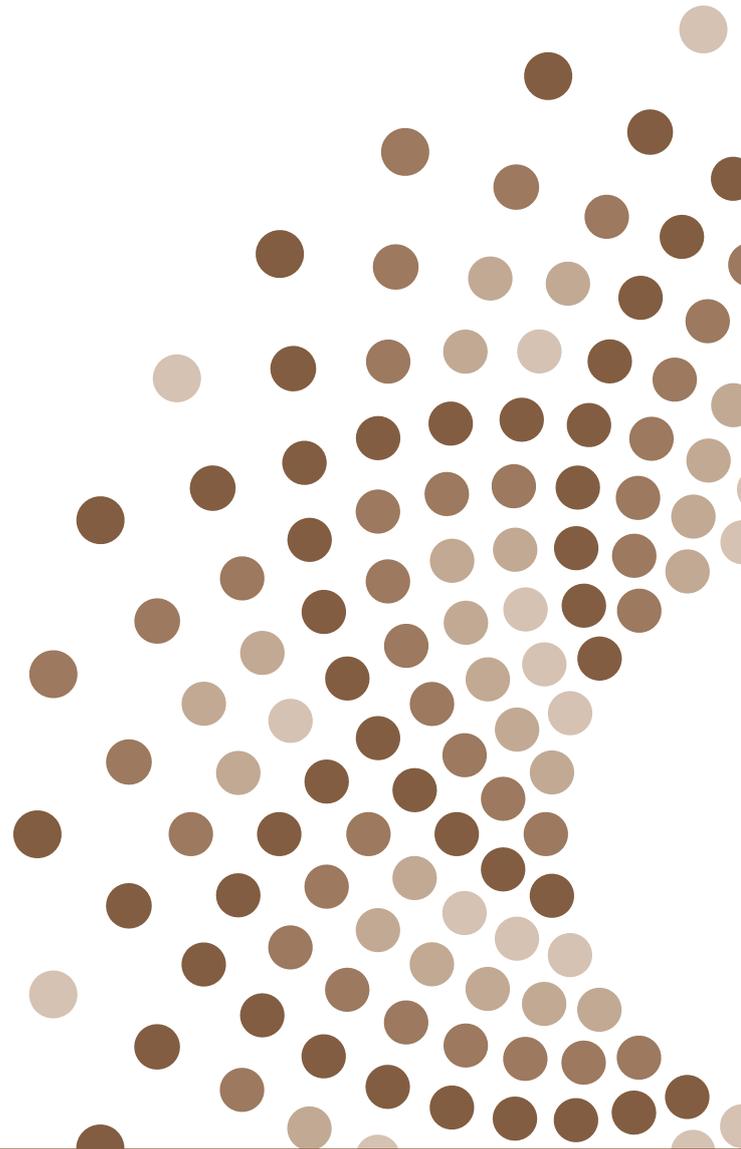




**World Dementia  
Council** Leading the Global Action  
Against Dementia

World Dementia Council

# Annual Review 2016–2017



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Yves Joannette, Raj Long and Dennis Gillings, February 2016.

## Foreword by Yves Joannette, Chair of the World Dementia Council

The period January 2016 to March 2017 has been a very significant time in the evolution of the World Dementia Council – a year in which we took steps to enhance our ability to fulfill our remit of leading the global fight against dementia.

In January 2016, the Council became independent, having been, in the two preceding years, constructed and driven forward by the UK Government's Department of Health. The Council's creation in 2014 was a key outcome of the Dementia Summit that the UK Government hosted in London in December 2013 during its G8 Presidency that year. From 2014 to February 2016, the Council was chaired by the World Dementia Envoy, Dr Dennis Gillings.

We acknowledge and thank the participants in the Dementia Summit for their foresight, Dennis Gillings for his inspiring leadership and the Department of Health for the enthusiasm and energy that it dedicated to the Council's creation and initial work programme. This provided firm foundations that we are determined to build on as an independent organisation, with the aim of improving prospects for people living with dementia and their families throughout the world.

In February 2016, we formally relaunched with a new and truly global membership, drawing in participants from six continents and a wide range of expertise from all stakeholder sectors. This positions the Council like no other organisation to catalyse and accelerate the global response to dementia. Behind the re-launch was our desire to ensure that the Council is strongly placed to enable the changes that are so urgently needed across our five themes: research, finance, integrated drug development, risk reduction and care.

Inevitably, a main focus in 2016 was on the transition to an independent organisation and securing status as a legal entity. However, at the same time, we embarked on refreshed action areas under the five themes, creating Global Teams to lead the delivery of each.

We also worked on increasing WDC's visibility, raising awareness of dementia and collaborating with Governments and NGOs on the major developments of the time, not least the preparation of the World Health Organization's very welcome Global Action Plan on the Public Health Response to Dementia 2017–2025 and the Global Dementia Observatory.

**“We warmly thank all the supporters who worked with us in our first 15 months.”**

We set ourselves an ambitious agenda and are proud of what we have achieved – for example, beginning a detailed examination of dementia research and research funding; enhancing international research co-ordination through encouraging expansion of the EU's Joint Programme in Neurodegenerative Diseases; and raising awareness of dementia and breakdown of stigma by working with the World Federation of Science Journalists to create a Dementia Toolbox to support journalists interested in dementia, particularly in low and middle income countries, to report more accurately and effectively.

Raj Long, the Council's Vice-Chair, and I warmly thank all the supporters who have worked with us in our first 15 months, from organisations who generously provided financial contributions and grants that were essential to enable the independent Council to 'get off the ground' to those who have worked in collaboration with us.

Dr Yves Joannette

# The World Dementia Council's history

During its 2013 Presidency of the G8, the UK took a decisive approach to one of the most pressing challenges facing the world today – dementia.

The Dementia Summit hosted by the Prime Minister in December 2013 was a prominent element of this approach. For the first time ever, the Summit brought together health and science ministers from the G8 countries, international experts and researchers, leaders of the global pharmaceutical industries, and OECD and WHO. The nations committed to accelerating progress towards effective treatments and cures for dementia, and agreed that delivering this global challenge requires co-ordinated international leadership, co-operation and effort.

In response – and among other initiatives by the UK and the other nations – the UK Prime Minister appointed Dr Dennis Gillings as the first World Dementia Envoy and created the World Dementia Council.

The Council's purpose was to provide global advocacy and leadership on the key challenges posed by dementia. Chaired by Dr Gillings, the Council was hosted and administered throughout 2014 and 2015 by the UK Department of Health. By the end of 2015, the Council had appointed 19 high-profile members drawn from countries across the world in key stakeholder sectors, agreed its Terms of Reference, appointed a Governance and Nominations Committee, established five areas of focus for the Council's work and held its first six meetings.

## Dementia Summit, 11th December 2013, Lancaster House, London

In their declaration resulting from the Dementia Summit, the G8 Ministers agreed to:

- Set an ambition to identify a cure, or a disease-modifying therapy, for dementia by 2025
- Significantly increase the amount spent on dementia research
- Increase the number of people involved in clinical trials and studies on dementia
- Establish a new global envoy for dementia innovation, following in the footsteps of global envoys on HIV and Aids and on climate change
- Develop an international action plan for research
- Share information and data from dementia research studies across the G8 countries to work together and get the best return on investment in research
- Encourage open access to all publicly-funded dementia research to make data and results available for further research as quickly as possible.

Department of Health, UK (2014)

Nearly

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# 10 million

people develop dementia each year globally; one new case every three seconds.

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World Health Organization (December 2017)

# The World Dementia Council becomes independent

In January 2016, WDC took the next step in its evolution by transition to an independent organisation.

The Council held its seventh meeting – its first as an independent body – on 25th February 2016. At the meeting, the World Dementia Envoy handed over the post of Chair. Yves Joannette was appointed as the inaugural Chair of the independent Council, and Raj Long as Vice-Chair.

The national charity Age UK agreed to host the WDC in its central London office, and the Alzheimer’s Society of the UK agreed to act as charitable host to WDC until the Council had established itself as a legal entity. Initial executive support was provided by staff seconded from the UK Department of Health, with the Council subsequently appointing its own executive team.

The Council is indebted to the organisations that provided financial contributions and grants for the period from 1st January 2016 to 31st March 2017 to support the initial phase of the Council’s independent existence and a variety of specific projects.

## Thank you to:

Alzheimer’s Association USA

Alzheimer’s Research UK UK

Alzheimer’s Society UK

Dennis and Mireille Gillings Foundation USA

Department of Health UK

F. Hoffman-La Roche Ltd Switzerland

Health and Policy Research Institute Japan

Home Instead Senior Care USA

The Janssen Pharmaceutical Companies of Johnson & Johnson USA

The Council is pleased to report on its progress in its first 15 independent months, from January 2016 to March 2017 inclusive.

## Meetings

Up to its transition to independence, the Council had held six meetings. During the period of this report, four meetings were held.

<b>7th meeting</b>	<b>25th February 2016</b>	London, UK
<b>8th meeting</b>	<b>28th and 29th July 2016</b>	Toronto, Canada
<b>9th meeting</b>	<b>22nd November 2016</b>	Virtual, by teleconference
<b>10th meeting</b>	<b>27th and 28th February 2017</b>	Paris, France

We thank Age UK, the Alzheimer’s Association and the OECD for kindly hosting, respectively, the 7th, 8th and 10th meetings.



# The World Dementia Council's membership

By the time of the transition to independence, the Council was operating two categories of membership with formal processes in place, overseen by the Governance and Nominations Committee, for appointments and re-appointments.

## Full members

Members of the Council are individuals selected for their personal expertise and leadership in their sector, and a shared commitment to accelerating breakthroughs in addressing the global challenges of dementia. They are drawn from low, middle and high income countries across the world, and from all key stakeholder sectors:

- People living with dementia
- National and international non-government organisations
- The research sector, including those engaged in funding, commissioning or conducting research, including academic research
- Organisations engaged in health systems payment, reimbursement or health technology assessment
- Regulatory science and expertise
- Biosciences, e-health and technology industries
- Health and care systems service providers
- The finance and banking sector
- Media and communications.

The Council's multi-sectoral composition is unique and is its strength. It positions the Council like no other body to identify synergies and opportunities between sectors and organisations to accelerate progress in addressing the challenges of dementia, and to influence collaboration in ways that will help catalyse the global response to the condition.

**“The Council's multi-sectoral composition is unique and is its strength.”**

Members attend WDC meetings, vote on key issues and chair or participate in WDC's working groups, known as Global Teams.

## Associate members

Associate members are organisations, including national Governments, governmental organisations and non-governmental organisations. Their role is to help ensure that WDC's agenda aligns with other global dementia initiatives and stakeholders, and provide the Council with advice, guidance and intelligence.

Each associate member nominates a representative to WDC. The nominees attend WDC meetings and participate in Global Teams, but do not vote.

# Member appointments and renewal

At its 7th meeting In February 2016, the Council refreshed the principles for membership and agreed the future process for nomination and election of the Chair, Vice-Chair and members, along with periods of service.

A key principle was expansion from 19 to 24 full members. New appointments at the 7th meeting brought the number to 23, and the remaining place was filled later in 2016.

In its membership, the Council aims to keep a balance between the sectors listed on page 6. Other key principles are to reflect a geographic spread and diversity of gender, age and ethnicity among the members; and to maintain a balance of current and new members.

Each year, one-third of the full members (8) step down and are replaced by new members. To begin this rotation from February 2016 onwards, one-third of members were appointed for one year, one third for two years, and one third for three years. Members appointed for one or two years may be re-appointed for a further three years. The composition of the associate members is reviewed annually, in order to ensure that the group reflects the Council's evolving focus and priorities.

The Chair and Vice-Chair are elected from among the full members. Once a member is elected Chair or Vice-Chair, their term as a member expires and they begin a new term. The newly-elected Chair serves for two years and the Vice-Chair serves for two years in that appointment, followed by a further two years as Chair.

The appointment process continues to be overseen by the Governance and Nominations Committee.

The annual appointments process is the “membership refresh”. The first refresh was carried out in Autumn 2016, for appointments from February 2017. Five existing members were re-appointed and three new members were appointed. Yves Joanette was re-appointed as Chair for two years from February 2017 to February 2019, and Raj Long as Vice-Chair for February 2017 to February 2018.

**The full and associate members are listed in Appendix 1.**

## Governance and Nominations Committee *from February 2016*

George Vradenburg, Committee Chair

Philippe Amouyel

Hilary Doxford

Yves Joanette

Harry Johns

Raj Long

Meera Pattabiraman

Ronald Petersen

Paul Stoffels (to December 2016)

Kate Swaffer



George Vradenburg.



Meera Pattabiraman.



Jeremy Hughes.

## World Dementia Council Trustees

**Yves Joannette**, Chair, from December 2016

**Jeremy Hughes** from February 2017

**Raj Long** from December 2016

**Meera Pattabiraman** from February 2017

**George Vradenburg** from December 2016

# The World Dementia Council becomes a legal entity

As an independent organisation from January 2016, WDC operated initially as an unincorporated association under Terms of Reference that were agreed at the 7th meeting in February 2016.

From February to July that year, options for establishing WDC as a legal entity were explored by an ad hoc working group chaired by DY Suharya.

At its 8th meeting in July 2016, the Council agreed the working group's recommendation to establish WDC as a London-based charity in the form of a Charitable Incorporated Organisation (CIO). It was also agreed that the Trustees of the CIO should be the WDC Chair, the Vice-Chair, the Chair of the Governance and Nominations Committee and two other full Council members.

Following this decision, an application for registration as a CIO was made to the Charity Commission for England and Wales, which registers and regulates charities in those countries. The World Dementia Council was consequently registered as a CIO on 14th December 2016 under registration number 1170743.

The WDC Chair, Vice-Chair and Chair of the Governance and Nominations Committee – respectively Yves Joannette, Raj Long and George Vradenburg – led the application process. On granting of charitable status, they became the founding Trustees of the CIO. Following a call for volunteers and voting process among the other full members, Meera Pattabiraman and Jeremy Hughes were appointed as the other two Trustees on 28th February 2017.

Within the CIO format, the Council's full members are members of the CIO and the relationship with associate members is unchanged. In moving to an independent organisation and then to a CIO, the Council maintained as much of its previous culture and integrity, as enshrined in the Terms of Reference, as possible.

### CIO ad hoc working group 2016

*Council members*

**DY Suharya** Working Group Chair

**Philippe Amouyel**

**Harry Johns**

**George Vradenburg**

*Co-opted*

**Steph Harland** Age UK Deputy Chief Executive, for expertise on charity structures.

# The World Dementia Council's themes and Global Teams

By the end of 2015, the Council had adopted five themes for its work:

**Finance** – catalysing increased public and private investment in research on dementia.

**Integrated development** – accelerating regulatory pathways to accelerate development of new drugs for dementia.

**Research, open science and data** – encouraging sharing of, and access to, academic and other databases holding data relevant to developing effective interventions for dementia.

**Care** – stimulating improvements in care and support for people living with dementia and their families.

**Risk reduction** – approaches to reducing the risk of dementia.

In order to maintain continuity post-transition, the Council decided at its 7th meeting in February 2016 to continue its focus on these themes and to appoint Global Teams to drive each one forward. The decisions were rooted in the aim of achieving a balance in WDC's work between dementia treatments and cure, care and risk reduction.

The Global Teams would each be led by a full member and comprise other full members, associate members and experts external to the Council, and be supported by the WDC's executive team.

After the 7th meeting, volunteers were sought and, by the time of the Council's 8th meeting in July 2016, the Global Teams had been established and had set out their areas for action. Following review at the 8th meeting, the Global Teams commenced work on the action areas.

On this basis, WDC developed a document "Delivering the difference: World Dementia Council plan for 2016–2018" that was published in September 2016.

[Delivering the difference online](#)

In addition, the Council adopted cross-cutting themes that would apply across its work:

- Women and dementia
- Awareness
- Stigma
- Inequalities
- Low- and middle-income countries

In the following sections, we report on the aims, action areas and progress of the Global Teams to March 2017.

## The Global Teams and Leads

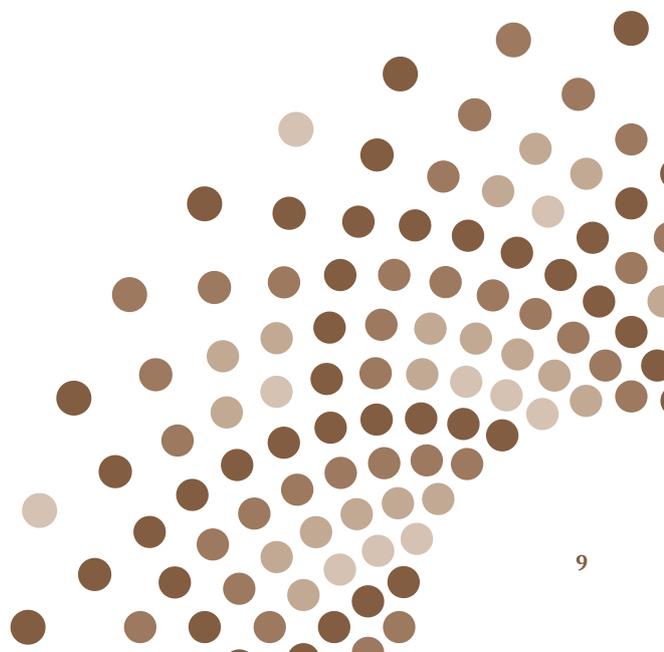
**Chris Llewellyn** Finance Global Team

**Raj Long** Integrated Development Global Team

**Philippe Amouyel** Research, Open Science and Data Global Team

**Harry Johns** Care Global Team

**Ronald Petersen** Risk Reduction Team



# Finance Global Team

## Aim

To catalyse an increase in global levels of public and private financing and investment into dementia research and help enhance its effectiveness, including by identifying funding approaches from other disease areas.

## Action areas

1

Design and promote a research funding dashboard, using existing data, to highlight global disparities between funding gaps and funds that are already available to tackle dementia.

2

Identify existing and/or innovative funding models and approaches from other disease areas, e.g. cancer and HIV, and determine how these can be applied to the field of dementia.

3

Bring together key figures to disseminate the dashboard and related intelligence around funding models, as a means of influencing the behaviour of funders in reducing and eliminating funding disparities and enhancing effectiveness.

## Progress

The Finance Global Team's first focus was on Action area 1, an ambitious and complex project.

Following the Council's meeting in July 2016, the Global Team shaped the project for feedback at the Council's meeting on 22nd November 2016 and formed a small Working Group to ensure rapid progress.

The Working Group comprised two Global Team members and two external experts who committed their time in-kind, supported by a member of the WDC executive team, and met almost weekly between December 2016 and March 2017.

By the end of 2016, the Working Group had designed the project in detail, developed the initial storyline to ensure targeted qualitative and quantitative data-gathering and analysis, developed a list of key experts in the dementia field to invite to take part in qualitative interviews, and agreed a set of initial interview questions. The expert interviews were each conducted by two members of the Working Group with the objective of gaining input on the areas of greatest need in research and funding.

In January 2017, the group engaged a consultant experienced in evidence synthesis and financial and economic analysis, and familiar with the topic of dementia. The consultant researched existing datasets and reached out to data experts. Contact was made with WHO, OECD and Alzheimer's Disease International to ensure that this project as designed would complement and not duplicate any work already undertaken. All information collected was collated and analysed, and compiled into a slide presentation.

The Finance Global Team met twice in February to review evolving drafts of the presentation, which was presented to the WDC10 meeting in February 2017. Breakout discussions helped further to shape the content and prioritise areas in which WDC could make impactful calls to action.

Following the meeting, a draft narrative report was prepared, edited and reviewed by the Working Group. This stage of the project continued until April 2017 and beyond, with the narrative report to be presented to the Council's 11th meeting in July 2017 for feedback before the final stages of external review, refinement and publication.



## The finance report will present a compelling narrative about:

- The current status of dementia research funding and under-investment against the background that there is currently no disease-modifying therapy for dementia and in relation to investment in other conditions that were selected as comparators for the project (cancer; cardiovascular disease); and
- Areas where targeted changes in dementia research funding could have significant impact on the future outcomes for people with dementia.

The results of this project will be a first on the worldwide stage.

### **Finance Global Team members**

#### *Full members*

**Chris Llewellyn** Team Lead

**Kiki Edwards**

**Jeremy Hughes**

**Paul Stoffels** (to December 2016)

**George Vradenburg**

#### *Representatives of associate members*

**William Hu**

# Integrated Development Global Team

## Aim

To increase the speed and reliability of delivering innovative dementia medicines through creating an efficient and effective global treatment development pathway, and increase patients' access to dementia medicines, treatments and health technologies across the world.

## Action areas

1

Identify and engage with key bodies that provide funds for, commission and/or enable access to dementia medicines and health technologies across the world.

2

Work with these bodies to develop and implement a global plan for developing effective dementia treatments and innovations.

## Progress

The Council wants to see acceleration in the development of new, effective medicines, treatments and technologies (“interventions”) to prevent and alleviate dementia, and quicker access to those interventions, when they become available, by people living with dementia and their families.

The former depends on increased investment and collaboration in research. The latter relies on two elements:

- The regulatory pathways that apply to gaining approval and registration for interventions to be placed on the market; and
- Once interventions are on the market, availability to patients and families depends on the structure of healthcare systems, decisions by ‘payers’ (e.g. public/government organisations that recommend or commission what interventions should be made available to patients; insurance companies paying for clients’ medical treatments in private health care systems) and affordability.

This is a complex picture, made more complex by differing research, regulatory and access frameworks within different geographies.

Having defined its aims and actions, the Integrated Development Global Team assessed the landscape in this area and concluded that further actions would overlap with existing initiatives by other stakeholders that had commenced between 2014 to 2017. An example of these initiatives is shown in the panel.

Since avoiding duplication is among the Council’s key principles, it was decided that the Global Team should not seek to drive a similar agenda forward for the time being and its work was therefore put ‘on hold’ in February 2017. It is, however, important to keep abreast of developments in this area, and Council members who are involved in various relevant initiatives at national and regional level keep the Council aware and informed.

The Council’s direct involvement and priorities in this area will be reviewed in early 2018.

# The ROADMAP project – towards patient access to treatments

In 2016, the Innovative Medicines Initiative (IMI) awarded funds for the ROADMAP project, which is running for two years to October 2018. IMI is a European public-private life sciences partnership that aims to accelerate the development of innovative medicines and patient access in areas of unmet need.

The ROADMAP project – “Real world outcomes across the Alzheimer’s Disease spectrum for better care: multi-modal data access platform” – is creating and testing methods and tools that will allow “...the scalable, transferable integration of data on patient outcomes in the real world.” This is a welcome step towards a Europe-wide platform on real world evidence for the disease. Hand-in-hand with this, tools for patient engagement will also be developed. The project has the potential to better inform regulators on efficacy and safety of potential interventions for the disease, providers on cost effectiveness and industry on pricing and manufacturing. This would underpin acceleration of decision-making on re-purposing current treatments and developing new treatments.

## **Integrated Development Global Team members**

### *Full members*

**Raj Long** Team Lead

**Kiki Edwards**

**Kiyoshi Kurokawa**

**Paul Stoffels** (to December 2016)

**George Vradenburg**

### *Representatives of associate members*

**Megan Zoschg-Canniere**

**Johannes Levin**

# Research, Open Science and Data Global Team

## Aim

To foster and promote: a culture of open science and collaborative global research into dementia; a strategic approach to research across the spectrum of the disease; and research into interconnected dementia related issues.

## Action areas

1

Facilitate the global expansion of research programmes, such as the EU Joint Programme – Neurodegenerative Diseases Research (JPND).

2

Develop a global WDC statement promoting open science, i.e. facilitating data sharing and collaboration.

3

Promote the use of national healthcare and administrative databases amongst public and private payers and commissioners to anticipate impact of treatments and care in real life.

4

Encourage stakeholders to be advocates for improved increased collaboration around dementia research and address barriers to them doing so.

5

Influence and encourage governments to invest in public intervention trials designed to demonstrate the potential for reducing the risk of dementia, in partnership with the Risk Reduction Global Team.

## Progress

### Expanding research collaboration

WDC is uniquely positioned to advocate for increased collaboration world-wide and to facilitate the global expansion of research programs such as JPND. JPND is a European initiative aimed at coordinating neurodegenerative disease research across national borders, in Europe and beyond.

Discussions with JPND in October 2016 focused on areas where joint working could add value to JPND's dementia research programming. As a result, the Global Team defined a strategy for WDC to facilitate expansion of the programme and agreed a protocol with JPND to support a systematic and synchronised approach of countries to this end. Two letters of support were agreed on between JPND and WDC, both to be used in accordance with the protocol. One letter aims to encourage countries already in contact with JPND to join, and the other to engage countries not yet in contact with JPND to consider joining.

This paved the way for WDC to write to key individuals in target countries – primarily at Ministerial level – identified jointly by WDC and JPND, using one of the agreed letters. South Korea and India have been confirmed as new JPND participants, and discussions have opened with two countries in the Asia region.

WDC also helped to facilitate discussions between JPND and the US National Institute of Aging, the primary US Federal agency supporting research on ageing, during a JPND management board meeting organised by the WDC Chair in Montréal in 2016. As a result, the two organisations each identified in 2017 two specific calls for dementia research grant applications that could find synergies and initiate a first collaboration.

Moving into April 2017 and beyond, regular cross-engagement between WDC and JPND has continued through the participation of WDC members in the JPND Management Board.

## Open science and data sharing

The objective for Action area 2 is to enhance open science and data sharing in academia and industry, based on recommendations made in the OECD 2015 report “Big Data for Advancing Dementia Research”.

While the report identified gaps and barriers, there is no consensus on best practices in and incentives for data sharing across the dementia community. The Global Team has discussed ways in which WDC could leverage its membership to encourage and advocate for more rapid data disclosure and identified existing efforts, including:

- The Collaboration for Alzheimer’s Prevention (CAP) statement on the timeliness and effectiveness for disclosure of clinical trial results.
- The Yale University Open Data Access (YODA) Project, a collaboration with Johnson & Johnson that allows scientists to gain access to J&J’s clinical trial data and to promote its use to generate new knowledge.

Moving into April 2017 and beyond, the Global Team will further consider endorsing these and similar initiatives and sending a letter on behalf of WDC to industry groups and trade associations encouraging companies to voluntarily disclose clinical trial data more rapidly.

## Promote the use of big databases and advocate for increased collaboration

There have been extensive discussions on Action areas 3 and 4 since the Council’s 8th meeting in July 2016 on what actions should be taken by WDC. The objective for Action area 3 is to build a permanent network between the owners/users of major national databases in the world to: (a) define the best way forward towards efficient, trans-national collaboration in the analysis of such big data; and (b) propose analytical strategies to test the impact of the introduction of new drugs into existing health care systems to improve the way regulators and payers make decisions when they receive these new drugs for evaluation. The objective for Action area 4 is to advocate for a more collaborative culture within the cohort community and to address barriers by convening relevant stakeholders to share data.

In February 2017, the Global Team concluded that WDC should convene a meeting to address both priorities. The Team subsequently started to compile a list of potential invitees, possible dates and explored opportunities to align with other major meetings. A small working group will lead continued planning for this meeting beyond Spring 2017.



Philippe Amouyel.

### Research, Open Science and Data Global Team members

#### *Full members*

**Philippe Amouyel** Team Lead  
**Hilary Doxford**  
**Paul Stoffels** (to December 2016)  
**George Vradenburg**

#### *Representatives of associate members*

**Dirk Pilot**  
**Martin Rossor**  
**Tom Russ**

#### *By invitation*

**Luc Truyen** (from 2017)

# Care Global Team

## Aim

To help improve the quality of life and delivery of high-quality and affordable care and support for people living with dementia, their care partners, and their families.

## Action areas

# 1

Create and distribute a bold, informed WDC statement on the importance of – and principles for – good dementia care.

# 2

Identify the gaps in current knowledge and research around dementia care, including the areas with the greatest potential in benefiting people affected by dementia and their care partners.

## Progress

Following the Council's 8th meeting in July 2016, the Global Team developed a detailed list of actions and timelines for each priority.

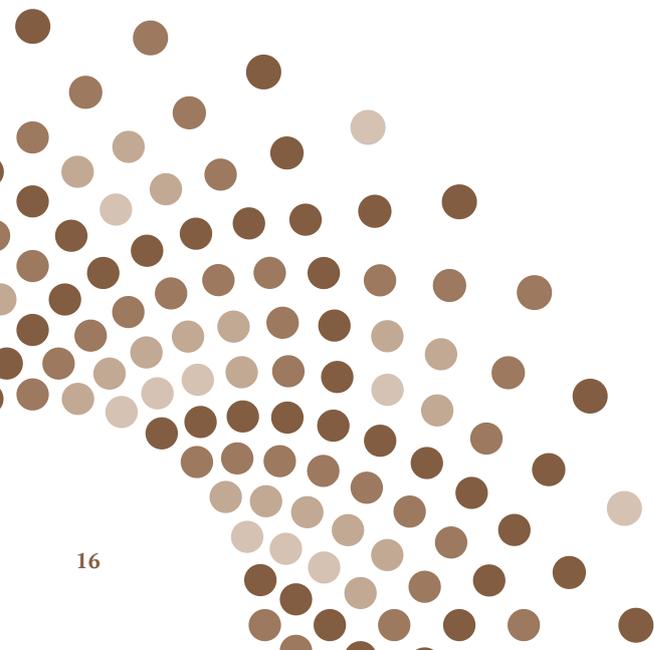
The Team's first focus then was on Action area 1 and the project was brought to near completion by the end of March 2017. The objective was to develop a statement that would (a) emphasise the importance of high-quality dementia care and support, including the human rights of people with dementia; and (b) establish culturally-sensitive key principles of high-quality dementia care and support, including the role of carers and their need for support, that are applicable to all countries.

By the time of the Council's 9th meeting in November 2016, information gathering had begun and continued through February 2017. Information was collected on economic and societal evidence and arguments for good dementia care, and on existing care principles, indicators and guidelines. Background work also included a definition of high-quality dementia care and support to provide consistency and context for comparisons across countries. The Global Care Team met twice in February to review evolving drafts of the statement.

Following presentation and discussion at the WDC10 meeting in February 2017, the statement was further refined with the input received and re-circulated to the full Council for final review and approval. The goal was to finalise the statement for distribution at the 70th World Health Assembly in May 2017.

The statement will represent diverse perspectives from across the care continuum and call on governments, governing bodies, providers, and payers to ensure those with dementia and their carers receive culturally-sensitive high-quality care and support.

**Thank you to the Alzheimer's Association for providing in-kind support and expertise to this project.**



**Care Global Team members**

*Full members*

**Harry Johns** Team Lead

**Paul Hogan**

**Jeremy Hughes**

**Meera Pattabiraman**

**DY Suharya**

**Kate Swaffer**

**Li-Yu Tang**

*Representatives of associate members*

**Kees van der Burg**

**Marjolein van der Marck**

**Shekhar Saxena**

WHO estimates that

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**50 million**

people worldwide (around 5% of people aged 60 and above) are affected by dementia.

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World Health Organization (December 2017)

Harry Johns.

# Risk Reduction Global Team

## Aim

To reduce the risk and impact of dementia by:

- Encouraging effective disease prevention methods; and by
- Increasing awareness and reducing risk amongst those who are most at risk.

## Action areas

# 1

Influence global programmes that focus on healthy ageing and brain health (e.g. those run by the Global Brain Health Institute and the Global Council on Brain Health).

# 2

Ensure that the perspectives of LMICs are included in these programmes and that their needs are prioritised.

# 3

Support LMICs in engaging in activities that reduce the risks of dementia, e.g. by encouraging the development of a proposed model for risk reduction, through a pilot programme in Indonesia.

## Progress

Following the Council's meeting in July 2016, the Global Team initiated strategic discussions with relevant organisations to explore collaborations on risk reduction.

WDC and Global Team members are advisors to, and actively engaged in, relevant organisations and initiatives, ensuring exchange of information and WDC's influence where appropriate. The Global Team update at the Council's 10th meeting in February 2017 included an overview by one of the Global Team members on risk reduction efforts in South America.

A key partner for WDC is the Global Council on Brain Health (GCBH). GCBH is an independent collaborative of scientists, health professionals, scholars and policy experts from around the world working in areas of brain health related to human cognitive function. The GCBH is convened by AARP with support from Age UK to provide evidence-based recommendations for people to consider incorporating into their lives. WDC's Chair and the Risk Reduction Global Team Lead are on the GCBH's Governance Committee, ensuring ongoing dialogue and engagement. They and other WDC members also participate in drafting and reviewing recommendations issued by GCBH. WDC has also facilitated a connection between GCBH and WHO.

Another important collaboration that has been initiated is with the Global Brain Health Institute (GBHI). Launched in 2015 by the University of California, San Francisco and Trinity College Dublin with support of The Atlantic Philanthropies, GBHI works to reduce the scale and impact of dementia around the world by training and supporting a new generation of leaders to translate research into effective policy and practice.

The GBHI has looked to WDC to help identify leaders in LMICs, and the Global Team has explored a collaboration with GBHI to facilitate a risk reduction pilot project in Indonesia. The objective is to identify a suitable candidate to undertake training at GBHI in San Francisco and to learn about a risk reduction model, which she or he would then apply in Indonesia under continued GBHI mentorship. If successful, the pilot project may be extended in other LMICs.



Ronald Petersen.

The WDC was also apprised of a study sponsored by the US National Institute on Aging in conjunction with the US National Academies of Science, Engineering and Medicine (NASEM) pertaining to an evidence-based medicine review of the literature on preventing cognitive decline. The report, Preventing Cognitive Decline and Dementia: A Way Forward, outlined the current state of the field regarding interventions and was published in June 2017. The Risk Reduction Global Team Lead, Ronald Petersen, was a member of the NASEM committee. [View the report here](#)

Beyond April 2017, the Global Team will continue to focus on strategic collaborations and influence global programmes focused on health ageing and brain health. It will also ensure co-ordination of relevant actions with other Global Teams.

### Risk Reduction Global Team members

#### *Full members*

**Ronald Petersen** Team Lead  
**Riccardo Allegri**  
**Hilary Doxford**  
**Meera Pattabiraman**  
**DY Suharya**  
**Kate Swaffer**

#### *Representatives of associate members*

**Martin Rossor**  
**Shekhar Saxena**  
**Whitney Wharton**  
**Tom Wright**

# Focus on low- to middle-income Countries

In today's ageing world, the prevalence of dementia is increasing globally at a significant rate, notably in low to middle income countries (LMICs), home to nearly 60% of all people living with dementia worldwide.

However, in many LMICs, dementia is poorly understood and/or associated with stigma and exclusion from society, and health and care systems are not adapted to provide support for people with dementia and their families.

For these reasons, the particular needs and perspectives of LMICs are a cross-cutting theme for the Council and are brought to the table by members from LMICs.

At its 10th meeting in February 2017, the Council agreed further to embed the interests of LMICs in its work by forming a dedicated LMIC group to make recommendations on how the Council can give voice and add value to efforts in LMICs to raise awareness of dementia and make progress in priority issues.

The group's first meeting on 24th March 2017 assessed the landscape and key issues for the LMICs, identifying that, common to all, awareness raising is the foundation on which their future ability to improve lives for people living with dementia and their families depends – from addressing stigma, to improved diagnosis and care, to government commitments to adopt national dementia policies, to creating dementia-friendly societies.

The group scoped actions and partnerships that the Council could pursue, for development in 2017–18.

## WDC LMIC group

**DY Suharya** Chair, Indonesia

**Kiki Edwards** Nigeria

**Meera Pattabiraman** India

**Li-Yu Tang** Taiwan

## Nearly

# 60%

of people with dementia currently live in low- and middle-income countries.

World Health Organization (December 2017)



DY Suharya.

# Working with emerging leaders in dementia

Following the G8 Dementia Summit in December 2013, a series of international Legacy Events took place in 2014 and 2015 to maintain and build on the global momentum on dementia action that the Summit had generated. The events were held in Ottawa, Tokyo, Washington DC and London.

The UK Science & Innovation Network invited emerging leaders working in diverse fields of dementia to meet at these events to develop innovative ideas across the breadth of the global dementia programme.

As a result, the invitees worked together to develop a set of proposals to present at WHO's First Ministerial Conference on Global Action Against Dementia in March 2015 and united to form a new network – the World Young Leaders in Dementia (WYLD) network.

Today, the network has developed to include over 200 millennials and xennials from 29 countries across six continents working in the clinical, academic, care, advocacy and commercial sectors.

The WDC is committed to encouraging the emerging leaders and to capturing their perspectives and innovative thinking in its work. The WYLD network has become an associate member of the Council, and WYLD members attend Council meetings and participate in each of the WDC's Global Teams. WYLD promotes the work of the WDC, for example by disseminating the Council's Global Care Statement and translating it into multiple languages. Among other activities, the network engages in Youth Dementia Awareness activities, and has initiated a working group on Dementia Friendly Communities.

The Council pays tribute to the young leaders' energy and passion, and the commitment and valuable contributions that they have made to the Council's work.



**Read more**

[WYLD website](#)

[Youth Dementia Awareness](#)

[Dementia Friendly Communities](#)

## WDC meetings

<b>7th meeting</b>	<b>25th February 2016</b>
<b>8th meeting</b>	<b>28th and 29th July 2016</b>
<b>9th meeting</b>	<b>22nd November 2016</b>

## WYLD network participant

Anja Leist
Laura Booi
Anja Leist

## WDC Global Teams

Finance
Integrated development
Research, open science and big data
Care
Risk reduction

## WYLD network participant

William Hu (US)
Johannes Levin (DE)
Tom Russ (UK)
Marjolein van der Marck (NL)
Whitney Wharton (US)

# Awareness and collaboration on the global stage

The Council aims to raise awareness and understanding of dementia across the globe and play a role in international developments. Increasing the newly-independent Council's visibility was also a focus in 2016–17.

## International developments

### The WHO Global Dementia Observatory

The First Ministerial Conference on Global Action Against Dementia took place in March 2015. Recognising the importance of monitoring global and national efforts on dementia, the conference called for development of a WHO Global Dementia Observatory.

Subsequently, WHO held a two-day consultation meeting in July 2016 on shaping the GDO. Five full members of the Council – Philippe Amouyel, Yves Joanette, Raj Long, Ronald Petersen and Kate Swaffer – were among the international experts present. The Council was one of six key stakeholders whose perspectives were heard in the opening session. Representatives of associate members in the Netherlands, Japan and the UK also took part in the meeting.

The systematic data that the Observatory will collect offers unprecedented opportunities to monitor progress in addressing and overcoming the challenges of dementia in four domains: national dementia policies to address the impact of dementia; resources for dementia prevention, treatment and care; research towards improved treatments and care; and epidemiology to assess the prevalence and burden of dementia.

The Council looks forward to working with the Observatory and using the monitoring data to advance its aims.

### The WHO Global Action Plan on the Public Health Response to Dementia 2017–2025

In June 2016, the Executive Board of WHO asked its Secretariat to draft a Global Action Plan on the Public Health Response to Dementia. The Council took part in the consultation process that followed, a process that led to approval of the proposed plan by the WHO Executive Board in January 2017.

Ultimately, the Plan was endorsed in May 2017 by the Seventieth World Health Assembly. The Council welcomed the decision and our six country associate members – Australia, Canada, Japan, Mexico, The Netherlands and the UK – delivered a joint statement to the Assembly supporting the Plan's adoption.

The Council looks forward to working with WHO and other stakeholders on implementation of the seven action areas of the Plan wherever we can add value to this effort.

### National dementia plans

In November 2016, the Council congratulated the Argentinian Government on its newly-adopted National Strategic Plan for Brain Health, Alzheimer's Disease and Other Dementias 2016–2019. In January 2017, Yves Joanette participated in meetings at the Argentinian Ministry of Health designed to stimulate actions to implement the Plan.

### WDC recognised by G7

In their Communiqué following their meeting in Kōbe in September 2016, the G7 Health Ministers reaffirmed their commitment to action against dementia and support of the Council's role in driving forward a global approach to meeting the challenges of dementia.

### The seven action areas of the WHO Global Action Plan on the Public Health Response to Dementia 2017–2025

- 1 Dementia as a public health priority
- 2 Dementia awareness and friendliness
- 3 Dementia risk reduction
- 4 Dementia diagnosis, treatment, care and support
- 5 Support for dementia carers
- 6 Information systems for dementia
- 7 Dementia research and innovation

# Increasing visibility, raising awareness

To increase awareness of dementia and the Council's profile, members have regularly taken to the stage at international conferences and meetings, as shown by the following examples.

## 2016

### April

#### **Alzheimer's Disease International: 31st International Conference (Budapest)**

In a session titled, "Global dementia policy updates," Yves Joannette presented on the new phase of the World Dementia Council's evolution and priorities.

### May

#### **Dutch EU Presidency conference: *Living well with(out) dementia (Amsterdam)***

Together, the Council (Yves Joannette) and WHO gave an introductory statement to the conference, expressing the complementarity and collaboration between the two organisations.

### July

#### **Dominantly Inherited Alzheimer Network-Trials Unit and the Alzheimer's Association: 2016 DIAD Family Conference (Toronto)**

Yves Joannette gave a presentation on the voices of people living with dementia in the global Alzheimer's disease ecosystem, advocacy and public policy.

### September

#### **Alzheimer's Disease International: 3rd African Regional Conference (Nigeria)**

Yves Joannette gave an address via video link on the Council's history and future plans.

### October



#### **Alzheimer Europe: 26th Conference (Copenhagen)**

Hilary Doxford addressed the Conference, explaining the Council's work and her own experiences of living with dementia, advocating for the inclusion of people with dementia in all debates on improving lives.

#### **Asian Society Against Dementia: 10th International Conference (Hangzhou)**

Raj Long gave a presentation on the global population challenges of dementia and the global response, and the history, role and priorities of the Council.

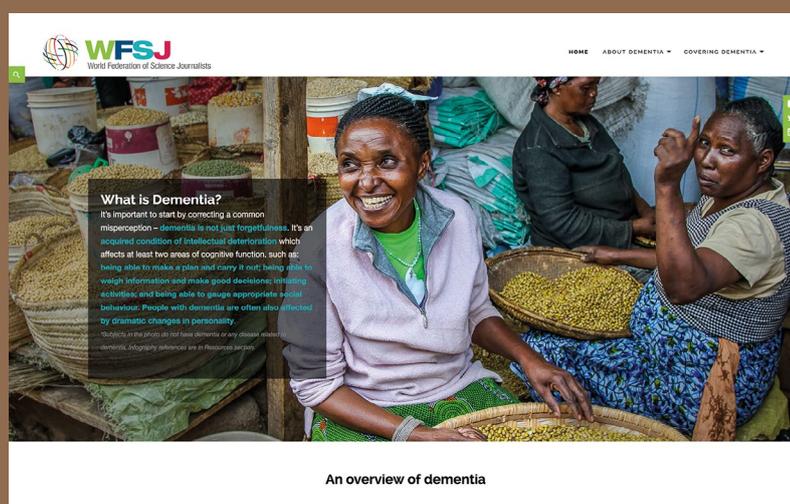
## 2017

### March

#### **Italian Society for Dementia: 12th Annual Meeting (Florence)**

In an invited lecture titled, "A Global Response to the Global Challenge of Dementia," Yves Joannette raised awareness of the diseases that cause dementia, the social and economic global impact of dementia, and the fear that dementia causes.

# The World Federation of Science Journalists – Dementia Toolkit



[www.wfsj.org/dementia](http://www.wfsj.org/dementia)

The World Dementia Council connected with the World Federation of Science Journalists (WFSJ), a not-for-profit organisation that represents 55 science journalists' associations across Africa, the Americas, Asia-Pacific, Europe and the Middle East.

The Federation creates Toolkits for journalists across the world to encourage understanding and accurate reporting in areas including health, medicine and technology. At the time of the Council's connection, the Federation had Toolkits for some health conditions, for example infectious diseases and Hepatitis C, but no Toolkit for dementia, despite the condition being a major global issue.

Drawing in additional partners, including Alzheimer's Disease International, the Council worked with WFSJ to create a Toolkit on Dementia, and provided modest financial support to enable the Federation to design and launch the Toolkit on its website.

The Toolkit aimed initially to support journalists in Sub-Saharan Africa given the scale but lack of understanding of dementia in this region. However, the content – including information, statistics and tips for appropriate reporting on dementia – is relevant worldwide.

## Communications and engagement

In 2017, work to develop a communications and engagement plan for the Council was initiated. To support delivery of the project, a communications consultant and a design agency were engaged.

In 2017, work to develop a communications and engagement plan for the Council was initiated. To support delivery of the project, a communications consultant and a design agency were engaged, the latter to work on a redesign of the website.

A proposed tone of voice, together with a refreshed vision and core messaging, was developed to effectively communicate WDC's role, function, vision and work priorities, and proposals for the website design and content were set out.

The proposals were presented to the Council at its 10th meeting in February 2017 and members' input fed into further development and refinement. This work continued into 2017–18 and the new website was launched and promoted using social media in May 2017.

In addition, work began on a communications strategy and stakeholder engagement plan, with the expectation that it would be completed in 2017–18.

These activities enhanced WDC's focus on communications, providing the foundation for the Council to continue to build its presence and visibility and build its stakeholder infrastructure and engagement.

Full and associate members came together with selected external experts to work on developing a strategic approach to communications and advising on the refreshed messaging and website.

### Communications and engagement development group

#### *Full members*

**Jeremy Hughes** Chair

**Riccardo Allegri**

**Philippe Amouyel**

**Phyllis Ferrell**

**Paul Hogan**

**Yves Joannette**

**George Vradenburg**

#### *Representatives of associate members*

**Kim Elmslie**

**Frank Hagelstein**

**Jaqueline Hoogendam**

#### *By invitation*

**Sarah Knapp**

**Amy Little**

**Luc Truyen**

## Monitoring and evaluation

Work was undertaken to establish a framework for evaluation to enable the Council to monitor its performance and progress in meeting its objectives.

The framework identified key issues (such as attribution of impact in the complex, multi-sector environment in which the Council works) and set out a Theory of Change model together with sub-frameworks for monitoring and evaluation of each of the Global Teams' actions. The Council expects to continue this line of work in 2017–18.

# Financial information

For the initial stage of the Council's independent existence, before establishing itself as a legal entity in the form of a Charitable Incorporated Organisation (CIO), the Alzheimer's Society in the UK kindly agreed to act as its charitable host.

This arrangement, which commenced in January 2016, not only provided financial administration but also enabled donations and grants to be raised to fund the Council's activities. The Alzheimer's Society placed all income for this purpose in a restricted account within their financial set-up, and all payments from the account were made only by agreement of nominated representatives of the Council.

The Council was registered as a CIO by the Charity Commission for England and Wales on 14th December 2016. This enabled the Council to initiate direct financial transactions and its own banking arrangements; a bank account was opened in March 2017. Given these developments, the Alzheimer's Society ceased acting as charitable host on 31st March 2017, and transferred the balance of funds in its restricted account for the Council into the Council's bank account in April 2017.

The Council's office is within the premises of Age UK in London. Age UK became responsible for the supporting the Council's financial administration on 1st April 2017.

The Council thanks all organisations who made its establishment as an independent organisation possible through donations and grants in the period January 2016 to March 2017; the organisations are listed on page 5. The Council also thanks the Alzheimer's Society for acting as charitable host in those 15 months.

The Council's first set of independently examined or audited annual accounts as a CIO will be due in 2018. In the intervening period, the Trustees of the Council elected to satisfy themselves that the administration of funds from 1st January 2016 to 31st March 2017 had been appropriate and in line with the underlying agreements. This was confirmed by Crowe Clarke Whitehill LLP, Chartered Accountants, through their performance of Agreed-Upon Procedures in accordance with International Standard on Related Services 4400 "Engagements to Perform Agreed-Upon Procedures Regarding Financial Information." Please note: this does not represent an independent examination or audit.

A summary of financials for this 15-month period is set out below. The first set of formal accounts for the CIO will date from the date of registration on 14th December 2016.

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The estimated cost of dementia to society is US\$

**818 billion**

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Alzheimer's Disease International, World Alzheimer Report 2015.

## Summary Income and Expenditure

1st January 2016 to 31st March 2017

Charitable Income	£710,056.60
Staff costs	£299,028.17
Travel and conference expenses	£49,209.48
Office costs	£30,694.76
Legal and audit costs	£18,951.72
Marketing and strategy costs	£35,539.11
Net surplus	£276,633.36

## Statement of Financial Position

as at 31st March 2017

<i>Current assets</i>	
Accrued Income	£41,960.40
Cash at bank and in hand	£234,672.96
Net Assets	£276,633.36
Available funds*	£276,633.36

\*The available funds were transferred by the Alzheimer's Society into the Council's bank account in April 2017.

**The Council thanks all organisations who made its establishment as an independent organisation possible.**

# Appendix 1

World Dementia Council membership February 2016 to March 2017.

## Full members

Full members of the Council are individuals selected for their personal expertise and leadership in their sector, and a shared commitment to accelerating breakthroughs in addressing the global challenges of dementia. They are drawn from low, middle and high income countries across the world, and from all key stakeholder sectors.

Name	Sector	Appointments and retirements
Ricardo Allegri	Research	Appointed February 2016. Reappointed February 2017 to February 2020.
Philippe Amouyel	Research	Appointed February 2016 to February 2019.
Deborah DiSanzo	Industry (technology)	Appointed April 2016, retired December 2016.
Hilary Doxford	Person living with dementia	Appointed February 2016 to February 2018.
Kiki Edwards	Care (service provision)	Appointed February 2016 to February 2019.
Dennis Gillings CBE	Industry (pharmaceutical/contract research)	Appointed February 2016, retired February 2017.
Adrian Gottschalk	Industry (pharmaceutical)	Appointed February 2016, retired in 2017.
Margaret Hamburg	Regulatory	Appointed February 2016 to February 2018.
Paul Hogan	Care (service provision)	Appointed February 2016 to February 2018.
Jeremy Hughes	NGO	Appointed February 2016 to February 2018.
Franz Humer	Industry (pharmaceutical)	Appointed February 2016, retired December 2016.
Yves Joannette	Research	Appointed February 2016 as Chair. Reappointed February 2017 to February 2019.
Harry Johns	NGO	Appointed February 2016 to February 2019.
Kiyoshi Kurokawa	Research	Appointed February 2016. Reappointed February 2017 to February 2020.
Chris Llewellyn	Finance	Appointed February 2016 to February 2019.
Raj Long	Regulatory	Appointed February 2016 as Vice-Chair. Reappointed February 2017 to February 2018.
Tetsu Maruyama	Industry (funding)	Appointed February 2017 to February 2020.
Pierluigi Nicotera	Research	Appointed February 2016. Reappointed February 2017 to February 2020.

## Appendix 1 – Continued

Name	Sector	Appointments and retirements
Meera Pattabiraman	NGO	Appointed February 2016. Reappointed February 2017 to February 2020.
Ronald Petersen	Research	Appointed February 2016 to February 2019.
Larry Renfro	Payment, reimbursement and health technology assessment	Appointed February 2016, retired in 2017.
Lisa Rometty	Industry (technology)	Appointed February 2017.
David Ricks	Industry (pharmaceutical)	Appointed February 2016, retired in 2017.
Paul Stoffels	Industry (pharmaceutical)	Appointed February 2016, retired December 2016.
DY Suharya	NGO	Appointed February 2016 to February 2019.
Kate Swaffer	Person living with dementia	Appointed February 2016 to February 2019.
Li-Yu Tang	NGO	Appointed February 2016. Reappointed February 2017 to February 2020.
George Vradenburg	NGO	Appointed February 2016 to February 2018.

### Two new members were appointed in 2017, after the period of this report:

Name	Sector
Samantha Budd Haeberlein	Industry (pharmaceutical)
Phyllis Ferrell	Industry (pharmaceutical)

## Appendix 1 – Continued

### Associate members

Associate members are organisations, including national Governments, governmental organisations and non-governmental organisations. Each associate nominates a representative to WDC. Their role is to help ensure that WDC’s agenda aligns with other global dementia initiatives and stakeholders, and provide the Council with advice, guidance and intelligence.

### Governments

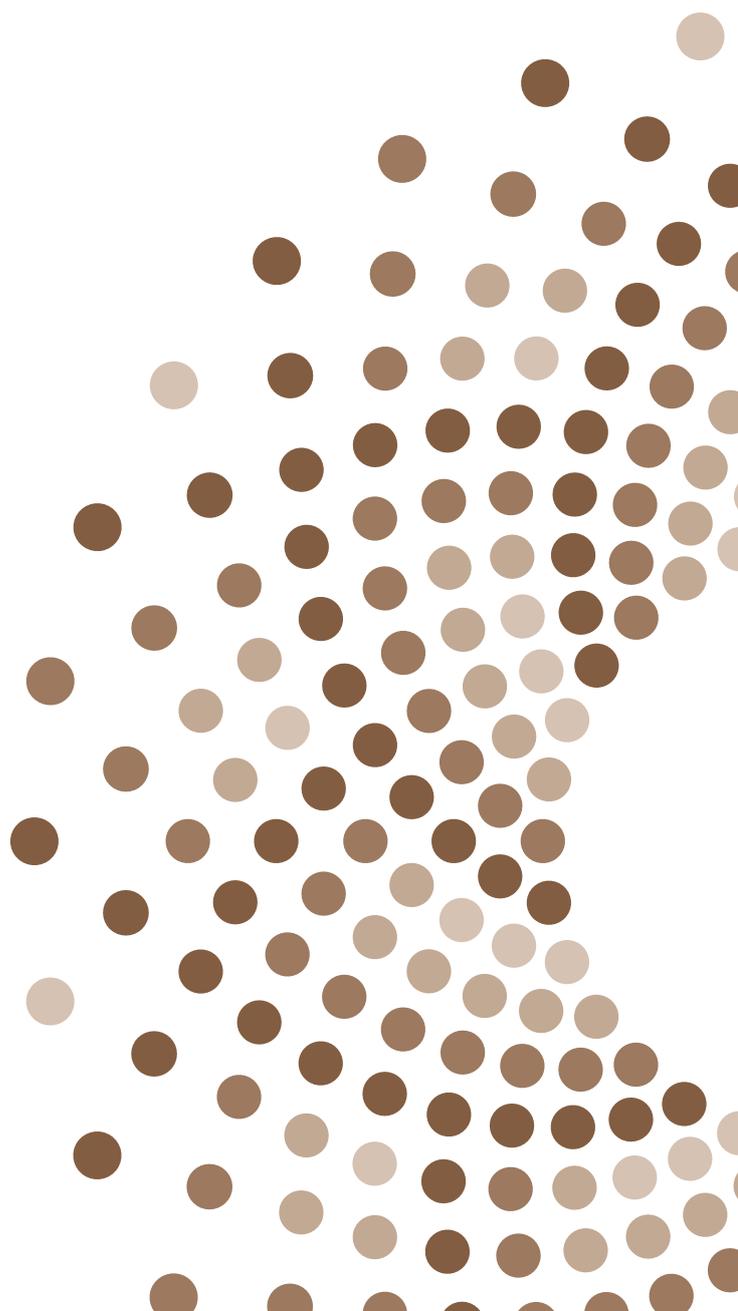
National Governments	Participating Government department	Nominated representative
Australia	Department of Health	Tony Hobbs
Canada	Public Health Agency of Canada	Kim Elmslie
Japan	Ministry of Health, Labour and Welfare	Hiroki Hamaya
Mexico	National Institute of Neurology	Teresita Corona
The Netherlands	Ministry of Health Welfare and Sport	Kees van der Burg
United Kingdom	Department of Health	Martin Rossor

### Governmental and non-governmental organisations

Organisation	Nominated representative
Age UK	Tom Wright (to September 2017)
European Commission	Herta Adam
OECD	Dirk Pilat
World Health Organization	Shekhar Saxena
World Young Leaders in Dementia Network	Anja Leist

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

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E [info@worlddementiacouncil.com](mailto:info@worlddementiacouncil.com)





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

