Defeating dementia: progress and challenges on the road to 2025

Driving collective action to deliver the 2025 dementia solutions

Reception:	Tuesday 4 December 2018 19:00 – 21:30 Reading Room, Wellcome Collection	**Summit:**	Wednesday 5 December 2018 08:00 – 16:30 Wellcome Trust, Gibbs Building, 215 Euston Road

Summit Agenda Wednesday 5th December

Moderator: Vivienne Parry, science journalist and broadcaster

Time	Session	Details
08:00	Registration opens	
09:00 – 09:20	**Welcome**	• Harry Johns, Chair, World Dementia Council • Marty Reiswig, DIAN study participant, United States • Lenny Shallcross, Executive Director, World Dementia Council • Sir Jim Smith, Director of Science, Wellcome
09:20 – 10:00	**Opening session:** Government leadership	• The Rt Hon Matt Hancock MP, Secretary of State for Health and Social Care, UK • His Excellency Hugo de Jonge, Deputy Prime Minister and Minister for Health, Welfare and Sport, The Netherlands • Kenji Suwazono, Assistant Minister for Health and Welfare for Elderly and Persons with Disabilities, Japan • Ulrik Vestergaard Knudsen, Future Deputy Secretary General, Organisation for Economic Co-Operation and Development
10:15 – 11:15	**Workstreams – session one**	• Science workstream: Data sharing • Society workstream: Care
11:30 – 12:30	**Workstreams – session two**	• Science workstream: Funding and incentives • Society workstream: Technology
12:30 – 13:15	Lunch	
13:15 – 14:00	**Lunch session:** Are we on track?	• Dr Richard Hodes, Director, National Institute on Aging • Stéphane Hogan, Head of Sector Neuroscience, European Commission • Dr Husseini Manji, Global Head, Janssen Neuroscience • Dr Maria Carrillo, Chief Science Officer, Alzheimer's Association
14:15 – 15:15	**Workstreams – session three**	• Science workstream: Clinical trials • Society workstream: Brain health and the public policy response
15:15 – 15:45	Coffee	
15:45 – 16:15	**Afternoon session:** The 2025 challenge	• Maria Shriver, Founder, Women's Alzheimer's Movement • The Rt Hon David Cameron, Former Prime Minister of the United Kingdom 2010-2016
16:15 – 16:30	**Close**	• Lenny Shallcross, Executive Director, World Dementia Council • Dr Husseini Manji, Global Head, Janssen Neuroscience • Harry Johns, Chair, World Dementia Council

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Science workstream

Workstreams session one:
Data sharing

Panellists: Dr Maria Carrillo (Chief Science Officer, Alzheimer's Association), Sir Simon Lovestone (Vice-President, Janssen), Professor Takeshi Iwatsubo (Department of Neuropathology, University of Tokyo)

The potential of data sharing to accelerate research was recognised at the 2013 London summit. We live in an increasingly data-rich world, and the benefits that this brings to all walks of life have been widely recognized. While dementia research is no exception, challenges exist with regard to data sharing. These range from societal issues such as consent, privacy, and respectful use of data, to technical issues such as data harmonisation and interoperability, data visibility, and access control, to personal issues such as data ownership (researcher vs funder vs. donor). This is a particular challenge in Europe, with confusion around the impact of GDPR. This workstream will consider data sharing initiatives five years after the G8 London summit, the role of governments and others in promoting data sharing, and the opportunities that might be realised in the five years ahead.

Workstreams session two:
Funding and incentives

Panellists: Hilary Evans (CEO, Alzheimer's Research UK), Professor Bart de Strooper (Director, UK Dementia Research Institute), Dr Laurence Barker (Chief Business Officer, Dementia Discovery Fund), Dr Paul Stoffels (Chief Scientific Officer, Johnson & Johnson)

Since the challenge issued by the 2013 London summit, many nations have substantially increased funding for dementia. Although governments, charities, and philanthropists have together increased dementia funding, dementia research remains underfunded relative to the size of the unmet need. Beyond the amount though, the bigger challenges surround the 'right sort' of funding. For instance, is the need greater for more investigator-led funding or for topic-specific directed funding? For large, expensive, moon-shot type initiatives or for many smaller diverse projects? For people or for infrastructure? For platforms or programmes? How does one incentivise those outside government to make research investments? This workstream will work on the assumption that increased funding is a necessity and consider what works best and whether innovation in the form of 'push and pull' incentives is needed.

Workstreams session three:
Clinical trials

Panellists: Dr Samantha Budd Haerberlein (Vice President, Biogen), Dr Catherine Mummery (Clinical Director Neurology, UCL Dementia Research Centre), Dr Lynne Hughes (Vice President and Head, Global Medical Strategy, CNS, IQVIA), Professor Ricardo Allegri (Cognitive Neurologist, FLENI)

The cost in human and monetary resources for clinical trials in is enormous. The trials are typically longer and are technically more challenging than other therapeutic areas. These challenges become even greater as we follow the science and move towards trials focusing on people in increasingly earlier stages of the disease. What can be done to make trials in Alzheimer's disease and other causes of dementia, more effective, shorter, and less burdensome to patients? Is it registries or biomarkers? Platform trials or innovative designs? How do we increase the number of patients newly diagnosed with disease or those at risk to take part in clinical trials? How can health care systems and governments help to create a trials-efficient environment?

Workstream close:

Professor Ronald Petersen, Director, Mayo Clinic Alzheimer's Disease Research Center

Society workstream

Workstreams session one:
Care

Panellists: Paul Hogan (Founder, Home Instead), Shekhar Saxena (Visiting Professor, Harvard and Former Director, World Health Organization), Kees van der Burg (Director-General, Long-Term Care, Ministry of Health, Welfare and Sport, The Netherlands), Elina Suzuki (Health Policy Analyst, Organisation for Economic Cooperation and Development)

Even if the next five years, or the 15 after that, bring disease-modifying therapies, dementia will remain with us. In this respect, care for people with dementia should remain at the forefront of our efforts but how can we best achieve this? How can we collect better, and internationally-comparable, data to accelerate good care? And how do we better translate research into practice, not just in high income countries but in LMICs?

Workstreams session two:
Technology

Panellists: Brad O'Connor (CEO, Cogstate), Vaibhav Narayan (Vice President, Research Technology, Janssen Pharmaceuticals), Dr Iain Simpson (Principal, QL Consulting), Maxine Mackintosh (Doctoral Student, Alan Turing Institute, UCL), Dr Peter Peumans (Senior Vice President, Life Science Technologies, IMEC)

Today, most people on the planet carry in their pockets a computer of such power that it was near unimaginable when many of us ended our education. Indeed, it will not be too long before our refrigerators and vacuum cleaners are digitally enabled, and most of our cars already are. How can this rapidly changing world of information technology be harnessed for the cause of dementia, both in terms of care and research? What role might digital biomarkers, connected digital medical records, AI, and autonomous algorithms play in improving outcomes? How can we best equip our services, researchers, and infrastructures for the coming world of overwhelming data, which promises to contain information on everything from sequenced genomes to connected selves? What role do governments, health managers, and regulators have to incentivise the development of new technology and to protect patients and caregivers from being exploited?

Workstreams session three:
Brain health and the public policy response

Panellists: Sarah Lenz Lock (SVP Policy and Brain Health, AARP), George Vradenburg (Chairman, UsAgainstAlzheimer's), Dr Tarun Dua (Programme Manager, World Health Organization), Jeremy Hughes (CEO, Alzheimer's Society), Professor Sheung-Tak Cheng (Chair, Professor of Psychology and Gerontology, The Education University of Hong Kong)

Although the number of people with dementia is rising relentlessly, some evidence suggests that the incidence has begun to fall in some countries and there is growing evidence around prevention. How can public attitudes to brain health be shifted so that "brain health" has similar public recognition to, for instance, "heart health"? What can we do to grow dementia-friendly societies, break the stigma of dementia, and provide better care where those who need it live? How do we deliver on the public policy challenges of human rights agenda and a gender based approach and ensure solutions work for high income countries and LMICs. No matter the progress towards therapies that work, dementia care will remain a significant and growing challenge for society. This need is one that demands action and may even achieve impacts sooner than the hard hunt for drugs and other therapies.

Workstream close:

Professor Kiyoshi Kurokawa, National Graduate Institute for Policy Studies

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