

THE WORLD DEMENTIA COUNCIL'S YEAR-ON REPORT 2014/15



Contents

	Page
1. Summary of WDC Recommendations	3
2. Foreword from Dr Dennis Gillings	5
3. The Global Dementia Challenge	7
4. The World Dementia Envoy and Council	8
5. Finance	10
6. Global Integrated Development	12
7. Open Science and Data	14
8. Care	17
9. Risk Reduction	19
10. What Next for the World Dementia Council?	21
Annex A WDC Pen Pictures	22
Annex B WDC Terms of Reference	35

1. Summary of WDC Recommendations

Finance

- ❖ The World Dementia Council calls on all governments to significantly and rapidly increase investment in dementia research for care, treatment and prevention. The Council particularly calls on the G7, who committed to such increases in their December 2013 Declaration.
- ❖ The Council wishes to see within the next year an urgent examination of how payment and reimbursement policies and other incentives are impacting on investment decisions and how these could be adapted to accelerate the development pipeline whilst ensuring affordable access.
- ❖ The Council wishes to see a robust proposition for innovative funding mechanisms for other stages of the drug development pathway, e.g. for late stage assets, including an in-perpetuity mechanism.

Integrated Development

- ❖ The Council calls upon governments and regulators around the world to commit to continue to work collaboratively and speedily to support the UK's critical effort on Global Integrated Development.
- ❖ The Council wishes to see within the next year a complementary programme of activity developed to address affordable access to new dementia drugs over the coming months. Health technology assessment bodies and payer organisations will need to be consulted.

Open Science and Data

The World Dementia Council is keen for OECD and its partners to pursue at pace the following approaches to strengthening cooperation among existing data initiatives, so that within the next year there is success against:

- ❖ a survey of existing successful multinational approaches to identifying best practices and the common data elements that might underpin future studies;
- ❖ more demonstration cases spanning geographical regions and a range of data areas; and
- ❖ a minimum set of principles and examples of best practice for funders and associated government agencies.

Care

- ❖ The World Dementia Council advocates that improvements to dementia care globally always include the views of individuals with dementia and their carers, consider the potential opportunities of technology and seek to demonstrate improved outcomes.

- ❖ The Council would like to see within one year significant progress on the development of a proposal to coalesce international collaborations on dementia care, specifically focusing on supporting the ongoing spread of learning, supporting the use of outcome metrics for governments, organisations, and individuals, and providing a sustainable model of collaboration as part of the ongoing global action against dementia.
- ❖ The Council is convinced of the urgent need to see a cost-benefit analysis on short-term investment in different forms of technology to identify the potential returns over a three, five and ten-year basis.

Risk Reduction

- ❖ The Council encourages governments around the world to take action on dementia risk reduction, by:
 - (i) embedding dementia risk reduction/management in to their public health policies and campaigns and their non-communicable disease strategies and action plans, as some countries are already doing; and/or
 - (ii) urgently investing in further research in this area, including running population-level intervention studies, to build the evidence base on dementia risk reduction.
- ❖ The Council would like to see countries and other interested stakeholders work collaboratively to produce a common set of dementia risk reduction messages, along the lines of the UK's *Blackfriars Consensus Statement on Dementia Risk Reduction*. This may help to make a stronger case for a risk reduction approach to dementia to be explored in those countries that have not yet fully recognised its potential through its dementia, public health or non-communicable disease strategies, including the need to increase the evidence base.

2. Foreword from the World Dementia Envoy



I am very pleased to be introducing the World Dementia Council's Year-On Report, covering April 2014 to March 2015. Progress has been made against our five priorities, and the report sets this out. Equally, the Council is under no illusion that the achievements of the last year go more than part of the way towards truly tackling dementia and that, therefore, there is a huge amount to do. Throughout the report we have made recommendations for further action. We believe that these are critical to not only continuing, but accelerating, the global momentum of the last year.

A commitment to support the UK Government to appoint a World Dementia Envoy was made at the G8 Dementia Summit in London in December 2013 and I was delighted to be asked to perform the role by the UK Prime Minister, David Cameron. To help me to tackle my challenging remit, which was to help to stimulate innovation around development of treatments and care for people, I then formed the World Dementia Council. Over the past year, our focus has widened.

On the Council, I have worked alongside a broad range of international experts from academia, the research community, the pharmaceutical industry, finance, medicines regulation, patient advocacy and, critically, a person living with dementia. We have brought these perspectives to our roles as advocates and champions for global efforts to tackle this terrible, life-shattering disease. Many of us, myself included, have direct personal experience of the impact of dementia on loved ones, driving us forward; but the views of people with dementia, and their families and carers, need to be routinely included in conversations about how to improve dementia prevention, diagnosis, treatment and care.

In addition to the acute personal cost of dementia, the Council is also well aware of the huge financial cost to health and social care systems. The figures are staggering; by 2050, 135 million people around the world will have dementia. In 2010, the global cost of dementia care was estimated at US \$604 billion. Based on current estimates, this figure is expected to rise to an extraordinary US \$1 trillion by 2030. We simply can't afford to do nothing; governments cannot afford to do nothing.

The truth is that we need to do far more, far faster, if we are to avert the projected global burden of dementia becoming unsustainable. Despite all the efforts of the last year, the Council members and I still don't see the necessary degree of urgency from governments. There is a pressing need to act decisively to accelerate the development of effective

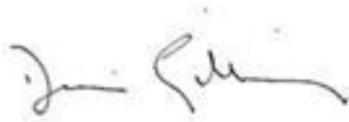
treatments; improve care and support for carers (including investment in technology); and to make dementia risk reduction a global priority. Underpinning these challenges is the simple fact that we still don't understand the disease; and the investment in basic science is still wholly insufficient to combat this.

Time is running out.

While I remain hopeful that these challenges can be addressed, now is not the moment to step back from the fight. During the past year, I have been struck by the many people I have spoken to around the world who have remarked on this increased focus on dementia. We need to continue to build on the momentum that the UK Government's leadership has created, both in G7 countries and far beyond.

The World Dementia Council has played a key role in building this momentum by encouraging, supporting, debating and providing steers on many of the most important global issues and initiatives. However, our judgement set out in in this report, is that we have to go much further, which is why we have identified these challenging recommendations for future action.

The global efforts to tackle dementia over the past 18 months should be just the first step in a global collaboration to solve a global problem. I urge all governments and dementia organisations to join with and respond to the continuing global fight-back against this wicked disease.



Dr Dennis Gillings CBE
World Dementia Envoy

Readers should note that the Council is one part of a wider Global Action Against Dementia programme that was developed to deliver the 2013 G8 Declaration commitments. A one-year report documenting progress against the wider G7/global dementia deliverables has been produced to sit alongside the WDC one-year report, and the two reports should be read in tandem.

3. The Global Dementia Challenge

What is dementia?

The term “dementia” describes a set of symptoms that include loss of memory, mood changes and problems with communicating and reasoning. These symptoms occur when the brain is damaged by certain diseases, such as Alzheimer’s disease or a series of small strokes. 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; many people have a mixture of the two.

Dementia is a progressive condition, so symptoms become more severe over time. This means people with dementia and their families have to cope with changes such as a reduced capacity to make decisions about major life events as well as day-to-day situations.

The impact of dementia now and in the future

Dementia is a growing, global challenge. It is one of the most urgent health and care issues the world faces. The condition affects more than 47 million people worldwide, a number that, according to WHO, is expected to reach 75 million in 2030 and 135 million in 2050, as the population ages.

There has been very little success to date in finding a cure or a disease-modifying treatment - only three new drugs have entered the market in the past fifteen years. The financial cost is vast, with dementia now one of the largest pressures on national healthcare systems. It costs an estimated US\$604 billion annually, about one per cent of the world’s GDP. Without urgent global action this will only rise.

2013 G8 Dementia Summit

As part of its Presidency of the G8 (which is now the G7), the UK hosted an international summit on dementia in London on 11 December 2013. It brought together health and science ministers from all the G8 countries, international experts and researchers, leaders of the global pharmaceutical industries, the Organisation for Economic Co-operation and Development (OECD) and the World Health Organization (WHO).

It was agreed that accelerating progress towards effective treatments and cures cannot be done by one country or organisation alone but instead requires co-ordinated international cooperation and effort.

The G8 signed up to an agreed vision for international collaboration on dementia and a series of high level actions set out in a Declaration and Communiqué:

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

4. The World Dementia Envoy and Council

World Dementia Envoy and Council

On 28 February 2014, the UK Prime Minister David Cameron appointed Dr Dennis Gillings as the first World Dementia Envoy, for an initial period of twelve months.

Dr Gillings has since created a World Dementia Council (WDC) to provide global advocacy and leadership on tackling the key dementia challenges. The Council currently has nineteen high-calibre members from a number of countries across the world, representing a wide range of expertise and disciplines, including research, the pharmaceutical industry, finance, academia and patient advocacy, and one member who has dementia. Members' pen pictures are included at **Annex A**.

WHO and OECD have actively participated in all four of the Council's meetings, in a non-member technical advisory capacity, and more recently the European Commission has taken on a similar role. The Council thanks those organisations, and a number of other guest speakers and attendees who have attended one or more of our meetings, for their excellent contributions to its work.

Council's Terms of Reference

The Council's Terms of Reference, agreed at its first meeting in London in April 2014 and subsequently updated, are at **Annex B**.



Source: OECD/Hervé Cortinat

WDC priorities

The WDC met four times during 2014/2015: in London in April and October 2014, in Paris in July 2014 and in Bethesda, near Washington DC, in February 2015.

Following the 2013 G8 Dementia Declaration, the Council was formed to work together to promote new incentives to correct the market failure in dementia research and drug development and push to find a cure or a disease-modifying therapy by 2025. While there

was already a number of relevant strands of work going on around the world at the time of our formation, we set out to create an environment to consider market mechanisms and tools of finance that if aligned could expand, extend and achieve success more quickly.

To achieve this, we prioritised our efforts in the following **three priority areas**:

(i) **Finance:**

To address the lack of public and private investment in dementia drug research, the Council proposed a new financing structure that would catalyse private investment and thereby adjust the risk-reward ratio in favour of greater innovation and investment. This would include a unique partnership between government and industry to help invigorate the financial climate around dementia drug development.

(ii) **Global Integrated Development:**

We agreed that encouraging new finance would not be enough in its own right if other important areas were not also addressed. Therefore, we committed to supporting the assessment in which the regulatory pathway could be used to accelerate drug development efforts.

(iii) **Open Science and Big Data:**

Access to and the sharing of joint data between stakeholders is needed. The Council agreed to support global efforts to build single inventories of research activity and databases to overcome barriers to data sharing, or where the required data are not publically available such as with company data.

The Council agreed that prioritising the above three areas in parallel was critical in order to stimulate innovation and act as a catalyst for the changes that are needed to tackle dementia. Promoting global integrated development, accelerating the path of medicines from research through to market; increasing public and private sector funded research budgets; and encouraging a culture of open science, so unleashing the enormous potential for sharing information and knowledge, were all essential components of our strategy to help create incentives to achieve the 2025 ambition.

With work on cure underway, our attention then turned to those for whom that cure would come too late and to those who might be able to delay onset of dementia or possibly avoid the disease completely. Therefore, at later meetings, we agreed that we should also add a **fourth priority**; focusing on **improvements in care** for the millions of people already living with dementia around the world while we await the breakthrough cure or disease-limiting therapy. Most recently, we agreed a **fifth Council priority**; encouraging a **risk reduction** approach to dementia which, at this time, offers the only realistic hope of delaying onset and possibly reducing prevalence.

The following chapters set out the WDC's analysis of the challenge, our commentary on the progress that has been made across the G7 to date (including where the Council has offered steers, insights and leadership), as well as our challenge for greater progress through a number of recommended next steps, that are also listed together on pages 3 and 4.

5. WDC Priority Area: Finance

The challenge

Significantly increasing investment into dementia drug development is a key part in expediting the journey towards a cure for dementia. The World Dementia Council is clear that the relative lack of investment is a damning reflection of the low priority accorded to dementia and a significant impediment to improving treatment for dementia: yet we all know that unless this is meaningfully tackled, dementia itself will remain a growing global issue. Indeed, tackling this challenge was one of the main reasons that we came together as a Council. We believe there is huge scope for innovative funding solutions which have hitherto been unexplored.

WDC analysis of progress

The Council was encouraged by a presentation at our third meeting by JP Morgan on the results of a market-scoping exercise (commissioned by the UK Department of Health) which set out three possible funding options for the Council to consider endorsing. JP Morgan's findings suggested that focusing our efforts on increasing investment in the pre-clinical space had the greatest potential at this time to impact on the drug development pipeline.

Investing in the pre-clinical space offers the possibility of both exploring new molecule hypotheses, and supporting innovative asset development. We are persuaded that this could potentially improve the likelihood of a cure or a disease-modifying treatment being found by 2025, which is a 2013 G8 Summit commitment. We also believe a pre-clinical investment could usefully draw from the work of academia and biotech and pharmaceutical companies that has in turn been stimulated by increased funding for new and pioneering areas of research, leading to a resultant widening of the pipeline for future drugs going into phase I and phase II trials.

The Council unanimously endorsed the proposal for the establishment of a pre-clinical fund. With this in mind, the UK Government has driven fund development work forward, exploring options in more detail with potential investors since the third Council meeting.

In February 2015, the UK Government confirmed it had come together with investors from the private and philanthropic sectors to establish a multi-million pound fund for pre-clinical research, which includes a £15 million UK government contribution and we look forward to further updates on the fund's progression.

WDC commentary

The World Dementia Council welcomes the development of a public/private pre-clinical fund: we are relieved to see some innovative approaches to funding dementia drug development. However, we are clear that this is only one important potential solution to the much wider lack of investment.

It is absolutely vital that governments and other stakeholders continue to increase research funding - including on the basic science - translational research and implementation research across cure, care and risk reduction. The Council believes governments, industry and others have a responsibility to rapidly explore other innovative ways of stimulating investment.

The Council would like to see a rapid exploration of further public/private partnerships which address different stages of the drug development process (specifically pre and post proof of concept), creating a funding pipeline which is ready to take forward successful outputs of the pre-clinical fund. We would also like to see a wider range of financial products, perhaps including crowd funds and bond structures.

WDC recommendations for further action

- ❖ The World Dementia Council calls on all governments to significantly and rapidly increase investment in dementia research for care, treatment and prevention. The Council particularly calls on the G7, who committed to such increases in their December 2013 Declaration.
- ❖ The Council wishes to see within the next year an urgent examination of how payment and reimbursement policies and other incentives are impacting on investment decisions and how these could be adapted to accelerate the development pipeline whilst ensuring affordable access.
- ❖ The Council wishes to see a robust proposition for innovative funding mechanisms for other stages of the drug development pathway, e.g. for late stage assets, including an in-perpetuity mechanism.

6. WDC Priority Area: Global Integrated Development

The challenge

As well as increasing the relatively low investment in dementia drug development and neuroscience, the Council agrees with, and endorsed, Prime Minister Cameron's call for the creation of incentives, innovative regulatory approaches and affordable access. If successful, this would help shape an innovative approach to accelerate drug development efforts. The Council wholeheartedly agreed that a global regulatory approach to address unmet medical needs was urgently required.

WDC analysis of progress

The UK Government asked Council member Raj Long, a senior regulatory officer at the Bill and Melinda Gates Foundation, to develop a strategy to address Prime Minister David Cameron's call, including facilitating engagement with the regulators. The strategy has two main elements:

- **Engagement with regulatory agencies:** ensuring collaboration and innovation, in the context of the research gaps and development challenges, using existing laws and regulations in the most optimal way.
- **Spearheading adaptive clinical development:** focusing on the possibility of medicines regulators and developers working multilaterally to facilitate the development of safe, effective and affordable medicines.

This is the only global regulatory initiative on dementia, to enable regulators and developers to work collectively to improve drug development efforts.

The World Dementia Council was extremely encouraged by the first joint meeting of regulators, convened by Raj Long on behalf of the UK Government in November 2014, at which eleven regulators from ten jurisdictions across the European Union, the United States, Canada, Japan and Switzerland were brought together for the first time, to work collaboratively on dementia.



The regulators identified six areas of regulator-led priority action, underpinned by an appetite to widen multilateral cooperation internationally:

- ***Attrition analysis*** to assemble and analyse a relevant sample of data and examine the features of terminated development.
- ***Clinical trial efficiency*** to draw together transferable insights from oncology, rheumatology and antimicrobial resistance, including adoption of master protocols designs, consent forms and data mining in order to improve the 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 cognitive measures that could be in a composite end point for the early stages of AD (mild, not 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.

WDC commentary

The WDC is encouraged by both the progress made on Integrated Development over the past year, and the plans for the regulators to continue working collectively, which the Council believes will be critical to the ultimate success of the project. However, the Council is clear that it is critical that affordable access to new dementia drugs also needs to be rapidly addressed in the same robust manner.

WDC recommendations for further action

- ❖ The Council calls upon governments and regulators around the world to commit to continue to work collaboratively and speedily to support the UK's critical effort on Global Integrated Development.
- ❖ The Council wishes to see within the next year a complementary programme of activity developed to address affordable access to new dementia drugs over the coming months. Health technology assessment bodies and payer organisations will need to be consulted.

7. WDC Priority Area: Open Science and Data

The challenge

We still do not have a shared understanding of dementia pathology, and this critically impedes our efforts to find effective pharmaceutical therapies (as well as hindering our approach to diagnosis, risk, and risk reduction). Efforts to address this are hugely undermined by the lack of dementia data available. The World Dementia Council has focused not only on this lack of data of dementia data available from around the world *per se* but also the lack of systematic data sharing.

The dramatic increase in personal health and other data offers huge and unrealised resources for addressing dementia, yet data access and sharing remain a major challenge. While the Council recognises technical barriers, we believe that the most significant challenge is cultural.

WDC analysis of progress

With the aim of addressing this lack of systematic data sharing, at our first meeting, the Council asked the OECD to consider:

- good practices in data governance;
- principles and guidance for data governance; and
- enabling cooperation and integration across big data initiatives.

The development of good practices on data governance

The OECD and the Oxford Internet Institute examined data governance practice, to seek out good practice and create tools to improve data sharing. A report on this joint work will be published by the OECD and the Oxford Internet Institute in March 2015. The OECD also explored opportunities and challenges in the use of big data at an international workshop in Toronto in September 2014. The resulting report on “Dementia Research and Care: Can Big Data Help?” was released in February 2015:

<http://www.oecd.org/els/dementia-research-and-care-9789264228429-en.htm>

Principles and guidance for data governance

OECD set out existing principles: <http://www.oecd.org/sti/sci-tech/38500813.pdf> which offer a policy framework for accessing publically funded research data. These need updating in the light of the rapidly moving data arena: the 2015 meeting of OECD Science and Technology Ministers will explore what progress can be made.

The WDC also asked for an exploration of the feasibility of developing “Bermuda Principles” for dementia. The Bermuda Principles set out rules for the rapid and public release of DNA sequence data, as part of the multinational effort to sequence the human genome. Global dementia researchers participated in a round table discussion to address specifically whether dementia research activity could be accelerated by developing a

similar set of principles: attendees summarised the human genome example – its impact, strengths and weaknesses and any unintended consequences – and considered the commonalities and differences between the human genome project and dementia.

Participating researchers were united in their opinion that future progress might be enhanced by an audit of the access to current datasets aligned with work done by the OECD, and that the development of dementia exemplars should be explored with current data sharing initiatives, such as those of the Global Alliance for Genomics and Health (<http://genomicsandhealth.org>).

Enabling cooperation and integration across big data initiatives

Progress has also been made on enabling cooperation and integration across existing big data initiatives. OECD has brought together key players in the big data area to explore practical steps to provide international join-up across initiatives and two concrete examples of global data sharing have been created, reported on, and discussed at WDC meetings.

The Global Alzheimer's Association Interactive Network (GAAIN) links eleven international partners from four continents through a federated network of data resources. Its capability is being extended significantly through connections with the French National Alzheimer's Database (BNA), the European Medicines Informatics Framework (EMIF), and the Canadian based Longitudinal Online Research and Imaging System (LORIS).

The Canadian Consortium on Neurodegeneration in Aging (CCNA) and the Dementias Platform UK (DPUK) will collaborate to create an integrated system to share and analyse large-scale complex cohort-based datasets encompassing both broad and deep data from up to two million individuals, including imaging, genomics and health data.

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.

New data

At the same time, the UK Government is piloting a Dementia Citizen Science Platform in line with the 2013 G8 Dementia Declaration Open Science and Data commitments through an innovative mechanism for crowd-sourcing new knowledge about dementia care.

WDC commentary

The Council of course welcomes the number of international collaborative projects that are currently attempting to enable greater and more effective data sharing globally. However, we would like to see tangible outcomes of those projects very soon, with systematic data sharing across borders becoming a reality in the shortest possible timeframe.

In addition, while the Council is heartened by the conclusion of the group examining the applicability of the Bermuda principles that existing guidance is sufficient, it is equally frustrated that these existing guidelines are not implemented appropriately and would like to see this addressed extremely quickly.

WDC recommendations for further action

The World Dementia Council is keen for the OECD and its partners to pursue at pace the following approaches to strengthening cooperation among existing data initiatives, so that within the next year there is success against:

- ❖ a survey of existing successful multinational approaches to identifying best practices and the common data elements that might underpin future studies;
- ❖ more demonstration cases spanning geographical regions and a range of data areas; and
- ❖ a minimum set of principles and examples of best practice for funders and associated government agencies.



8. WDC Priority Area: Care

The challenge

Forty-four million people live with dementia and their quality of care varies greatly within, and between, countries. The work being done to identify a cure or disease-modifying therapy will not be completed in time to impact on these people. The World Dementia Council strongly asserts that governments have a responsibility to make improvements in care to significantly and immediately improve the quality of life for them, their families and their carers.

WDC analysis of progress

At our third meeting, the Council unanimously agreed to make dementia care our fourth priority. While we recognise that care varies culturally and geographically, the Council believes that there are opportunities to improve care across national boundaries: to that end, we have supported a number of international work packages to improve care, including:

The development of a care framework to monitor performance and quality of dementia care

The OECD and WHO are leading the development of a framework, mapping care pathways from diagnosis to end of life. The aims of the care framework are to: describe how international collaboration can support countries in improving their policies for people with dementia; identify ten key objectives that all countries could consider when designing their approaches to dementia policy, based on an OECD review of dementia policy; highlight possible policy approaches to these objectives; and stress the need for robust indicators to monitor progress.

An OECD report “Addressing Dementia: The OECD Response” (March 2015) presents approaches for better addressing the needs of people with dementia and boosting research and innovation for dementia care (<http://www.oecd.org/health/dementia.htm>).

A legacy event in Japan discussing new care and prevention models

The Japanese G7 legacy event on prevention and care provided World Dementia Council members with an insight into the Japanese care system, including its use of robotic technology to improve the quality of care. Following this, the Council reinforced the message that international collaboration and shared best practice, viewing care models from different perspectives, has huge value for improving care delivery. The World Dementia Council is pleased that the plans to secure the sustainable continuity of dementia action will establish and sustain collaborations beyond the G7 to support improved care across the globe.

Quality outcome metrics for dementia care

The Scottish Government has partnered with the International Consortium on Health Outcome Measures (ICHOM) to develop a minimum set of standards for dementia care

which have international applicability, and to which dementia patients and carers have contributed. The Scottish Government published a draft standard set of outcomes for the WHO Ministerial Conference in March 2015.

The Council is clear that a lack of internationally comparable indicators relating to dementia places significant limits on the ability of countries to measure their progress relative to others. Building on the OECD/WHO dementia care framework and the Scottish Government's work with ICHOM, the OECD is looking at developing a set of measures that can be collected internationally, and is working with WHO to ensure that these indicators can be applied at a global level in the longer term.

WDC commentary

The World Dementia Council is very encouraged by these collaborative global or pan-European projects to improve the quality of care, and sees real value in international support for a focus on outcomes in service models and improvements to care. However, we are absolutely clear that the greatest value can be derived by a coherent global approach that exploits synergies, avoids duplication of effort and speaks to nations of all levels of wealth. For example, the outcome metrics for dementia care should speak to the WHO/OECD Care Framework, and opportunities for active learning around culturally and geographically distinct approaches to care should be maximised.

WDC recommendations for further action

- ❖ The World Dementia Council advocates that improvements to dementia care globally always include the views of individuals with dementia and their carers, consider the potential opportunities of technology and seek to demonstrate improved outcomes.
- ❖ The Council would like to see within one year significant progress on the development of a proposal to coalesce international collaborations on dementia care, specifically focusing on supporting the ongoing spread of learning, supporting the use of outcome metrics for governments, organisations, and individuals, and providing a sustainable model of collaboration as part of the ongoing global action against dementia.
- ❖ The Council is convinced of the urgent need to see a cost-benefit analysis on short-term investment in different forms of technology to identify the potential returns over a three, five and ten-year basis.

9. WDC Priority Area: Risk Reduction

The challenge

Our final priority area is risk reduction. While a cure or disease-modifying therapy is being developed, managing the risk of populations of developing dementia is the only way to manage prevalence which, as we know, is increasing at an extraordinary rate, so that by 2050, the World Health Organisation estimates that 135 million people globally will have dementia. The World Dementia Council is aware that there is an increasing interest in a risk reduction approach to dementia from governments, academics and others, born of growing evidence linking some modifiable risk factors with dementia. However, the evidence is not conferred with the same level of credibility by all. For some, there is a need for greater evidence; for others, the evidence is sufficient to act upon. Wherever governments and others fall in this debate, the Council would want to see a risk reduction approach given significant weight in all public health or research spend planning.

WDC analysis of progress

Council member Harry Johns produced an international review of the global dementia risk reduction evidence and reported to the third Council meeting. In light of that review and the Alzheimer's Disease International's *World Alzheimer Report 2014, Dementia and Risk Reduction*, the Council acknowledged that as the evidence base is incomplete, it was not well placed to highlight particular risk factors. However, members did agree that cognitive decline at population level may be affected by behaviour changes acting on cardiovascular risk factors, and so decided to make dementia risk reduction our fifth priority.

Good progress has been made since that meeting. The Council publically prioritised risk reduction in November 2014. Furthermore, we highlighted risk reduction as a key tool for governments (and others) to tackle dementia, and to encourage them to adopt or strengthen such an approach, through the publication of a risk reduction statement in January 2015, which is reproduced in part in the "WDC recommendations for further action" section overleaf.

WDC commentary

In addition to trying to find a cure or disease-modifying therapy and continuing to improve diagnosis, care and quality of life for those living with dementia, the World Dementia Council believes that a risk reduction (or risk management) approach must also be an important area of focus. 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, while also helping to prevent many other non-communicable diseases; based on a "what's good for the heart is good for the brain" mantra.

WDC recommendations for further action

- ❖ The Council encourages governments around the world to take action on dementia risk reduction, by:
 - (i) embedding dementia risk reduction/management in to their public health policies and campaigns and their non-communicable disease strategies and action plans, as some countries are already doing; and/or
 - (ii) urgently investing in further research in this area, including running population-level intervention studies, to build the evidence base on dementia risk reduction.
- ❖ The Council would like to see countries and other interested stakeholders work collaboratively to produce a common set of dementia risk reduction messages, along the lines of the UK's *Blackfriars Consensus Statement on Dementia Risk Reduction*. This may help to make a stronger case for a risk reduction approach to dementia to be explored in those countries that have not yet fully recognised its potential through its dementia, public health or non-communicable disease strategies, including the need to increase the evidence base.



Source: OECD/Hervé Cortinat

10. What next for the World Dementia Council?

This report sets out the contribution of the World Dementia Council to the wider global action against dementia since the Council was formed a year ago. Our primary function has been to act as advocates and champions for the changes we believe need to happen to improve dementia prevention, diagnosis, treatment and care. And while we are pleased with the outputs of the last twelve months, this is dwarfed by the sheer scale of what there is left to do.

Our role is to challenge, to push, to be demanding and unrelenting. So in this report we have called on governments worldwide to do more, and work faster, to significantly and rapidly increase investments in dementia research for care, treatment and prevention.

We remain committed to this role and passionately believe that the Council should remain part of the global dementia infrastructure. We can, and therefore should, continue to challenge and exert pressure on governments, as well as all the organisations and individuals who can make the breakthrough.

The future potential of the Council must be seen in light of the global continuity plans set out at the WHO Ministerial Global Dementia Conference in Geneva in March 2015, as the efforts move from G7 countries to the whole world.

Conclusion

The World Dementia Council hopes very much to be involved in the development and implementation of those plans.

Dr Dennis Gillings CBE

World Dementia Envoy

Executive Chairman,
Quintiles



Dr Dennis Gillings was appointed as the World Dementia Envoy in February 2014. As the founder and executive chairman of Quintiles, the world's largest provider of biopharmaceutical development and commercial outsourcing services, Dr Gillings has more than 30 years' experience. He has worked with numerous biopharmaceutical companies and with many health organisations. Prior to this Dr Gillings spent some time in academia as Professor of Biostatistics at the University of North Carolina.

Dr Gillings also has personal experience of dementia, as his mother lived with the condition for 18 years until her death in 2013. Having seen first-hand the devastating effects of the condition and lack of effective treatment, he is passionate about harnessing innovation in care; bringing together ideas from around the world to try to prevent the condition and improve the lives of those living with dementia the condition. Other key priorities of the World Dementia Council are to reduce barriers to investment in research and speeding up drug development, with the ultimate goal of finding a cure or disease modifying therapy by 2025.

Dr Gillings, who was born and educated in the UK, was awarded a CBE in 2004 for services to the pharmaceutical industry.

Dr Daisy Acosta

Honorary Vice-President,
Alzheimer's Disease
International



Daisy Acosta is a Medical Doctor having graduated in Santo Domingo, Dominican Republic at Universidad Nacional Pedro Henriquez Ureña (UNPHU), specializing in general psychiatry with a further qualification in geriatric psychiatry. Dr Acosta is certified by the American board of psychiatry and neurology and has an added qualification in geriatric psychiatry and forensic medicine.

Dr Acosta has dedicated her professional life to the study of Alzheimer's disease and related disorders and has a large clinical practice based in The Dominican Republic, where she is very well known for her dedication to the care and treatment of people with dementia.

Dr Acosta is the author of several scientific articles published in national and international journals and co-author of several books on dementia in the Latino American region. In addition, Dr Acosta is the principal investigator of the 10/66 Dementia Research Group Center in the Dominican Republic, and is in charge of organizing and teaching the psycho-geriatric unit at Universidad Nacional Pedro Henriquez Ureña, (UNPHU), where her students call her " lady Alzheimer's" as a result of her determination that none of them should leave medical school without knowing all there is to know about this disease. She is also co-founder of The "Asociacion Dominicana de Alzheimer", (ADA).

Dr Acosta is a past chairperson of Alzheimer's Disease International, (ADI), and Honorary Vice-president at the moment. Dr Acosta is involved in and very familiar with, the strengths and weaknesses of the Alzheimer's associations in her region (Latino America and The Caribbean) and is very familiar with the needs of people with dementia and their caregivers as both a professional and a caretaker herself.

Professor Philippe Amouyel

General Director,
Fondation Plan Alzheimer



Trained as hospital medical resident in Neurology, Philippe Amouyel, MD, PhD, is Professor of Epidemiology and Public Health at the University Hospital of Lille. Since 1998, he heads a research unit of 50 persons dedicated to the public health and the molecular epidemiology of age-related diseases. Part of its work is devoted to cardiovascular diseases and to the understanding of their multiple determinants. The other part of his research focuses on the study of the determinants, mainly genetic, of neurodegenerative diseases associated with cognitive decline and Alzheimer's disease in particular. Since 2012 he obtained an excellence laboratory from the government, named Distalz that brings together seven of the very best French research teams whose objective is the development of innovative strategies for trans-disciplinary approach to Alzheimer's disease. He published more than 600 articles and participated in the discovery of 20 confirmed genetic locus predisposing to sporadic Alzheimer's disease.

He headed from 2002 to 2011 the Pasteur Institute of Lille, a non-profit foundation dedicated to the improvement of the health of man and his environment. Since 2008, he heads the National Foundation for Scientific Cooperation on Alzheimer's disease and related disorders that participated to the implementation of the research measures of the French Alzheimer Plan 2008-2102. This non-profit foundation dedicated to Alzheimer's disease and related disorders research, thanks to several partnerships, funds and supports research programs from basic research to social and health care research, including clinical and translational research.

At the European level, Philippe Amouyel chairs the European Joint Programming Initiative on research on neurodegenerative diseases and Alzheimer's in particular (JPND) that groups 28 countries including Canada and whose main objective is to combine the strengths of European and global research to tackle more efficiently these diseases.

Sir William Castell

Chairman, Wellcome Trust



Sir William Castell is Chairman of the Wellcome Trust, a global charitable foundation dedicated to achieving extraordinary improvements in human and animal health. The Trust supports the brightest minds in biomedical research and the medical humanities. The breadth of support includes public engagement, education and the application of research to improve health. Prior to taking up this appointment in 2006 Sir William was President and Chief Executive Officer of GE Healthcare, the global medical diagnostics and biosciences business of the General Electric Company, of which he was also a Vice Chairman. Sir William retired as a Director of the General Electric Company in April 2011. From 2006 to 2012 he served as a non-executive director, and latterly senior independent director, of BP plc. Sir William is Chairman of Chichester Festival Theatre.

Before its acquisition by GE in April 2004, Sir William was Chief Executive of Amersham plc. During his tenure with Amersham, he successfully oversaw a major expansion of the business through organic growth and acquisitions, culminating in 1997 with the mergers of Amersham International with Pharmacia Biotech and Nycomed asa. The resulting business, Amersham plc, was a world leader in *in vivo* medical diagnostics and life sciences research technologies.

Prior to joining Amersham, Sir William held various positions with The Wellcome Foundation. In 1986, he was appointed Commercial Director, Wellcome plc. Previous positions with Wellcome included being head of the newly formed Wellcome Biotechnology and Head of Finance and Administration for Continental Europe, Africa and Asia.

In June 2000 a knighthood was bestowed for his services to the life sciences industry. A strong proponent of business being active in society, Sir William participated in Business in the Community's work to revitalise areas blighted by unemployment and social exclusion. In 1998, he was appointed Chairman of The Prince's Trust by HRH The Prince of Wales and served in this role for five years. In January 2004, he received the honour Lieutenant of the Royal Victorian Order for services to the Royal Family.

Sir William served as a member of the UK's Medical Research Council from 2001 to 2004. Currently, his other activities include being a Trustee of the Education and Employers' Taskforce, a Royal Commissioner and member of the board of the Royal Commission of 1851, a UK Business Ambassador, an Honorary Fellow at Green Templeton College Oxford, an Honorary Fellow of the University of Cardiff, an Honorary Fellow of King's College London and an Honorary Fellow of the Academy of Medical Sciences. He formed and chaired the High Street Fund 2012-13. He received his BA in Business Studies from the City of London College. His wife Renice is a physician. They have two daughters, a son and nine grandchildren.

Professor Dame Sally Davies

Chief Medical Officer,
Department of Health



Professor Dame Sally Davies is the Chief Medical Officer (CMO) for England and also advises the UK Government. She holds responsibility for Research and Development, and is the Chief Scientific Adviser for the Department of Health.

The CMO is the independent advisor to the Government on all medical matters, with particular responsibilities regarding Public Health. In particular, she provides professional leadership for Directors of Public Health and will lead a public health professional network for those responsible for commissioning and providing public health services.

The CMO supports the Health Secretary in strengthening the Government's collective effort to protect, promote and improve the health and wellbeing of the people of England.

The CMO carries the rank of Permanent Secretary and advises the Secretary of State for Health on medical matters. She is also the professional head of the Department's medical staff and head of the Medical Civil Service

Sally has been actively involved in NHS R&D from its establishment. As Director-General she established the National Institute for Health Research (NIHR) with a budget of £1 billion.

Sally led the UK delegation to the World Health Organization (WHO) Ministerial Summit in November 2004 and the WHO Forum on Health Research in November 2008. She spoke on R&D at the World Health Assembly in May 2005 and is a member of the WHO Global Advisory Committee on Health Research (ACHR). She also chaired the Expert Advisory Committee for the development of the WHO research strategy, endorsed by the World Health Assembly in May 2010. She is a member of the International Advisory Committee for A*STAR, Singapore and has advised many others on research strategy and evaluation including the Australian NHMRC.

Her own research interests focused on Sickle Cell disease.

Sally was awarded a DBE (Dame Commander of the British Empire) in the New Year Honours 2009 for services to medicine.

In September 2011, Sally was conferred as Emeritus Professor at Imperial College London.

Hilary Doxford

Vice Chairperson,
Alzheimer's Europe



In December 2012, at the age of 53 Hilary was diagnosed with early onset Alzheimer's Disease. She is keen to do all she can to assist in finding a cure for dementia and volunteers for the Alzheimer's Society in England as part of their research network and user involvement programme.

She is still working and intends to continue working for as long as possible to show that people with dementia can still make a valuable contribution to their organisation.

At home she enjoys anything to do with archaeology and she and her husband love the sea and walking their dog Tilly.

Hilary joined the European Working Group for People With Dementia (EWGPWD) in October 2014, nominated by the Alzheimer's Society.

Dr Tim Evans

Director, Health, Nutrition
and Population, Human
Development Network,
World Bank



Before joining the World Bank he was the Dean of the James P. Grant School of Public Health of BRAC University in Bangladesh. Previously he served as Assistant Director General at the World Health Organization, heading the Evidence, Information, Research and Policy Clusters, where he oversaw the production of the annual World Health Report.

Dr. Evans has been a leader in advancing global health equity and health systems performance throughout his career, notably through his work with the Rockefeller Foundation and the Harvard School of Public Health and with his contributions to the development of innovative partnerships, including the Global Alliance on Vaccines and Immunization, INDEPTH and Health Metrics networks, the Global Health Workforce Alliance and the World Alliance for Patient Safety.

Dr. Evans earned his DPhil in agricultural economics at Oxford, and pursued medical and postgraduate studies at McMaster and Harvard Universities.

Dr Franz Humer

Chairman, Roche



Dr. Franz B. Humer, born in 1946 in Salzburg has Austrian and Swiss nationalities, a PhD in Law and an MBA.

Career: Schering Plough, Glaxo Holdings, until March 2014 Chairman of Roche Holdings, Basel, Switzerland

Since 2005 Board member of Diageo plc, London, since 2008 to date Chairman Diageo plc, Chairman of INSEAD, Board member of Citigroup Inc. and Jacobs Holding Ltd, member of the International Advisory Board of Allianz SE and Chairman of the Board of the International Centre for Missing and Exploited Children.

Dr Yves Joanette

Scientific Director,
Canadian Institutes of
Health Research (CIHR),
Institute of Aging



Yves Joanette is Professor of Cognitive Neurosciences and Aging at the Faculty of Medicine of the Université de Montréal. He is currently the Scientific Director of the *Institute of Aging of the Canadian Institutes of Health Research (CIHR)* and the co-Lead of the CIHR research strategy on dementia which has a strong international collaborative component (JPND, COEN, ADNI, Canada-China, Canada-France-Quebec) as well as a Canadian component which should soon take the form of the *Canadian Consortium on Neurodegeneration in Aging*.

Professor Joanette has a long standing experience in research management and partnership with stakeholders: from 1997 to 2009, he was Director of the *Centre de recherche de l'Institut universitaire de gériatrie de Montréal*. From 2009 to 2011, he was President & CEO, as well as the Chair of the Board, of the *Fonds de la recherche en santé du Québec (FRQ-S)*.

Professor Joanette's own research interests relate to the aging process of the cognitive brain and cognitive deficits in the elderly. Using combined cognitive and neuroimaging approaches, he and his team contribute to the understanding of (a) the neuro-functional reorganization that allows for the preservation of cognitive abilities in aging corresponding to cognitive reserve which has the potential to delay the clinical signs of dementia, and (b) the heterogeneity of the cognitive deficits in dementia.

His contribution has been recognized through many distinctions, including the André-Dupont Award from the *Club de recherches cliniques du Québec*, in 1990, and the Eve-Kassier Award, in 1995, for exceptional professional accomplishment. Yves Joanette is a Fellow of the *Canadian Academy of Health Science*. In 2007, the *Université Lumière de Lyon* in France presented him with an Honorary Doctorate.

Harry Johns

President and CEO,
Alzheimer's Association



Harry Johns is the President and CEO of the Alzheimer's Association, the global leader in Alzheimer's advocacy, research and support.

Since his arrival at the Association in 2005, thanks to the mobilization and important work of millions in communities across America as well as a dedicated staff, the Association has changed the public discussion about Alzheimer's, raising the epidemic and its devastating human and economic consequences to significant new levels of recognition and support.

The Alzheimer's Association has achieved public policy advances including the passage of the National Alzheimer's Project Act and the creation of the National Alzheimer's Plan as required by the Act. Through those and other public policy approaches, critically-needed increases in federal research funding have begun. The Association's direct leadership in Alzheimer's research now includes annually convening the world's largest gathering of Alzheimer's researchers, multiple ground-breaking international collaborations and successful direct investments in cutting-edge, field-changing research which have helped to advance Alzheimer's science to new levels of insight and opportunity.

According to Thomson Reuters' Web of Science, the Alzheimer's Association is a global leader in Alzheimer's research, ranked only behind the U.S. National Institutes of Health and the Chinese government in terms of impact. Philanthropedia called the Association the most influential nonprofit for aging issues in its most recent ranking of the field. And, since The Nonprofit Times first began evaluating nonprofit employers in 2010, the Alzheimer's Association has been consistently ranked one of its Best Nonprofits to Work For, including rankings of 1st or 2nd among large non-profits four years in a row.

Harry was appointed by the Secretary of Health and Human Services in 2011 to serve as a member of the Advisory Council on Alzheimer's Research, Care, and Services. Following the 2013 G8 Dementia Summit, he was named to the World Dementia Council. He also serves as CEO of the Alzheimer's Impact Movement and on the Executive Committee of Research!America. Prior to joining the Alzheimer's Association, he was one of the four members of the executive team of the American Cancer Society. Harry is a graduate of Eckerd College and Northwestern University's Kellogg School of Business.

Professor Martin Knapp

Director, Health &
Personal Social Services
Research Unit, London
School of Economics &
Kings College London



Martin Knapp is a researcher in the areas of health and social care policy and practice. He has been Professor of Social Policy and Director of the *Personal Social Services Research Unit* at the London School of Economics and Political Science (LSE) since 1996. Since 2009, Martin has also been Director of the *School for Social Care Research* funded by the National Institute of Health Research. Until early 2014 he was also Professor of Health Economics at the Institute of Psychiatry, King's College London, having established the Centre for the Economics of Mental Health there in 1993.

Martin's research emphases in recent years have primarily been child and adult mental health, dementia, autism and long-term social care, with much of his work having an economic focus. He has published his research widely, including in more than 450 peer-review articles and 15 books. His work has fed through to have a number of impacts on policy and practice discussions in the mental health and long-term care areas, both in the UK and elsewhere.

Dr Kiyoshi Kurokawa

Professor of the National Graduate Institute for Policy Studies and former Science Advisor to the Cabinet of Japan



Dr. Kurokawa, Professor Emeritus of the University of Tokyo, has been an Academic Fellow of the National Graduate Institute for Policy Studies (2009.11-); Chairman, Health and Global Policy Institute (2005-); Commissioner on the WHO Commission for Social Determinants of Health (2005-2008); Chair and Founder, IMPACT Foundation Japan; Representative Director and Chair, Global Health Innovative Technology Fund (2013-); Adjunct Senior Research Scientist of the Earth Institute of Columbia University (2011-); Distinguished Research Affiliate, the MIT Media Lab.

Dr. Kurokawa received a MD degree from the University of Tokyo. Following clinical training in internal medicine, then in nephrology at the Department of Medicine of the University of Tokyo, Faculty of Medicine, he spent 15 years in USA; professor of medicine, Department of Medicine, UCLA School of Medicine (1979-84). After returning from USA; he was professor of medicine of the University of Tokyo, Faculty of Medicine (1989-96); Dean and Professor of Tokai University School of Medicine and Director of the Institute of Medical Sciences (1996-2002), Research Institute of Science and Technology (2002-04), Tokai University; Adjunct Professor, the Research Center for Advanced Science and Technology, the University of Tokyo (2003-06).

Dr. Kurokawa has served as president and/or executive officer to many prestigious national and international professional societies in medicine, nephrology, science academies and science policy organizations. He is Master of the American College of Physicians, and Founding Governor of the Japan Chapter of American College of Physicians (2004-2011). He is an elected member of many prestigious professional societies including Science Council of Japan (President, 2003-06), Member of InterAcademy Panel (2001-06), and InterAcademy Council (2001- 06), Association of American Physicians, and the Institute of Medicine of the National Academies of the USA. He is also Board Member of Biobliotheca Alexandria, Egypt (2006-2010), Khalifa University of Science and Technology of Abu Dhabi Government (2008-), Okinawa Institute of Science Technology Graduate University and Advisory Board to the Prime Minister of Malaysia.

Dr. Kurokawa, Special Advisor to the Cabinet (2006-08), has served and serves many committees of the Ministries and Cabinet Office of Japan, e.g., Committee for Science and Technology Policy and as Science Advisor for the Ministry of Education, Science and Culture, Chairperson of the Hideyo Noguchi Prize Committee, and he chaired the Fukushima Nuclear Accident Independent Investigation Commission by the National Diet of Japan (NAIIC) (2011.12-2012.7).

He is a recipient of Order of Purple from the Government of Japan for Excellence in Academic Achievements (1999), Order Legion de Honour of the Government of France (2009), Person of the Year of the American Chamber of Commerce of Japan (2010), the Order of the Rising Sun, Gold and Silver Star (2011 Spring), "Scientific Freedom and Responsibility Award" of AAAS (2012) and of "100 Top Global Thinkers 2012" of 'Foreign Policy'.

Raj Long

Senior Regulatory Officer
– Integrated
Development, Bill &
Melinda Gates Foundation



Raj has over 25 years of experience in the pharmaceutical industry and in the last 15 years has held senior international regulatory roles. Raj is currently with the Bill & Melinda Gates Foundation (BMFG) as a Senior Regulatory Officer.

Raj brings a wide range of expertise in Regulatory Science having worked with the EU EMA, US FDA, China CFDA and other BRIC regulatory authorities. She has also led various regional/global regulatory teams in Europe, Asia Pacific, Latin America and the US.

Prior to joining BMFG Raj was the Global Head of MDx Regulatory in GE Health Care. In Oct, 2013 she successfully led the regulatory team to obtaining a FDA approval for Vizamyl (flutemetamol) a beta amyloid PET imaging agent for the evaluation of Alzheimer's disease or other cognitive decline. Preceding that she was Head of International Regulatory based in Novartis, Switzerland. Her role included setting and implementing a new strategic regulatory organizational model for the regions with a strategic focus on the Emerging Markets. She also held a number of senior roles at Bristol-Myers Squibb where she spent over 19 years and her last role was Vice President - Regulatory International based in Princeton, NJ.

During her career Raj has made significant contributions at various levels including being Expert Member in the International Congress on Harmonisation (ICH), International Federation of Pharmaceutical Manufacturing & Associations (IFPMA) Regulatory Committee.

More recently she has been an adviser and speaker in international forums like the Organization for Economic Cooperation and Development (OECD) in Paris, Big Change Summit at Oxford University and the G8 Summit on Dementia, December 2013. She has also been advising in a consultative role with the BMFG since 2012.

Raj holds a double Masters in Psychology and Education from the University of Glasgow and Edinburgh respectively, Scotland.

Professor Joël Ménard

Professor of Public Health
at the Faculty of Medicine
Paris-Descartes



Joël Ménard obtained his degree in medicine from the Faculty of Medicine in Paris in 1970. From 1971 to 1974, he was a research executive and then master of research at the National Institute of Health and research (INSERM) in Paris. Following this, he was Head of the Hypertension Clinic and then of the Cardiovascular Preventive Medicine Center at two hospitals in Paris for 11 years, being appointed Chief Medical Officer of the Ministry of Health in 1997. Within the framework of his scientific activities, he has carried out research in Montreal, Bethesda, Paris, Basel and Berlin-Büch.

Since 1999, Joël Ménard has been Professor of Public Health at the Faculty of Medicine Paris-Descartes. Between 2000 and 2006, he was Delegate for Clinical Research at the "Assistance Publique/Hopitaux de Paris. In 2007 he was appointed by President Nicolas Sarkozy to assist in the drafting of the French national Alzheimer Plan. His report on "Research, treatment and care", published in 2007, informed the content of the Plan Alzheimer, which entered its first phase in 2008.

From 2008-2013 he was President of the Scientific Advisory Council of the French national Alzheimer Plan. He remains an active player on international dementia issues.

Prof Pierluigi Nicotera

Scientific Director and
Chairman of the Executive
Board, German Center for
Neurodegenerative
Diseases



A renowned scientist and leading international expert in the field of neuronal cell death, Professor Nicotera was appointed Scientific Director and Chairman of the Executive Board of DZNE in April 2009.

He was trained in General Medicine and Cardiology at the University of Pavia, Italy. He obtained his Ph.D. at the Karolinska Institute in Stockholm, where he worked subsequently as associate professor. From 1995 to 2000 Nicotera headed the division of Molecular Toxicology at the University of Konstanz and was then appointed Director of the UK Medical Research Council Toxicology Unit. His research has been centred on the molecular mechanisms that lead to neuronal demise following chronic and acute insults. Loss of neuronal synaptic connections and apoptosis play central roles in neurodegenerative diseases.

Meera Pattabiraman

Chairperson, Alzheimer's
and Related Disorders
Society of India



A post graduate in business administration, Meera entered the field of social work and dementia care because of her personal experience of being a carer for her father who had Alzheimer's disease.

Meera joined ARDSI in 1997 and has been working in the field of dementia care, management and advocacy for the past 17 years. Starting as founder secretary of the Trivandrum chapter, Meera was then elected as Secretary General of the national office, where she has served 3 terms, during which period the number of chapters of ARDSI has grown from a handful to 18 chapters all across the country.

Meera has work experience at all levels, as a counsellor for carers and family members, in planning and setting up day care and residential care facilities for persons living with dementia in addition to working with governmental agencies to conduct short and long term dementia focussed training programmes.

Meera was part of the editorial board that produced the India Dementia Report in 2010, this is now used by the Ministry of Health and the Ministry of Social Justice and Empowerment as the reference guide in all matters relating to dementia. Based on the Report, India has developed a strategy for making dementia a public health priority and to address the problems of 3.8 million persons with dementia in India. Meera is part of the national think tank to develop better health care for the elderly and has taken part in national health policy meetings.

**Professor.
Ronald C.
Petersen,
M.D., Ph.D.**

Director, Mayo Clinic
Alzheimer's Disease
Research Center



Dr. Ronald C. Petersen received a Ph.D. in Experimental Psychology from the University of Minnesota and graduated from Mayo Medical School in 1980. He completed an internship in Medicine at Stanford University Medical Center and returned to the Mayo Clinic to complete a residency in Neurology. That was followed by a fellowship in Behavioral Neurology at Harvard University Medical School/Beth Israel Hospital in Boston, Massachusetts. Dr. Petersen joined the staff of the Mayo Clinic in 1986 and rose through the ranks to become a Professor of Neurology in 1996. In 2000 he was named the Cora Kanow Professor of Alzheimer's Disease Research and Mayo Clinic Distinguished Investigator in 2011.

He is currently the Director of the Mayo Alzheimer's Disease Research Center and the Mayo Clinic Study of Aging and has authored over 550 peer-reviewed articles on memory disorders, aging, and Alzheimer's disease. He has edited five books, *Memory Disorders*, *Mayo Clinic on Alzheimer's Disease*, *Mild Cognitive Impairment: Aging to Alzheimer's Disease*, *Mayo Clinic Guide to Alzheimer's Disease* and *Mayo Clinic on Alzheimer's Disease (2013)*.

Dr. Petersen is one of the recipients of the 2004 MetLife Award for Medical Research in Alzheimer's Disease and the 2005 Potamkin Prize for Research in Picks, Alzheimer's and Related Disorders of the American Academy of Neurology. Dr. Petersen also received the inaugural Ronald and Nancy Reagan Research Institute Award in 2004 from the Alzheimer's Association and the inaugural Leon Thal Prize of the Lou Ruvo Brain Institute in 2007. In 2012 he received the Khachaturian Award of the Alzheimer's Association and the Henry Wisniewski Lifetime Achievement Award in 2013. In 2011 he was appointed by the Secretary of Health and Human Services, Kathleen Sebelius, to serve as the Chair of the Advisory Committee on Research, Care and Services for the National Alzheimer's Project Act.

Dr Paul Stoffels

Global Chair, Johnson &
Johnson



Paulus Stoffels is the Chief Scientific Officer, Johnson & Johnson, and Worldwide Chairman, Pharmaceuticals. As Chief Scientific Officer, he works with the R&D leaders across Johnson & Johnson to set the enterprise-wide innovation agenda. Dr. Stoffels serves as a member of the Executive Committee and the Management Committee. Dr. Stoffels has more than 20 years of global experience in both pharmaceutical and HIV/AIDS research and development and has held many leadership positions within Johnson & Johnson.

Dr. Stoffels joined Johnson & Johnson in 2002 with the acquisition of Virco and Tibotec, where he was Chief Executive Officer of Virco and Chairman of Tibotec. In 2005, he was appointed Company Group Chairman, Global Virology where he led the development of PREZISTA® and INTELENCE®, leading products for the treatment of HIV.

In 2006, he assumed the role of Company Group Chairman, Pharmaceuticals, with responsibility for worldwide research and development for the CNS and Internal Medicine Franchises. Dr. Stoffels was appointed Global Head, Research & Development, Pharmaceuticals, in 2009 and in 2011 became Worldwide Chairman, Pharmaceuticals Group, with responsibility for research and development, business development and global strategy and innovation. In this role, he leads global teams across Janssen to discover and develop innovative medicines and vaccines for unmet medical needs worldwide and to leverage the power of science for global health. In October 2012, Dr. Stoffels was appointed Chief Scientific Officer, Johnson & Johnson. He chairs the company's Worldwide Research & Development Council, and provides oversight to Johnson & Johnson Development Corporation, the Johnson & Johnson innovations centers, and for product safety for all products of the Johnson & Johnson Family of Companies worldwide.

Dr. Stoffels began his career as a physician in Africa, as part of the Janssen Research Foundation (JRF) under the mentorship of Dr. Paul Janssen, focusing on HIV and tropical diseases research. He studied Medicine at the University of Diepenbeek and the University of Antwerp in Belgium and Infectious Diseases and Tropical Medicine at the Institute of Tropical Medicine in Antwerp, Belgium. Throughout his career, Dr. Stoffels has had a passion saving lives and improving quality of life and for using the power of science to solve health care challenges in the developing world. He was instrumental in building the relationship between UNAIDS/WHO and the pharmaceutical industry on provision of HIV drugs in Africa, and has a continued interest in exploring new and collaborative solutions to address serious unmet healthcare needs in the developing world.

Dr. Stoffels also represents Johnson & Johnson in discussions on global health topics at international forums such as the annual World Economic Forum in Davos, Switzerland and the Pacific Health Summit.

George Vradenburg

President & Chairman,
Vradenburg Foundation &
USAgainst Alzheimer's



George Vradenburg is the Chairman and Co-Founder of USAgainstAlzheimer's (USA2), a disruptive and catalytic force committed to stopping Alzheimer's by 2020. The USA2 platform seeks to escalate the fight against Alzheimer's through a broad range of powerful voices from various walks of life: WomenAgainstAlzheimer's, African-AmericanNetworkAgainst Alzheimer's, ActivistsAgainstAlzheimer's, ResearchersAgainstAlzheimer's, ClergyAgainstAlzheimer's and LatinosAgainstAlzheimer's. USA2 serves as the convener of the only industry coalition dedicated to stopping Alzheimer's -- the Global CEO Initiative (CEOi) on Alzheimer's -- as well as the co-convener of a 60+ member coalition of the Alzheimer's-serving community -- Leaders Engaged on Alzheimer's Disease. As a result of his USA2 work, George was appointed in 2011 by the United States Secretary of the Department of Health and Human Services to serve on the National Alzheimer's Advisory Council on

Research, Care and Services for the first-of-its-kind National Alzheimer's Strategic Plan. In 2013 George was appointed by Congress to the Long Term Care Commission charged with devising a comprehensive long term support and services plan for the United States. Among other efforts, George has testified twice before the U.S. Congress regarding the Global Alzheimer's pandemic; conceived and supported the Alzheimer's Study Group; and, through the Vradenburg Foundation, has supported the Alzheimer's Disease International World Alzheimer's Reports and the National Institute of Health's Global Alzheimer's Research Summit. Before his retirement, George served in senior executive positions at AOL/Time Warner, FOX and CBS. George is a member of the Council on Foreign Relations and the Economic Club of Washington, DC. George received his B.A. from Oberlin College, magna cum laude, where he was elected to Phi Beta Kappa, and his J.D. from Harvard Law School, cum laude.

Background:

1. Following the 2013 G8 dementia summit and the declaration that followed, the World Dementia Council (WDC) was formed at the invitation of the UK Government to support the World Dementia Envoy in his role of championing the cause of innovation in dementia across diagnosis, treatment and care.

Overarching goal:

2. The WDC is a steering and advocacy group, independent of any government or particular interest, using its convening power and voice to stimulate innovation, development and commercialisation of life enhancing drugs, treatments and care for people with dementia, and in protection of those at risk of dementia, within a generation.

Objectives:

3. The WDC will work towards a framework to enable and incentivise the ecosystem around dementia and a ten year plan to achieve our goals. Specifically, the WDC will build upon the G8 declaration goal of finding a cure or disease modifying therapy by 2025.
4. The objectives of the WDC in achieving this include, but are not limited to, the following priority areas:
 - Advise on the development of new incentives and **financial structures** that drive new investment by lowering risk and increasing reward.
 - Develop incentives that would catalyse new **research partnerships** between government, academia and industry, with an emphasis on entrepreneurial effort and a patient-focussed research approach.
 - Support the optimisation of **regulatory pathways** and find other ways to make it more flexible and efficient, in order to accelerate drug development.
 - Assist in supporting global efforts to build **single inventories of research activity** and databases; addressing disincentives for collaboration in both industry and academia and seeking to increase opportunities to share data and establish networks and platforms for synthesising and disseminating knowledge to different stakeholders.
 - Support the identification and dissemination of **best practice (innovative and existing) in the care** of people with dementia and make this knowledge available to those with dementia throughout the world, as well as their families and other carers.
 - **Raising public awareness** of the scale of the economic and social challenge we face and the urgency of the need for a radical global response, with a view to changing policies and practice to increase diagnosis rates and to improve the treatment and care of those with dementia.

Membership:

5. Members of the WDC are drawn from a range of backgrounds and nations. They are united in a passion to make an urgent and fundamental breakthrough in the diagnosis, treatment and care of people with dementia.

Roles and responsibilities of members:

6. Within the framework of their respective mandates, backgrounds and technical expertise, members are expected to:
 - 6.1 ***Commit to the goals and objectives of the WDC and work towards those goals.***
 - 6.2 ***Be open, transparent and independent in their work for the WDC.***
The WDC will provide independent advocacy and global leadership.
 - 6.3 ***Be transparent in declaring relevant interests.***
WDC Members are expected to declare their interests, and those must be kept on record by the Department of Health secretariat. Members will be responsible for updating their interests as they change. Members may not attend meetings if their declared interests are not up-to-date.
 - 6.4 ***Be clear about when they are acting in their capacity as a WDC member (or not).***
WDC members may also be conducting work on dementia outside of the WDC remit and this distinction should be clear.
7. The World Dementia Envoy and the World Dementia Council will be appointed until the end of March 2015 and will be reviewed at the end of this period. The Envoy will be asked to nominate empowered deputies where he is unable to attend in person.

Sub-working groups:

8. Each work stream deriving from WDC priorities and facilitated by the UK Department of Health, will have a WDC sponsor and a steering group on which the sponsor sits. The sponsor will be responsible for presenting the work to the WDC, and for representing the views of the WDC in between the quarterly meetings.

Meetings:

9. The WDC will meet quarterly, unless agreed otherwise, until March 2015 and then review. Meetings will normally be a mix of half and full day in duration.
10. Members will be advised of the location, date and time at the earliest opportunity ahead of each meeting. Dates of meetings will be fixed well ahead. Most meetings will be held in person, but video conference and dial in facilities will be available.
11. Papers will be circulated to give at least three working days before each meeting. The Minutes from the Council will not be restricted documents unless otherwise marked. The terms of such restriction will be agreed with the Council in advance.
12. An agenda will be issued in advance of Council meetings. Papers/issues to be included as an agenda item for a meeting must be with the secretariat at least six working days prior to a meeting.
13. Other communication will be by email, and WDC members may be asked to consider documents virtually, outside of the quarterly meetings.

Project accountability:

14. The Council will be chaired by Dr Dennis Gillings CBE, World Dementia Envoy. The secretariat will be provided by the UK Department of Health and the OECD.

Work Plan:

15. Time-bound activities, outputs and outcomes will be agreed, developed, and reported on during the WDC quarterly meetings. Routine progress will be monitored through updates during teleconferences, emails, and meetings on specific activities by the secretariat, in communication with the Envoy and work-stream sponsors.