UPDATE ON OECD WORK ON ALZHEIMER’S DISEASE AND OTHER DEMENTIA

Healthy Ageing and Biomedical Innovation for Alzheimer’s Disease and other forms of Dementia

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Delegates are to note that this document is for discussion under Item 8.

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HEALTHY AGEING AND BIOMEDICAL INNOVATION FOR ALZHEIMER'S DISEASE AND OTHER FORMS OF DEMENTIA

Background and context

1. Alzheimer’s disease is the most frequent form of dementia in elderly people. It describes a syndrome which progressively leads to brain damage and the deterioration of an individual’s functional capacity and social relations.

2. Dementia represents a significant challenge for public research and health systems worldwide. In 2010 the number of people with dementia worldwide was estimated at 36 million (42% of whom lived in high-income countries) and at a worldwide cost of USD 604 billion (70% of this cost incurred in Western Europe and in North America)\(^1\). This number of sufferers could rise to as many as 115 million worldwide in 2050. Critically, this is not a challenge for OECD countries alone, 58% of the people living with dementia in 2010 being from middle and lower-income countries.

3. The cost of dementia is not just a cost of diagnosis and treatment but also in the loss in social and economic terms of those that care for dementia sufferers. In 2010, over 15% of people aged 50 and over provided care for a dependent relative or friend, including people with dementia, with over 60% of these informal carers being women and with two thirds of all carers providing care on a daily basis. Family carers providing more than 20 hours of caring per week to frail dependent elderly have a 20% higher prevalence of incurring mental health problems (such as depression), a higher risk of reducing hours of paid work, and are at higher risk of becoming poor\(^2\).

4. This document looks how the OECD is working in the area of biomedical and health innovation with a special focus on the work being undertaken by the Working Party on Biotechnology (WPB). It should be noted that significant work is also ongoing within the Committee on Information Communications and Computer Policy (ICCP) and the Health Committee of the OECD (e.g. to promote greater data sharing at international level; to assess the socio-economic impacts of dementia on health systems and carers; and on new, smarter models of care)\(^3\). The global importance of the work was highlighted in the UK G8 Summit in December 2013.

Introduction

5. Topics in biomedical research and health innovation have been under discussion at the Working Party on Biotechnology for many years\(^4\) and the group is now particularly focusing on how innovation in


governance and regulation can facilitate research and its translation to clinical practice, dementia, and in particular Alzheimer’s disease provides a good case study and proxy for other health conditions.

6. Policymakers have a leading role in the creation of an innovative biomedical research environment to address the multifactorial problem of Alzheimer’s disease and associated dementia, through the combination of support for: 1) basic and translational biomedical research, 2) the use of emerging biomedical technologies, and 3) the development of an adequate clinical research and regulatory environment. Through the Working Party on Biotechnology, the OECD is aiming to enable the exchange of good practices in these areas to strengthen effective co-operation at a global level for the governance of biomedical innovation for dementia and other neurodegenerative diseases.

7. Key issues to be considered in global, cross-functional frameworks for biomedical research and health innovation for dementia are:

- Harmonising international strategies, processes and structures for scientific research and biomedical innovation to manage risks and reduce failure, especially in the field of emerging biomedical technologies and combination products;
- Supporting the transfer of emerging biomedical technologies from laboratories to clinical use through policies that balance benefits and risks in the health innovation system and through the use of suitably flexible policy frameworks;
- Strengthening cross-sector collaboration for sharing of resources and knowledge along the value chain of drug discovery (see also the work below of the ICCP on data sharing); and
- Governing with long-term vision that can support innovative financing and risk-sharing models in a complex environment of multinational stakeholders.

8. Questions remain how to balance oversight and regulation with the flexibility required for innovative research and use of emerging biomedical technologies. Harmonised governance frameworks, efficient oversight mechanisms, and adaptive regulatory procedures with a strong medical scientific basis would be needed. In particular, a deepening of discussion on the ethical and social issues, associated risks and variability of national regulatory mechanisms would support evidence based decision making at governmental level.

**OECD Work on Biomedical and Health Innovation**

**Healthy Ageing and Biotechnology – Research and Policy Issues**

9. Initiated by the OECD Tokyo workshop on Healthy Ageing and Biotechnology – Research and Policy Issues (2000), this topic has long been an important focus area of the Working Party on Biotechnology. The workshop discussed key scientific and health care policy issues around the use of biotechnological tools and techniques for a better understanding of the ageing processes. Expert recommendations are documented in a key publication (Biotechnology and Healthy Ageing, Policy implications of new research, OECD, Paris).
Implications of New Research, 2002), and have been guiding the ensuing work of the Working Party of Biotechnology.

**Better Health through Bio-medicine: Innovative Governance**


11. Workshop participants discussed the need to adapt existing governance systems to facilitate the translation of new health innovations from bench to bedside. Participants discussed a range of new collaborative and integrated approaches to governance and regulation that are emerging in response to the rapidly evolving biomedical science and technology landscape in a number of countries and regions. These approaches typically involve earlier and broader interaction or collaboration amongst stakeholders across the innovation system, and are evolving into subsystems of governance in areas such as product coverage, licensing, standards-setting, risk management etc.

12. The main conclusion arising from the workshop was that there is a need to find new ways to proactively respond to and support biomedicine and health innovation. In particular there is a need for rethinking policies - and to creating new collaborations, partnerships and models - to develop the new tools of regulatory science by drawing on the latest advances in genomics and the other “omics”, high throughput screening, systems biology, new algorithms and tools for massive data, etc. At the same time, there is also a need to recognise and manage associated risk and uncertainty, and to foster development of governance frameworks that move from an all-or-none approach to one that recognises the complexity and iterative nature of new regulatory science.

**Integrating Omics and Policy for Grand Challenges: Healthy Ageing**

13. The joint OECD/Human Genome Organisation (HUGO) workshop in Singapore in April 2013 on “Integrating Omics and Policy for Grand Challenges: Healthy Ageing” was an important opportunity for expert talks and discussions on key issues of biomedical and health innovation (see Annex 1). Issues for discussion included the underlying molecular mechanisms and genetics of healthy ageing; and the role of new omics tools, and their application in epidemiologic studies of ageing – in particular of brain ageing. On research, the workshop concluded that significant governance challenges and opportunities remain within the structures supporting research into age-related diseases and dementia. In particular, “omics” technologies are supporting medical innovation in the field of ageing. They represent an important tool for the discovery and development of new solutions for the prevention, diagnosis, monitoring and treatment of age-related diseases, notably by enabling the discovery of new biomarkers.

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5 The term “omics” refers to fields of study in biology, such as genomics, proteomics, metabolomics. Omics technologies aim at the collective characterisation and quantification of pools of biological molecules.
14. In the area of collaborative research and business models, participants noted that the strengthening of stakeholder collaboration through, e.g., new financing models and investments would help to overcome challenges associated with the development and validation of new interventions for age-related conditions. New cost- and risk-sharing mechanisms (e.g. pre-competitive consortia) for collaborations and incentives targeting at engaging industry partners in the business of dementia research would be needed.

15. On regulation, the workshop concluded that modernised governance and regulatory science are important to allow for innovation in breakthrough technologies to emerge and reach the patient. Processes are needed, which enable regulators to navigate through an environment of uncertainty vis-à-vis emerging technology-driven solutions for ageing. This should be supported by regulatory systems that are dynamic, future oriented and have a strong scientific basis in order to facilitate innovation in emerging fields to take place and to be better able to deal with the uncertainties around these emerging technology-driven solutions. In effect, it was agreed that regulatory science and governance frameworks must co-evolve to create the conditions and means to share and manage knowledge on a global scale to achieve successful translation of biomedical research into clinical practice.

Unlocking Global Collaboration to Accelerate Innovation for Alzheimer’s Disease and Dementia

16. Also in 2013, the Working Party on Biotechnology work was informed through an expert consultative workshop in Oxford in June 2013 on “Unlocking Global Collaboration to Accelerate Innovation for Alzheimer’s Disease and Dementia”. This was a joint event of the WPB and WPIE and took place with support from the Global Coalition on Ageing and Oxford University (Harris College).

17. Participants reiterated the need for integrative research through a combined effort at all stages of research – from basic laboratory science to applied research in the clinics. Many such innovations are likely to be technology-driven and dependent on rapid advances in emerging fields of science and technology. The importance of standardised scientific tools, processes, and disease models in translational research for Alzheimer’s were stressed. They also emphasised the need for a better use of existing resources at local, regional, national and international levels. This could be achieved through further alignment of stakeholders and national policy strategies to reduce fragmentation.

Biomedical and Health Innovation for Alzheimer’s Disease Dementia

18. In summary, the events to date have shown that there are three main areas for policy discussion and future action under the WPB on the health innovation cycle that are being brought forward in current work:

- **Research and innovation**: mechanisms are needed to support the development of emerging fields of science and technology that could lead to breakthrough innovation in dementia research. Addressing the biological complexity of dementia syndromes will require broad scope policies that stimulate integrative approaches. Investments in basic and applied research need to continue to enable the clarification of the biological mechanisms, in particular the pathways that lead to the failure in the brain system.

- **Regulation and governance**: modernised regulatory frameworks could support the use of new, technology-driven solutions and would facilitate the transition from the research laboratories to clinical applications. The support of emerging technological solutions and biomarkers in the context of clinical research would be critical.
• **Collaborative research and business models**: governance frameworks should be developed that support greater collaboration across the relevant stakeholder groups in dementia research. In response to the rapid evolution of biomedical technologies, there is growing interest in a range of new collaborative and integrated approaches to governance and regulation.

19. Work on these topics is being undertaken in 2013-2014, specifically through further information gathering from countries about the policies they have in place for biomedical and health innovation for dementia and on public-private partnerships, through case studies. This work aims to provide good practice guidance and learning between countries and for multi-stakeholder collaborative mechanisms.

20. The questionnaire on “Government Approaches for Supporting Biomedical Innovation for Alzheimer’s Disease and other Dementia” has been prepared to send to WPB delegates for completion. The questionnaire forms the basis of an inventory of government approaches to support the development of biomedicine and health innovation for Alzheimer’s disease and other forms of dementia. The literature review is ongoing at the Secretariat.

21. The information for the case studies is being gathered using a template prepared by TIP. The case studies have three main goals: 1) identifying the main initiatives that are being developed in countries to foster translational research for Alzheimer’s disease; 2) identifying the factors that have affected progress in these initiatives; and 3) identifying good practice and drawing lessons for future use. As the case study templates are returned to the Secretariat, descriptive analysis will be undertaken, to be completed during the 2nd quarter of 2014. In parallel, a literature review is underway on the opportunities and challenges of strategic, multilateral collaborations to support joint thinking and acting across sectors along the value chain.

**The Global Context for OECD Work: the G8 Summit 2013**

22. Addressing the challenge of dementia has become a major endeavour at international level. A landmark G8 Summit on dementia, held in London in December 2013 concluded with a declaration calling for countries to accelerate research; promote open science and greater data sharing at international level; and improve the quality of care of for people with dementia (see Annex 2). Underpinning the achievement of all of this is the need for a supportive policy environment.

23. The OECD features prominently in the declaration. The G8 Ministers have asked the OECD to take further steps towards a global research and policy agenda for better international data collaboration and better data systems for dementia care. This will also require looking at how privacy concerns can be addressed in a way that is protective of individuals while enabling discovery and improvements in care.

24. Besides open access to and wider use of data, there was recognition that incentives for research in new diagnostics and treatments for dementia must improve. The OECD has been called by G8 countries to: “take stock of national incentive structures for research, and consider what changes could be made to promote and accelerate discovery and research and its transformation into innovative and efficient care and services.”

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6  [http://www.oecd.org/health/dementia.htm](http://www.oecd.org/health/dementia.htm)
Next steps: Supporting an Ageing Society, Addressing the Challenge of Dementia

25. The remainder of 2014 will see the reporting of the current work on PPPs and governance models for Alzheimer’s disease and other dementia. In 2015-2016, further work is proposed on biomedical technologies for health: Supporting an Ageing Society, Addressing the Challenge of Dementia. An international biotechnology and health innovation meeting, a “Berlin II”, is also proposed to draw together the findings of work to date and to identify next steps (date to be decided).

26. Depending on voluntary contributions, the event (and background papers) may, for example, look at the governance and regulatory blockages in biomedical research and health innovation (specifically but not exclusively related to dementia and Alzheimer’s disease, as highlighted by the G8 and others) and the technical, regulatory and societal challenges of developing and introducing new technology-based innovations often delay the development of diagnostics and therapeutics and hinder the transfer of these and other innovations from the laboratory bench to the patient’s bedside. New opportunities, such as those provided by the use of synthetic biology for health applications, begin in the research laboratory and have a very long and complex value chain that policy-makers and regulators are still grappling with.

27. The event could explore: 1) the policies needed to support an ageing society through the development and application of new diagnostics and therapeutics; 2) the implications of emerging and enabling technologies for regulatory and governance systems; and 3) the policies needed to support innovation, address barriers and harness the contribution of new and emerging technologies to health and medical innovation, both in the context of dementia and more broadly. Topics for exploration could include:

- New regulatory paradigms for biomedicine and health innovation—managing uncertainty;
- Ethical and social implications of biomedicine and health technology innovation: engaging the public;
- New business models (e.g. stakeholder alliances, PPPs) and new investment models;
- Socio-economic scenarios for new diagnostics and therapies; and
- Governing innovative fields: the convergence of technologies.

28. Planning for the event is at a very early stage but it is expected that it will engage policy makers, the business community and regulators and will be undertaken to complement work by the ICCP and Health Committees at the OECD.

Conclusion

29. The Working Party on Biotechnology has been engaged in work on biomedical and health innovation since the Tokyo workshop in 2000. This document identifies past work, current activities and future plans for work to support governments in developing and implementing supportive measures to ensure that new discoveries and new processes can translate into diagnostics and treatments, thereby helping to relieve the large and growing numbers of people in both OECD and non-OECD countries that suffer, directly and indirectly, from neurodegenerative diseases including dementia.
ANNEX 1


This is a report on a workshop jointly organised by the WPB and the Human Genome Organisation (HUGO). The workshop served as a forum for discussion on issues such as: the molecular mechanisms and genetics of healthy ageing, the role of new omics tools and their application in epidemiologic studies of ageing. The workshop also addressed governance and policy issues linked to new developments in omics technologies for ageing, focusing on the regulatory challenges and the mechanisms to support effective translational research through, for example, new collaborative models of investment and risk-sharing initiatives. The workshop examined the underlying principles of challenge driven innovation policy for healthy ageing, notably putting the emphasis on the central role of patient empowerment and user-driven innovation. The workshop concluded that important governance challenges are remaining for supporting research in age-related diseases and dementia, in particular 1) reinforcing strategic collaboration, 2) supporting innovation, 3) modernising regulatory science.


This document identifies the knowledge gaps and barriers for developing policies to address the grand global challenges of Alzheimer’s disease. The specific aim of this report is to provide a basis for strategic thinking among policymakers, leading to the identification of areas requiring new work to address the healthcare challenge. The report proposes a roadmap for action for OECD countries to consider. It lays out the critical issues in developing a multi-national plan to tackle the global challenge of this and other neurodegenerative disease.


This is a summary report on an expert consultation on unlocking global collaboration to accelerate innovation for Alzheimer’s disease and dementia. The consultation was jointly organised by the OECD and the Global Coalition on Ageing. The objective of the consultation was to begin to identify a framework for policy making and stakeholder engagement. The consultation was comprised of expert talks in the areas of: 1) biomedicine and health innovation in Alzheimer’s disease and dementia, and 2) “big data” and data sharing challenges.

This report examines examples of new and emerging governance models that aim to support the responsible development of diagnostics and treatments based on the latest advances in the biomedicine. It draws on previous work of the OECD Working Party on Biotechnology (WPB) that addressed new models of governance for biomedicine and health innovation, for example, work on the governance of pharmacokinetics and biomarkers.


This synthesis report presents the main lessons and policy messages related to innovation and regulation of biomedical research. It was developed as a thematic contribution to the OECD Innovation Strategy, a comprehensive policy strategy to harness innovation for stronger and more sustainable growth and development, and to address the key societal challenges of the 21st century. The recommendations in this report aim to serve as useful reference and resource to those governments, member or non-member, interested in fostering health innovation and improving the economic and health impacts of their biomedical research sector.


This report originated at a workshop in Tokyo (2000), which was held to identify the contributions of biotechnology to alleviating major age-related diseases and conditions in OECD countries. It identifies the fields in which biotechnology contributes most to the goal of healthy ageing and discusses the social or economic roadblocks to the dissemination and use of these technologies. The publication is divided into four parts: Part I identifies the concerns that motivated the workshop and the policy recommendations reached by the expert participants. Part II presents different perspectives on the economic impact of the ageing of OECD countries. Part III reviews the epidemiological trends behind the major age-related diseases and conditions and the avenues of research for altering the prevalence of these diseases in our populations. Part IV identifies the social trade-offs that a policy for healthy ageing entail and gives a number of examples of how OECD governments are addressing these trade-offs.
ANNEX 2

G8 DEMENTIA SUMMIT DECLARATION, Signed by G8 Health and Science Ministers on 11 December 2013:

Introduction

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.

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.

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.

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.

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.

Therefore, and in accordance with national, sub-national and local responsibilities, we commit ourselves to:

1. Call for greater innovation to improve the quality of life for people with dementia and their carers while reducing emotional and financial burden. We therefore welcome the UK’s decision to appoint a global Dementia Innovation Envoy to draw together international expertise to stimulate innovation and to co-ordinate international efforts to attract new sources of finance, including exploring the possibility of developing a private and philanthropic fund to support global dementia innovation;

2. The ambition to identify a cure or a disease-modifying therapy for dementia by 2025 and to increase collectively and significantly the amount of funding for dementia research to reach that goal. We will report biennially on expenditure on publicly funded national dementia research and
related research infrastructure; and we will increase the number of people in dementia related research studies;

3. Work together, share information about the research we fund, and identify strategic priority areas, including sharing initiatives for big data, for collaboration and cooperation;

4. Develop a co-ordinated international research action plan which accounts for the current state of the science, identifies gaps and opportunities, and lays out a plan for working together to address them;

5. Encourage open access, where possible to all publicly funded dementia research and to make the research data and results available for further research as quickly as possible, while protecting the privacy of individuals and respecting the political and legal frameworks of the countries in which the research is conducted;

6. Take stock of our current national incentive structure for research, working in partnership with the Organisation for Economic Co-operation and Development (OECD), and consider what changes could be made to promote and accelerate discovery and research and its transformation into innovative and efficient care and services;

7. Hold a series of high-level fora throughout 2014, in partnership with the OECD, WHO, the European Commission, the EU Joint Programme on Neurodegenerative Disease (JPND), and civil society, to develop cross sector partnerships and innovation, focused on:

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

8. Call upon the WHO and OECD to identify dementia as an increasing threat to global health and support countries to strengthen health and social care systems to improve care and services for people with dementia;

9. Call upon the UN Independent Expert on the enjoyment of all human rights by older persons to integrate the perspective of older people affected by dementia into their work;

10. Call upon all sectors to treat people affected by dementia with dignity and respect, and to enhance their contribution to dementia prevention, care and treatment where they can; and

11. Call upon civil society to continue and to enhance global efforts to reduce stigma, exclusion and fear.

12. We will meet again in the United States in February 2015 with other global experts, including WHO and OECD, to review the progress that has been made on our research agenda.
G8 DEMENTIA SUMMIT COMMUNIQUE, Signed by G8 Health and Science Ministers on 11 December 2013:

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 coordinate 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.