

## **G8 DEMENTIA SUMMIT COMMUNIQUE**

### **Introduction**

1. We, the G8 Health Ministers, met at the G8 Dementia Summit in London on 11 December 2013 to discuss how to shape an effective international response to dementia.
2. We acknowledge the on-going work occurring in our countries and globally to identify dementia as a major disease burden and to address issues related to ageing and mental health, including the World Health Organisation's 2012 report, *Dementia – A Public Health Priority*. Building upon the significant research collaborations that exist between our countries and our multilateral partners will strengthen our efforts and allow us to better meet the challenges that dementia presents society.
3. We recognise that dementia is not a normal part of ageing. It is a condition that impairs the cognitive brain functions of memory, language, perception and thought and which interferes significantly with the ability to maintain the activities of daily living. We also acknowledge that dementia affects more than 35 million people worldwide, a number that is expected to almost double every 20 years.
4. We note the socio-economic impact of dementia globally. Seventy per cent of the estimated annual world-wide cost of US\$604 billion is spent on informal, social and direct medical care. Yet nearly 60 per cent of people with dementia live in low and middle income countries so the economic challenge will intensify as life expectancy increases across the globe.
5. These costs are expected to increase significantly if therapies to prevent dementia and improve care and treatment are not developed and implemented. We recognise the need to strengthen efforts to stimulate and harness innovation and to catalyse investment at the global level. Recognising the division of health responsibilities between national and sub-national levels of government that is unique to federated states;

### **Research and Innovation**

6. We recognise that through research, knowledge translation and care, we can reduce the increasing impact of dementia on society and we commend all efforts in the development of breakthroughs to prevent, delay, treat or stop dementia. We want to ensure that we support the research likely to have the greatest impact and which addresses the areas of greatest need. We agree to work together, to share information about the research we fund, and to identify strategic priority areas, including sharing initiatives for big data, for collaboration and cooperation. We understand the importance of using existing evidence and knowledge to inform decision-making, as well as creating better and more robust monitoring and evaluation evidence.

7. To realise these ambitions, we must draw on the existing research infrastructure. Therefore, we welcome the offer of research funders including NIH, MRC, CIHR, and AVIESAN to act as co-convenors, building on the existing work and capability offered at the European level (through the JPND, the Innovative Medicines Initiative and the Horizon 2020 initiative) to identify priorities and to develop a co-ordinated international action plan for research which accounts for the current state of the science, identifies gaps and opportunities, and lays out a plan for working together to address them.
8. Furthermore, we commit to:-
  - The ambition to identify a cure or a disease-modifying therapy for dementia by 2025 and to increase collectively and significantly the amount of funding for dementia research to reach that goal. We will report biennially on expenditure on publicly funded national dementia research and related research infrastructure; and we will increase the number of people in dementia related research studies.
  - Encourage open access, where possible, to all publicly funded dementia research and to make the data and results available for further research as quickly as possible while protecting the privacy of individuals and respecting the political and legal frameworks of the countries in which the research is conducted;
9. Although we embrace the need to increase spending on dementia research, this will not be sufficient on its own. Mutual efforts to stimulate and harness innovation at the global level therefore need to be strengthened. Consequently, we call for greater innovation to improve the quality of life for people with dementia and their carers while reducing the emotional and financial burden. We therefore welcome the UK's decision to appoint a global Dementia Innovation Envoy to draw together international expertise to stimulate innovation and to co-ordinate international efforts to attract new sources of finance, including exploring the possibility of developing a private and philanthropic fund to support global dementia innovation.
10. We acknowledge the need to attract new investors and the need to support the disruptive technology and innovation in companies and academia that is currently being postponed or shelved because of the technical and financial threat of failure. We recognise that both public and industry-led research and capacity must be encouraged to enable new approaches to be identified and developed. We must explore all avenues of innovation. Priorities for investment include:
  - Research to elucidate the mechanisms underlying the initiation and progression of neurodegeneration as a basis for identifying new targets for therapeutic development;
  - Prevention of dementia;
  - Making timely diagnosis and early intervention feasible, affordable and cost effective;
  - Facilitating the integration of care and helping individuals and their carers access care and social services in their homes and communities; and
  - Making care homes more responsive to needs.

11. To reduce the impact of dementia on an ageing society, we need to think and act differently, and we need to stimulate new investment to help address the current innovation gap. We recognise the need to build on existing capabilities and capacities to stimulate innovation across the life science, healthcare, home care, social care, and wellbeing sectors. To this end, we agree to take stock of our current national incentive structure, working in partnership with the OECD, and consider what changes could be made to promote and accelerate discovery and research and its transformation into innovative and efficient care and services.

### **Leadership, Cross-Sector Partnerships and Knowledge Translation**

12. We see the G8 dementia summit in London as the start of a process which will allow us to step up our efforts to reduce the human and economic impact of dementia. We are keen to continue to work together but we also want to engage other countries with a similarly strong interest in dementia.

13. To develop innovation and cross sector partnership efforts, we will hold a series of high-level fora throughout 2014, in partnership with the OECD, WHO, the European Commission, JPND and civil society, to develop cross sector partnerships and innovation, focused on:

- Social impact investment – UK-led
- New care and prevention models – Japan-led
- Academia-industry partnerships - Canada and France co-led

14. We will meet again in the United States in February 2015 with other global experts, including WHO and OECD, to review the progress that has been made on our research agenda.

15. The world has been slow to adapt to population ageing and dementia and this continues to worsen fiscal and societal risks, threatening sustainable growth. We need more data on prevalence and incidence of dementia, as well as prevention and treatment. As the 'baby boom' generation of the late 1950s and early 1960s come to care for their own parents affected by dementia, there is an opportunity to offer greater involvement and support. We should explore ways to connect people affected by dementia, particularly to support collaborative problem solving.

16. Increased age is the greatest predictor of dementia. It has been estimated that delaying dementia onset by 2 years could decrease global disease burden in 2050 by 22.8 million cases. We therefore recognised that a new approach to delaying and preventing dementia is needed and requires:

- New approaches to sharing and using data and analyses developed collectively, including the use of open access and innovative crowdsourcing strategies, collected in ways which suit local and national circumstances;
- Collaborative efforts between countries to “pool” cases, methodologies, approaches and solutions;
- Prevention trials to obtain evidence based conclusions.

17. Dementia is a global challenge and one which is set to intensify. History shows major diseases can be made manageable, even preventable, with sufficient political will. We therefore need to better understand risk factors for dementia in younger generations, identify available options to reduce risk, and develop and implement rigorously designed public health programmes. We recognise the importance of taking a comprehensive and coordinated approach to the prevention of dementia, tailored to national and local needs, and to take prevention measures in the near term based on existing knowledge. We will encourage countries to make dementia a public health priority as their populations grow and generations age.

18. Responding effectively to dementia requires policy makers across government to work together. Governments can also learn from one another. To learn from one another and facilitate knowledge exchange, we will strive to improve the way in which we share government policy documents on treatment, services, interventions and research for people affected by dementia.

### **Supporting People Affected by Dementia and their Carers**

19. Depending on its cause, dementia may progress from mild cognitive impairment, including difficulties organising daily life, to significant alterations in personality, disintegration of cognitive functions, loss of self and identity, incontinence, loss of physical abilities and finally death. Dementia can be both a contributory factor to, and a primary cause of death. Progress of the disease and its impact are very distressing for people with dementia, their families and carers.

20. Dementia is our collective social responsibility. We affirm our commitment to improving the lives of people affected by dementia, regardless of nationality, identity, background, culture socioeconomic status, language or religion. Furthermore, we encourage the involvement of Indigenous peoples and communities in the development, implementation, and evaluation of dementia policies, plans and programs where appropriate, while promoting the development and strengthening of capacity at various levels and recognising the cultural heritage and traditional knowledge of Indigenous peoples.

21. Dementia requires long term health and social care support. Providing care for those with dementia can present challenges for families and carers. We need to provide better and more concrete measures for improving services and support for people with

dementia and their carers, to improve their quality of life and wellbeing.

22. We pledge to disseminate successful approaches to supporting people with dementia and their carers including:-

- Provision of advice, including on care planning, management and wellness support
- Appropriate use of medication, particularly antipsychotics, and delaying and/or reducing secondary complications
- Community-based programmes fostering inclusion and improved quality of life
- Delivering services through a continuum of care, including primary care
- Individual tailoring of care
- Realisation of new, ambulant living options
- Helping care homes to meet the needs of people with dementia
- Affordable options for care and everyday support
- Addressing end of life care

23. Carers themselves are often older adults, mainly women, who may be dealing with their own health problems. We call for greater social responsibility and innovation to improve the quality of life for carers and improve care while reducing costs and financial burden including:-

- Training for carers, including how to deal with dementia related behaviours
- Improve the reconciliation of care and career for carers
- Support carers in acute situations and crises
- Local and affordable options for care and everyday support
- Promote civic engagement and the development of social networks
- Attract and train community representatives to support people with dementia in social environments
- Creating better and robust evaluation evidence
- Using existing evidence and knowledge

24. Appropriate autonomy and self-determination, including substitute or supported decision making, for people with dementia must be protected and strengthened. Therefore national and local policies should be in place to ensure appropriate autonomy and self-determination are recognised and protected.

### **Reducing stigma and fear**

25. Dementia is not a normal part of ageing. As people age, many fear the potential onset of dementia-related symptoms or a diagnosis of dementia. Negative reactions from family, friends, and professionals can impact a person's willingness to seek assistance, as well as their well-being and ability to manage the changes brought about by dementia. We commit to improving the understanding of community attitudes towards people with dementia across generations.

26. Responding effectively to dementia requires a response from all sectors of society. Therefore, we call upon all sectors to treat people affected by dementia with dignity and respect, and to promote various forms of civic engagement on dementia awareness, and to contribute to the prevention of dementia and to improve care and treatment where they can.
27. Addressing stigma and ensuring that people with dementia are treated with dignity and respect are critical. We therefore commend the creation of the UN Independent Expert on the enjoyment of all human rights by older persons and we ask that the perspective of older people affected by dementia is integrated into their work.
28. Civil society is also well placed to play a major role in changing public attitudes. Therefore, we agreed to call on civil society to continue and to enhance global efforts to reduce stigma, exclusion and fear.

### **Conclusion**

29. We will continue our efforts to work together in line with the commitments in this Declaration and Communiqué, but we recognise that dementia is an issue which affects people in countries throughout the world. Consequently, we encourage all countries and multilateral organisations to come together and take action to reduce the risk to health and to economic development which dementia currently presents.

**Signed by** G8 Health and Science Ministers on 11 December 2013

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