between countries and regions. Challenges include presenting the best evidence on risk reduction, ensuring people can access the best and most appropriate care, making society a safe and supportive environment and protecting people's human rights.

“By 2050, 135 million people around the world will live with dementia. In 2010, the global cost of dementia care was estimated at US \$604 billion.... With this in mind, we can't afford to do nothing. If research is currently not delivering the results we need, doing our best to live a healthy lifestyle is a sound investment for the future.” Dr Dennis Gillings, World Dementia Envoy, CBE.

Risk reduction

There is growing evidence that links modifiable risk factors such as physical inactivity, poor diet and smoking with dementia. However, for some the evidence currently available is not a sufficient basis upon which to include dementia risk reduction in public health and non-communicable disease policies, interventions and messaging. By helping people to make healthy lifestyle choices and address risk factors, we may be able to reduce the rate at which people get dementia and slow cognitive decline.

On 20 May 2014, 59 organisations and experts from across the dementia and public health community in the UK signed a consensus statement known as the Blackfriars Consensus Statement, confirming that scientific evidence on dementia risk reduction is evolving rapidly and is now sufficient to justify action to incorporate dementia risk reduction into wider health policies and to raise awareness about which factors may reduce the risk of developing dementia.

Care

The care of people living with dementia is a huge challenge for carers, health and care systems and economies. In most parts of the world, carers receive little or no support in caring for their loved ones, and unpaid care leads to impoverishment for families and loss of productive workers to the economy. Where residential or hospital care is available, the quality of care is often very poor. There is a need to develop new and innovative solutions to improve the efficiency and standard of care offered to people living with dementia, they need to be integrated, person centred and responsive to the needs of people living with dementia and their carers.

Stigma

As people age, many fear the potential onset of dementia-related symptoms or a diagnosis of dementia. Negative reactions from family, friends, and professionals can impact on a person's willingness to seek assistance, as well as their wellbeing and ability to manage the changes brought about by dementia. The report, 'New perspectives and approaches to understanding dementia and stigma', launched



by the OECD in Japan in November 2014, showed that the social stigma surrounding dementia impedes early diagnosis, care and research into the disease. According to data in the report, people over the age of 55 fear being diagnosed with dementia more than any other condition and at least 1 in 4 people hide their diagnosis, citing stigma as the reason.

Human rights

Since the summit, the G7 countries have been working closely together to share their experiences, successes and innovations. They have worked with experts, such as the care policy teams at OECD and WHO and the United Nations Independent Expert on the enjoyment of all human rights by older persons, and leaders of global and national Alzheimer's organizations, to explore ways in which people with dementia can have a better quality of life, wherever they live.

Whilst changes across society need to happen at a local level, there are clear opportunities for global collaboration and learning to facilitate and accelerate this activity.

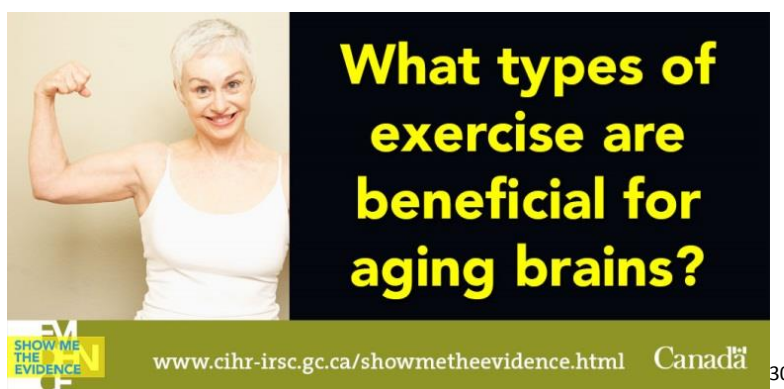
What has been achieved

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global and national Alzheimer's organizations, to explore ways in which people with dementia can have a better quality of life, wherever they live.

Risk reduction

Since adding risk reduction to its list of priorities in November 2014, the World Dementia Council has taken a leading role in calling for governments to adopt a risk reduction approach to dementia, including investing in further research to strengthen the evidence base linking modifiable behaviours such as physical inactivity, poor diet and smoking to dementia risk.



Care

The OECD and WHO have developed a framework to support countries in improving their policies for people with dementia. This builds upon an OECD review of dementia policies and includes the identification of ten key objectives, ranging from health services recognising and effectively managing people with dementia, to the potential of technology to transform dementia care which all countries may wish to consider when designing their approaches to dementia policy. Going forwards the intention is to develop a small cohort of metrics that will support global comparison.

Work is already underway to develop globally acceptable metrics to measure care. These are being developed from a number of sources, including the International Consortium on Health Outcome Measures (ICHOM), with whom the Scottish government have partnered to take forward work to frame global outcomes for dementia. This work is in collaboration with leading clinicians, policy makers and people living with dementia from across the world. The objective is to identify a small number of key outcomes that are framed from the experience of people living with dementia as a basis for improving their quality of life and which can be used in very different health and social care systems.

³⁰ Canadian Institute of Health Research

Technology and care

Technology is also growing as an innovative solution to meet care needs. Japan provides many examples of academia and industry innovating and collaborating, with relationships forged between firms and universities to develop new care solutions. The Japan Legacy Event played the role of showcasing technology, such as communication robots, assistive robots, and a robot suit.

Civil Society

The Global Alzheimer's and Dementia Action Alliance (GADAA) was launched in May 2014 with the aim of fostering global collaboration among international NGOs, professional associations, governments and international statutory bodies in an effort to coordinate actions and raise awareness about Alzheimer's disease and other dementias. This is the first global body to bring together government, health and social care sectors, non-profit organisations and wider civil society to tackle the challenge of dementia.



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There are now twelve organisational members of GADAA, representing a broad cross section of those with a role to play, with a further eight considering their position. This shows the level of support and enthusiasm, building on the three organisations who initially formed GADAA. Individual member organisations are developing at least one firm commitment or action they will undertake during 2015. An example is the commitment from Alzheimer's Disease International and HelpAge to work together to develop a programme to raise awareness in developing countries. GADAA have launched a website that will provide a mechanism to share learning and best practice and have established a social media profile.

³¹ Alzheimer's Disease International: Iran AlzheimerSociety

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Dementia friends

There has been a positive response to the Dementia Friends and Dementia Friendly Community programmes with learning being shared and new initiatives being developed in additional countries. For example, in September 2014, Canada announced its intention to launch its own Dementia Friends programme in 2015.

In February 2013, the UK PM launched England's Dementia Friends programme, run by Alzheimer's Society and Public Health England, with funding from the UK Cabinet Office and Department of Health. Dementia Friends aims to increase awareness and understanding of dementia by educating 1 million people to become 'Dementia Friends'. This was achieved in February 2015, with a new ambition set to educate an additional 3 million Dementia Friends by 2020.



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Japan has announced in its "Comprehensive Strategy to Accelerate Dementia Measures", that Japan will bring up to eight million Dementia Supporters (Dementia Friends) by the end of the fiscal year 2017. The target number was adjusted upward from six million according to the recent achievement of 5.8 million Dementia Supporters. Additionally, Japan will start advanced level lectures for Dementia Supporters to encourage them to voluntarily contribute to the creation of age and dementia friendly communities.

Human rights

The UN Independent Expert on the enjoyment of all human rights by older persons, Rosa Kornfeld-Matte, came into post in June 2014 and has actively sought to give priority to the human rights of persons with dementia as part of her mandate. Since then she has stressed the importance of protecting the human rights of those living with dementia on numerous occasions, and met representatives of local Alzheimer's Associations on the country visits that she has conducted so far. At the WHO Ministerial Conference on Global Action Against

³² Public Health England

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Dementia, the UN Independent Expert will call on countries to consider taking a human rights based approach to address dementia.³³

“Dementia should not be considered a normal part of ageing. Dementia is a disease, and can be the result of multiple factors. States and other stakeholders need to raise awareness and to adopt a human rights-based approach to protect the rights and dignity of all older persons with dementia.” UN Independent Expert on the enjoyment of all human rights by older persons, Rosa Kornfeld-Matte, 19 September 2014.

Risk reduction, care, stigma and human rights are all indelibly interlinked. All countries will have their own experiences, opportunities and challenges to make their society one that supports people with dementia. Work led by the G7 over the past year has framed a way of working and identified opportunities for further and wider engagement and learning.

³³ ‘Ensuring a Human Rights Based Approach to Dementia’, Background Paper Prepared for the World Health Organization Ministerial Conference on Global Action Against Dementia, March 2015.

G7 Key Achievements

Canada: Through the Sunnybrook Dementia Study, running since 1995, research is now suggesting the possibility that controlling risk factors like hypertension and high cholesterol could help prevent or delay forms of dementia. Scans have measured brain changes that can be linked to cognition and behaviour. In another project, technology has been developed to play a significant role in the care of people with dementia, using a mobile robot to offer assistance around the home.

France: To implement a process of integration through a network of partners involved in elderly care, assistance, or support, more than 500 MAIA (French acronym for Maison pour l'Autonomie et l'Intégration des malades d'Alzheimer) are being developed. The MAIA model comprises tools and mechanisms necessary to improve the integrated care process: in particular, case management for the elderly in complex situations.

To improve support at home, 500 Specialized teams organise tailored home support in terms of rehabilitation for subjects with mild-to-moderate dementia. For family carers, 2 days' training per year for carers are offered. About 18 000 family carers have been trained. An ambitious objective for training new professionals has also been set: 2070 occupational therapists and the creation of two new training qualifications: case managers (300) and gerontology care assistants (2500).

Germany: Germany has been making strides in care training, implementing a programme to train local community members. By the year 2016, Germany is to have up to 500 local alliances for persons with dementia located all over the country. The Federal pilot programme funded by the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth is intended to secure long-term improvements in the everyday life of persons with dementia and their relatives.

Italy: Living well with dementia has been addressed in the National Dementia Plan launched in October 2014. State & regions, in cooperation with the major Patients & Family Associations, have started to monitor its implementation at regional & local level. As for risk reduction, the specific reference to healthy lifestyles as a crucial tool for prevention of dementia has been included among the objectives of the "The National Plan 2014-2018".

Japan: Japan already has a three steps care practitioner training system, and will start the Basic Training for all newly appointed practitioners to enable them to acquire basic knowledge and techniques for dementia care. It is based on the idea that good health care and long-term care provided with the right understanding of dementia in a person-centred

manner could decelerate the progression of dementia and prevent the development of BPSD.

Japan has a variety of Neighbourhood-watch style networks specifically to look out for “wanderers”; people with dementia who become lost and confused away from home. One of the examples is “Hotto Anshin” (wandering) Network in Omuta city and an open house – “Suzu-no-ya” – scheme which is run by volunteers who offer local residents with dementia and their carers the weekly opportunity to access all-day care including lunch and tea. Japan has also started a special website for missing people with dementia which contains links to the proper website of each prefecture for missing or unidentified elderly.

United Kingdom: A better aware, educated and trained NHS and social care workforce: Over 437,920 NHS staff have already received Tier 1 (foundation level) dementia training[1] and more than 100,000 social care workers have received dementia awareness training. The College of Social Work is producing good practice guidance for social workers to improve the contribution that they can make in achieving best outcomes for people with dementia and carers.

Supporting better provision of post-diagnosis support: The government’s mandate to NHS England for 2015/16 includes a commitment to improve diagnosis, treatment and care for people with dementia.[2] This is supported by the government’s commitment that from 1 April 2015 everyone, including people with dementia, will be supported by a named GP with overall responsibility and oversight for their care. In February 2014 the Secretary of State for Health set out his ambition that everyone diagnosed with dementia should be offered high quality support after receiving a diagnosis of dementia. This may include personalised information, a dementia adviser, access to support services such as counselling and ongoing specialist care provided by specialist nurses. To support GPs and other primary care staff, an online Dementia Roadmap was launched in May 2014. The tool provides a framework that local areas can use to provide local information about dementia. It is aimed at assisting primary care staff to more effectively support people with dementia and their carers. People newly diagnosed with dementia and their carers are now able to sign up to a new email service on the NHS Choices website to get essential help and advice to support them to adjust to their recent diagnosis.

United States: The NIA supports an Alzheimer's Disease Education and Referral (ADEAR) Center to compile, archive, and disseminate information concerning AD for health professionals, people with AD and their families, and the public. As a public, U.S. Government-funded resource, the ADEAR Center strives to be a current, comprehensive, unbiased source of information about AD. All of its information and materials about the search for causes, treatment, cures, and better diagnostic tools are carefully researched and

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thoroughly reviewed by NIA and other scientists and health communicators for accuracy and integrity.

European Union: The EU Group of Governmental Experts on Dementia meets on a regular basis for policy exchanges and Alzheimer Europe is involved in the meetings.

5. Legacy events

Commitments 7 and 12 of the G8 Declaration outlined a commitment to hold a series of international events to maintain and build global momentum around dementia. Since the time that the Declaration was published, this ambition has been extended to include the first ever WHO Ministerial Conference on Global Action Against Dementia.

The Challenge

It was agreed at the G8 Dementia Summit that delivering the global challenge cannot be done by one country or one organisation alone. In order to build a sustainable platform from which to tackle dementia and in order to build sustainability it requires coordinated international cooperation and effort, in particular involvement of low to middle income developing countries as well as non-government sectors.

What has been achieved

The G7 countries, along with the OECD, EC and WHO have worked together to ensure that there is a legacy from the summit. Key to maintaining a momentum has been a series of legacy meetings and events during 2014 and 2015. These have provided an opportunity to focus in more detail on key themes from the Declaration and to develop more robust strategies for countries to work together to make a difference for people with dementia.

There have been five events. Each has targeted a different sector of the dementia community and focused on specific elements of the dementia challenge.

London Legacy Event, June 2014 – Finance and Social Impact Investment:

At this first legacy event, world health and finance leaders were brought together to investigate ways to unlock new investment for dementia research. They discussed the global challenge of dementia, barriers to investment in dementia research, ways we can increase investment in innovation and the financial mechanisms that can be harnessed to increase investment, including the potential for a global private and philanthropic fund for dementia.



Speaking at the summit, UK Prime Minister, David Cameron, said that immediate action was needed to address a market failure on dementia research and drug development, which had seen global spending on dementia at five times below research on cancer, with only three drugs making it onto the market in the last 15 years.

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The event brought together the dementia community for the first time since the summit and they heard about the visions and priorities of the World Dementia Envoy, Dr Dennis Gillings CBE and the role of the World Dementia Council.

Joint Canada-France Legacy Event, Ottawa, September 2014 - Harnessing the Power of Discoveries: Maximizing Academia-Industry Synergies:

At the second in the series of events, nearly 200 industry leaders, academia, and policy makers met in Ottawa, Canada, to discuss creating better partnerships between academia-industry, and how to facilitate innovation in dementia strategies for treatment, care and risk reduction. The event was co-hosted by Canada and France through the Canadian Institutes of Health Research (CIHR) and the French National Alliance for Life and Health Sciences (Aviesan).

The event brought together key players to achieve three main goals:

- To explore collaborative opportunities for research into novel diagnostic, pre-emptive, and therapeutic approaches to dementia by bringing together academia and industry.
- To improve understanding of the impact of the paradigm shift in pharmaceutical research on the development of new drugs against dementia and find appropriate incentives to engage the medical device and information technology (IT) industries in this field.
- To foster a collective approach to problem solving through the pooling of resources and the sharing of cohorts, data, and best practices.



"The impact of dementia on individuals, caregivers, families, and national economies is significant. Our government is providing national and international leadership in dementia that will lead to prevention, treatment, research and better care for people living with dementia. We must continue to work together to stem the tide and improve our understanding of these conditions, to alleviate the suffering it causes. I applaud organizations like the Alzheimer's Society of Canada for the work they are doing and look forward to bringing initiatives like *Dementia Friends* to Canada." The Honourable Rona Ambrose, Minister of Health, Canada.

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The ideas that came forward from the discussions in Ottawa will contribute to the development of an action framework for addressing the existing environmental challenges and barriers to fostering collaborations between academia and traditional and non-traditional industrial players in this field—including regulatory barriers that interfere with the ability of G7 countries to work together effectively to share ideas, data, platforms, and discoveries related to dementia research.

Japan Legacy Event, November 2014 – New Care and Prevention Models:

Over 300 Experts in dementia care and risk reduction met in Japan for the third Global Dementia Legacy Event. Prime Minister Shinzō Abe highlighted the importance of dementia care provision and the commitment of the Japanese government to take global action against dementia.

In response to this, Japanese Government launched “Comprehensive Strategy to Accelerate Dementia Measures” (New Orange Plan) in January 2015.

Sessions covered dementia friendly communities, Dementia Friends (originally launched in Japan as Dementia Supporters), innovative care solutions using information and communications technology (ICT) such as robotics and bio-computers, the importance of person centred care, prevention and risk reduction and the conclusions from the 2014 World Alzheimer Report ‘Dementia and Risk Reduction’. G7 countries also presented, in a dedicated session their National policies and strategies.



“Rather than only consider how to provide care, we should also look to provide support so these people can live better lives with dementia, addressing the issue from their perspective. This is the type of society our Cabinet is aiming realise, where one can tackle any challenge. We will do our best to enhance support at the earlier stages of dementia, working with teams of health care professionals and long term care specialists”. Prime Minister Shinzo Abe, Japan.

The Organization for Economic Co-operation and Development (OECD) launched 'Dignity in Dementia: How better policy can improve the lives of people with dementia'. The report states that dementia is the fastest growing cause of disability in the world today, and emphasises the need to develop and implement policies to improve dementia care, and to share learnings with the international community.

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A key message from the conference was that dementia could potentially be seen as a preventable condition, or at least one where onset might be delayed, and should be included in public health initiatives to reduce risks of chronic diseases like diabetes, cancer and cardiovascular diseases.

Along with the message, Japan is planning to start Nationwide Prospective Dementia Cohort; finding out risk factors and protective factors, and establishing effective prevention strategies in the community.

Italian EU Presidency event, November 2014 - Dementia in Europe

As holders of the rotating presidency of the EU, Italy hosted a Conference on Dementia in Europe. They built on the messages and priorities from the Global Dementia programme and aligned them with activity in European countries. The Italian Under-Secretary Vito De Filippo announced the first Italian national dementia plan.

US Legacy Event, February 2014 – Research

On February 9-10, 2015, the National Institutes of Health held a second Alzheimer's Disease Research Summit, designed to continue the development of an integrated multidisciplinary research agenda necessary to address critical knowledge gaps and accelerate the discovery and delivery of efficacious treatments for AD patients at all stages of disease. Key to achieving this goal is the identification of resources/infrastructure and multi-stakeholder partnerships necessary to successfully implement this research agenda and strategies to empower patients and engage citizens. On the day following this Summit, the US hosted a meeting in Washington, bringing together senior representatives from the G7 dementia research community, as well as international organizations, to discuss integrated development, the tracking of research from a global perspective, research spending, the engagement of participants in research, as well as critical areas for future collaborations.

Following the G7 Research meeting the UK Medical Research Council, working under the banner of the EU joint research programme agreed to develop a single global inventory of population studies and disease-focused cohorts so that researchers have access through one portal to the information they need. At the same time, the United States of America and the International Alzheimer's Disease Research Portfolio will provide a comprehensive and up to date registry of all clinical research including clinical trials. Both these initiatives will build and coordinate the global effort to advance dementia research.

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The World Health Organization first Ministerial Conference on Global Action Against Dementia

WHO is hosting the first ever WHO Ministerial Conference on Dementia, in partnership with OECD and the UK Department of Health, on 16 and 17 March 2015 as a result of the momentum that has been built over the past year.

The WHO conference marks an important transition for Global Action Against Dementia work. To date, while some non-G7 countries have been tackling dementia at a national level and a number of countries have engaged with the WDC and the Global Action Against Dementia programme, the work has primarily been led by the G7. At the WHO conference, it will expand to become a worldwide coalition. Dementia is not a problem faced by the G7 alone, it is a global problem which requires a truly global response.

The objectives of the conference are:

- To highlight evidence relating to the global burden and impact of dementia on health and socio-economic outcomes.
- To encourage governments worldwide to take action to prevent dementia and improve care services, based on current scientific knowledge, available evidence and global experience.
- To discuss the importance of measuring dementia care and monitoring progress.
- To stress identifying cures or disease-modifying therapies for dementia.
- To emphasise the need for increased investment in research.
- To review global actions undertaken between December 2013 and March 2014 and explore possibilities of supporting global cooperation and to move from commitment to action.

The conference will celebrate the achievements since the G8 Summit and will act as a platform from which to launch the new structure of Global Action Against Dementia.

6. Strengthening Global Leadership

Change happens when leaders provide clarity, present a visionary and rational case, act as role models, mobilise their own people and embed the vision in their own action orientated objectives. Commitments 1 and 8 of the G8 Declaration highlight that dementia needs to sit further up the global health agenda. They call on influential individuals and organisations to come together to identify dementia as a growing global threat and to support governments in their work on improving dementia care and services, as well as finding a cure or disease-modifying therapy.

The Challenge:

When the world has faced catastrophic challenges before, nations have marshalled significant resources behind clear goals and objectives to achieve great things. A decade ago, the world committed to an ambitious, aggressive and well-funded effort to prevent and treat HIV/AIDS, tuberculosis and malaria. Ten years later that effort has paid significant dividends in terms of lives saved and economic development fostered. Global



governmental organisations, multilateral government organisations, the private sector and NGOs have become increasingly alarmed by the predictable public health, fiscal and economic impacts of an ageing population and in particular, Alzheimer's and dementia, a disease that Professor Piot, head of United Nation's global AIDS effort, has compared in scope to the HIC/AIDS crisis. As a result, there was a need to call this problem to attention of leaders and experts across the world and to embrace a similar global effort to stop Alzheimer's and dementia

What has been achieved:

As part of its Presidency of the G8, the UK led an all-out global fight-back against dementia: a summit in London on 11 December 2013 brought together for the first time ever health and science ministers from all the G8 countries, international experts and researchers, leaders of the global pharmaceutical industries and the OECD and the WHO to accelerate progress towards effective treatments and cures. It was agreed that delivering this global challenge could not be done by one country or organisation alone and instead requires coordinated international leadership, cooperation and effort.

On 28 February 2014, the UK Prime Minister David Cameron announced the appointment of Dr Dennis Gillings as the World Dementia Envoy. Dr Gillings has since created a World

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Dementia Council, whose purpose is to provide global advocacy and leadership on the key challenges posed by Dementia.

The World Dementia Council announced the appointment of Hilary Doxford as a member on 29 January 2015. Hilary was diagnosed with early onset Alzheimer's Disease in 2012. Speaking about action against dementia she said: 'If you are in a position where you have the power to make change, or can influence those that do, then surely you do not need to go beyond considering the economics of dementia and the impact of your decisions to see what must be done.'

The World Dementia Council, now consisting of 19 high-calibre members from a number of countries from across the world, representing a range of expertise and disciplines, including research, the pharmaceutical industry, finance, academia and a member who has early onset dementia. The Council has identified five areas of focus:

- Promoting integrated development and accelerating the pathway of medication from research to market.
- Increased research budgets and financial incentives.
- Encouraging a culture of open science and shared access to data.
- Improvements in care and support.
- Encouraging a risk reduction approach to dementia.

Details of progress made so far on each area is set out in the WDC year-on report, presented to the WHO Conference and is also covered in this report.

"Dementia is a global challenge and a public health priority. WHO is ready to step up to this challenge." Margaret Chan, WHO Director General.

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A network of Young Leaders has been established to support the work of the World Dementia Council and the Global Action Against Dementia programme. The UK Science and Innovation Network have organised a series of meetings in Canada, Japan, the United States and the United Kingdom to bring together young leaders to develop innovative ideas on fighting dementia and to create a sustainable global network which will continue to address the challenges posed by dementia. The Young Leaders will be contributing a report of their work to the WHO Conference, covering innovation across the breadth of the global dementia programme.



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“Being involved in Dementia Advocacy work on a global scale with the UK Science and Innovation Network has been a life changing experience. Often we get caught up in our own independent silos of dementia work and miss out on the bigger picture. Through my involvement in the Young Leaders in Dementia initiative I have been able to branch out across all sectors and meet other like-minded, dementia obsessed, young professionals across the entire globe! I am thrilled to be connected with these truly inspiring emerging leaders in dementia and am excited about the impact we will have on the future of dementia action and progression” Laura Booi, PhD student in Gerontology, Simon Fraser University, Vancouver Canada, February 2015.

Support for Global Action Against Dementia has been strongly led by the WHO and OECD. Both organisations have undertaken significant work to progress a number of the Declaration Commitments and they have supported and advocated the work programme. Speakers from WHO and OECD have presented at each of the Legacy events to date and both organisations have observer status at World Dementia Council meetings. WHO and OECD have played a crucial role in supporting the spread of the programme beyond the G7 to the rest of the world.

³⁴ Canadian Institute of Health Research

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“The combination of our global reach, and ability to bring multiple perspectives, other partner international organisations, business and civil society, to the same table with governments, gives us all an excellent platform for doing the work that needs to be done. We look forward to working with international leaders, the research community and business, so that together we can ensure that in the future, dementia is no longer a disease to fear.” Yves Leterme, OECD Secretary-General.

While Commitment 8 called upon the WHO and the OECD to support Global Action Against Dementia, multinational support has actually extended beyond these two organisations alone. Regular Working Group meetings with the European Commission (EC) have ensured synergies between work that is being undertaken across the G7 and within Europe. The World Economic Forum has provided a platform for multi-stakeholder dialogues featuring dementia in the programme of their key events such as the Annual Meeting at Davos.

‘To succeed in the fight against dementia, countries need to join forces. Since 2009, working together on dementia is a priority for the EU. This has led to successful collaboration and coordination actions between EU-Member States and significant financial support for dementia research.

It is with great commitment and pleasure that the European Commission contributed to the implementation of the G7-initiative Global Action Against Dementia during the past year.’ Ladislav Miko, Acting Director-General Health and Food Safety, European Commission.

Leadership has come from many perspectives and levels. There is no one leader and the strength of this work has been in working together - in collaboration and sharing. The UK has provided a facilitative role, using the momentum from the Summit and building networks across the G7. Individual countries have hosted specific events, taking leadership for specific policy areas and challenges. This way of working is now well embedded and the G7 are optimistic about its continuation for the future, with wider involvement from countries around the world.

‘In many societies characterized by longevity, the number of people who will contract dementia is rising. They live in our families, neighbourhoods and communities. There is a need for action in many areas: Better cure, care and support, well organized and funded research, international exchange of best practices and approaches. The Global Action Against Dementia has successfully addressed these fields of action and has brought about a new attitude of how to face the global social challenge of dementia.’ Mr. Hermann Gröhe, Federal Minister of Health, Germany.

G7 Key Achievements

Canada: In September 2014, the Government released its National Dementia Research and Prevention Plan, which outlines the majority of federal efforts in these areas. In October 2014, Canada's health ministers agreed to collaborate on the coordination of research to advance the collective knowledge base on dementia, and to begin planning on a pan-Canadian dementia strategy.

France: In September 2014, France published the fourth iteration of the national dementia strategy prioritising clinical research for future investment.

Germany: In September 2014 the German Dementia Alliance launched "together for people with dementia" laying the foundation for a national dementia strategy. It brings together public agencies and civil society organisations, including self-help groups, who work to support people with dementia on a federal, state and municipal level, and pools the forces of all responsible stakeholders. The goal of the Alliance for People with Dementia is to improve the quality of life of them and their families, and preserve their prospects for the future.

Italy: Several regional plans are already in place and in October 2014, Italy launched its first ever National dementia strategy, focusing on a public health approach to dementia, strengthening the integration of services, promoting quality care and fighting against stigma.

Japan: In January 2015 Japan launched "Comprehensive Strategy to Accelerate Dementia Measures" (new Orange Plan) led by Prime Minister Shinzo Abe. The plan holds three foundational pillars such as an integrated community care system, age and dementia friendly communities, and prioritisation of the standpoint of persons with dementia and their families. Japan thinks highly of preventive approaches to dementia which range from primary prevention to prevention of acute exacerbation of BPSD.

United States: The United States Government first issued a National Plan to Address Alzheimer's Disease in 2012. The U.S. has updated its plan – and accompanying milestones – annually, with the next updated anticipated in May 2015. The Plan establishes five ambitious goals to both prevent future cases of Alzheimer's Disease and to better meet the needs of the millions of American families currently facing this disease. These goals focus on improvements in prevention/treatment, care, support, public awareness and engagement, and tracking of progress.

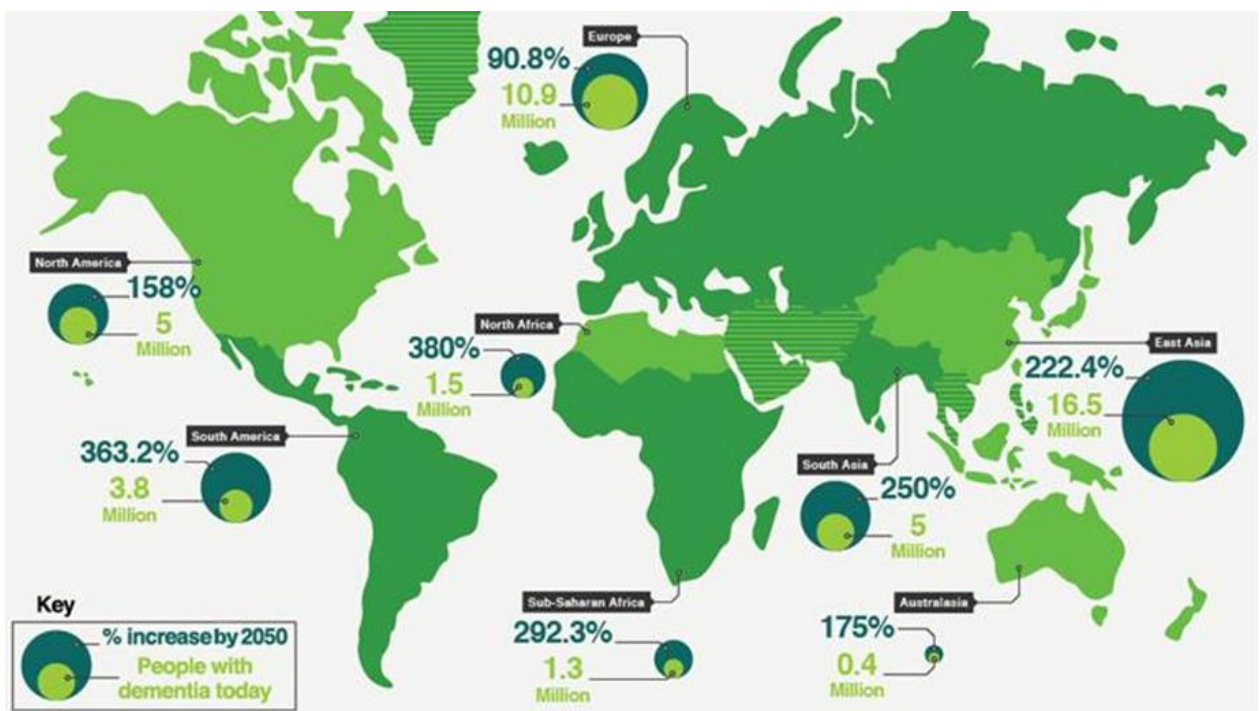
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United Kingdom: On 21 February UK Prime Minister David Cameron launched his challenge for the next five years on dementia to 2020, which outlines ambitions to boost research, improve care and increase public awareness.

European Union: A new European Joint Action on dementia under the EU-Health Programme is being prepared, to be led by Scotland on behalf of the United Kingdom.

7. The way forward

The 2013 G8 Dementia Summit represented a significant moment in launching a period of intensive and collaborative work across the G7 countries and beyond, towards both improving the way that people with dementia are cared for around the world and finding a cure or disease-modifying therapy by 2025. New alliances have been formed and ideas have turned into action. The World Dementia Council has proven to be a key driving force, bringing together experts from all fields and from around the world. The World Dementia Envoy has led the movement and his commitment and drive have galvanised global action. Support from the most senior levels in governments and national and multi-national organisations, not least from WHO DG Margaret Chan, will ensure that the impact of this work is lasting and that it reaches out to a diverse set of global stakeholders beyond the G7 countries.



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Dementia is a disease that affects everyone; it does not recognise boundaries, borders, wealth or social and cultural status. It is having, and will continue to have, significant global socio-economic impact. This is one of our biggest global health and care challenges; a challenge as big as the fights against HIV/AIDS, cancer and heart disease. No one country or society is immune from it; and no one country, organisation or sector can tackle this alone.

³⁵ 'The Global Impact of Dementia 2013–2050', Alzheimer's Disease International (December 2013).

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There is a broad consensus that the momentum created since the G8 Dementia Summit should be accelerated, expanding the ambition and breadth of the global effort – a response that is equal to the challenge faced.

The leadership shown by the UK government in launching the G8 summit in December 2013 and advancing the commitments made there between December 2013 and March 2015 are historic. Collaboration across countries, organisations and sectors has been critical in creating momentum to date and in future years will be seen as catalysing a global solution to the global challenge of dementia. Going forward, global leadership will be crucial in building and fostering collaborations and alliances between all stakeholders to drive forward and accelerate improved care and treatment; stimulate research; and to nurture and utilise expertise to maximum effect and win the battle against this devastating disease.

Annex A

The 12 Commitments

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

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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.

Annex B

Achievements

- **Integrated Development-** 11 regulators have been brought together for the first to discuss the development of dementia drugs through the regulatory pathway.
- **CCNA** launched September 2014.
- **'Join dementia research'** register launched in July 2014 in UK to seek to increase number of dementia patients involved in studies to 10% by 2017.
- **\$80 million** earmarked for NIA, the majority of which will be directed into Alzheimer's research, in accordance with US National Alzheimer's Plan.
- A new **Joint Action** under the EU Health Programme is under preparation.
- A **Citizen Science** platform is being developed to offer people living with dementia and their carers to actively participate in dementia research.
- In December 2014 the UK Government announced plans to invest **£15** in a public-private fund to stimulate and increase investment in dementia research.
- Alzheimer's Research UK launched a new **£100 million research campaign**; this builds on the announcement made last year by the Alzheimer's Society to spend at least £100 million over the next 10 years on dementia research.
- The **EPAD** research initiative was launched in Paris on 15 January 2015. Similar initiatives are emerging in the US and Canada.
- The **EPAD-GAP analysis** aims to develop infrastructure that efficiently enables the undertaking of adaptive, multi-arm Proof of Concept studies for early and accurate decisions on the ongoing development of drug candidates or drug combinations.
- In January 2015 the **JPND** called for collaborative research proposals on longitudinal cohort approaches, advanced experimental models, and risk and protective factors in neurodegenerative diseases for a total value of EUR 40 million.
- **AMP** will be a five-year endeavour, beginning in 2014, which has a budget on \$129.5m to carry out a bold, milestone-driven research plan for dementia.
- CEOi and Optum Labs announced a major **Big Data project** with the intention to build a global centre of excellence in Big Data.

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- **\$22 million** earmarked for Alzheimer's Disease education, outreach, and caregiver support in US.
- UK reached **1,000,000 Dementia Friends** in February 2015.
- **Human Rights** - UN Independent Expert on the Human Rights of Older People, Rosa Kornfield-Matte, demonstrated her commitment to the GAAD programme, stressing the importance of states adopting a human rights based approach when addressing the concerns of older people with dementia.
- **IMI2**: The total budget for the IMI 2 programme is **€3.276 billion**.
- **UKDP**: Announced on 19 June 2014. This is a £16m industry-partnered programme, comprising £12m from MRC and £4m from six industry partners from the biopharma sector, along with eight universities.
- Establishment of **EC-GAAD** working group - A European Commission-UK Working Group on Dementia has been established. The group has the mandate to explore the ways in which the Commission could make contributions to the implementation of the G7 work on dementia and to seek areas where there are synergies in our work.
- **WHO & OECD** have been key partners supporting the legacy events and fulfilling an advisory role in relation to the World Dementia Council and have taken a lead on some specific pieces of work.
- Successful support of the **World Dementia Envoy** and **World Dementia Council** - following the PM's appointment of the first World Dementia Envoy on February 28th, the Global Action Against Dementia Team has successfully supported the Envoy in numerous international visits including the US and Australia.
- On 21 February 2015 UK Prime Minister David Cameron launched the next phase of the UK's long-term strategy on dementia, outlining plans to boost research, improve care and increase public awareness over the next five years.
- The US Held a Summit in 2015 to review progress against their national Alzheimer's plan and to identify milestones on their path to 2025.
- Italy: Launched its first ever dementia strategy in November 2014, focusing on a public health approach to dementia, strengthening the integration of services, promoting quality care and fighting against stigma.
- Japan: Launched a new Orange Plan, replacing their old national dementia strategy early.

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- Germany: In September 2014 the German National Alliance launched 'together for people with dementia' laying the foundation for a national dementia strategy.
- France: Published 4th iteration of national dementia strategy in September 2014, prioritising clinical research for future investment.
- Canada: Now has an effective framework to address dementia within its national jurisdictions.

Annex C: Acronyms

CCNA	Canadian Consortium on Neurodegeneration and Aging
EC	European Commission
EMIF	European Medicines Informatics Framework
EPAD	European Prevention of Alzheimer's Dementia
GAAD	Global Action Against Dementia
GADAA	Global Alzheimer's and Dementia Action Alliance
GAAIN	Global Alzheimer's Association Interactive Network
GAP	Global Alzheimer's Platform
ICHOM	International Consortium on Health Outcome Measures
JPND	Joint Programming Initiative on Neurodegenerative Diseases Research, in particular Alzheimer
LMIC	Lower-Middle-Income Countries
LORIS	Longitudinal Online Research and Imaging System
MRC	Medical Research Council
NGO	Non-Governmental Organisations
NIA	National Institute on Ageing
NIH	National Institute on Health
NIHR	National Institute for Health Research
OECD	Organisation for Economic Co-operation and Development
R&D	Research and Development
UN	United Nations
WHO	World Health Organization

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