Third World Dementia Council Meeting Communique

We, the World Dementia Council (WDC), held our third meeting at the Foreign and Commonwealth Office, London, on Friday 17th October 2014. We discussed the significant progress made to date across each of the work streams. We were also grateful for a moving insight from Hilary Doxford who addressed the Council about her life with dementia.

Given the strength of feeling within the WDC that our work needs to be shaped by the experiences and needs of people living with dementia, we will be inviting a new member who is living with dementia join the World Dementia Council.

We will continue to focus our work on the initial three priority areas agreed at earlier meetings: Integrated Development; Finance and Incentives; and Open Science and Data. We have also added a fourth priority, Care; and a fifth, Risk Reduction (formerly referred to as Prevention).

Progress on each of the priority areas was outlined as follows:

1. **Integrated Development**
   
   Council member and UK Government Integrated Development Director, Raj Long, set out her team’s work on the development of an integrated regulatory pathway for dementia, which focusses on three areas:
   
   i. Bringing together an international team of key research and regulatory experts in dementia, to gain insights on critical learnings related to the development science of dementia drugs.
   
   ii. Highlighting opportunities for innovative thinking and approach.
   
   iii. Ensuring there is a transparent and effective approach to public policy-making governance.

   There had been significant progress in securing the engagement of regulators from around the world since the second Council meeting. So far these include the European Medicines Agency, the US Food and Drug Administration, the Pharmaceutical and Medical Devices Agency Japan, Health Canada, the Federal Institute for Drugs and Medical Devices Germany, the Medicines Evaluation Board Netherlands, the Danish Health and Medicines Authority, the Medicines and Healthcare Products Regulatory Authority UK and the Italian Medicines Agency. The World Health Organisation and the Organisation for Economic Co-operation and Development are involved and supportive.

   For the first time, these international regulators would be brought together in Geneva by the British Government on 10th November 2014 to discuss dementia with the ultimate aim of collectively and collaboratively shaping dementia drug development in a way that, when followed, could give drug developers the confidence and incentives that a successful drug could then be developed in the most optimal way globally.
Raj Long reinforced that the approach being taken is to bring the regulators together to look at ways of using existing laws and regulations to support dementia research and development and not about attempting to "harmonise" regulations.

Raj Long also noted that the meeting of regulators is being led by the UK Government and is independent of a two-day workshop being organised by the OECD looking at further opportunities in biomedical research and health innovation for Alzheimer's disease and other dementia.

2. **Finance and Incentives**

In response to the relatively low investment in funding dementia research, we continued our exploration of new types of financial product which could lead to accelerated innovation in dementia drug development.

As requested at the second Council meeting, JP Morgan presented the results of a market scoping exercise carried out since the second meeting, which provided three funding options for the Council to consider endorsing.

The findings of the exercise suggested that, at this time, increased investment in the pre-clinical space would most likely improve the probability of identifying a cure or disease modifying therapy.

*The Council unanimously endorsed the proposal for a Pre-Clinical Fund to be established,* and supported the possibility of industry collaborating to set up the Fund to drive investment into new pioneering areas of research.

3. **Open Science and Data**

Given the enormous potential of open science for sharing information and knowledge to accelerate progress in developing new treatments and care approaches, this priority area spans several work-streams.

OECD, which is a key partner to the WDC on Open Science and Data, shared with members its data strategy which has three main areas of focus:

i. Good practice in data governance.

ii. Principles of data sharing.

iii. Work to strengthen cooperation across big data initiatives and foster future integration.

Related to this strategy, OECD and WHO updated members on a methodology for enabling countries to report and compare spending on dementia research, numbers of people entering clinical trials and priorities for research. This methodology has been developed by OECD and WHO, working with Professor Martin Rossor and others. A request for the data has been sent to G7 countries. Once received, it be collated, analysed, discussed at the US legacy meeting on 11 February 2015 and presented at the WHO Conference in March 2015.

OECD will be bringing together a small group of experts on 15th December 2014 to further develop its strategy, including on stronger cooperation across big data initiatives.
The Council was also keen to explore the potential of citizen science in improving dementia research and care and a proposal for action in this area will be more fully considered at the next meeting.

4. **Care**

OECD and WHO described their work to date on developing a framework exploring how international collaboration could improve dementia care. The framework is built on the following four pillars:

i. An agreed set of objectives for international collaboration.

ii. Sharing best practice, understanding what the policy options are to improve dementia care in relation to the very specific objectives.

iii. Metrics for measuring progress, with indicators to measure how care is delivered.

iv. The key measurement enablers (systems which ensure coordination and transfers of data between, for example, health and social care systems

The dementia care framework was supported unanimously by members with the caveat that evaluation and the participation of those with dementia, including in research on dementia care, were added to the framework.

The next step would be to define how to utilise the framework to best effect, including identifying the enablers and metrics. We were clear that a top-down, message-based approach is not going to work and that a more sophisticated and more networked approach is required.

The meeting also heard from WDC member Dr Kiyoshi Kurokawa about Japan’s experience of improving dementia care, including through innovative technology, ahead of Japan’s G7 Legacy Event on dementia care and prevention on 5th-7th November 2014. Geoff Huggins of the Scottish Government spoke about Scotland’s improvements in diagnosis rates; and in the quality of post-diagnosis care; and its role on the European and global stages in leading improvements in dementia care.

The UK Government updated us on the work of the Global Alzheimer’s and Dementia Action Alliance (GADAA), launched at the World Health Assembly in May 2014, which was fostering global collaboration among international NGOs, professional associations, governments and international statutory bodies in an effort to coordinate actions and raise awareness about Alzheimer’s disease and other dementias. GADAA is developing a toolkit, to be tested with attendees at the Japan Legacy Event and then shared with civil societies so they can start to model it themselves within their own countries.

*The Council unanimously agreed to make dementia care its fourth priority.*

5. **Risk Reduction**

WDC member and President and CEO of Alzheimer’s Association, Harry Johns, presented his evidence review into existing research on the links between modifiable risk factors and dementia.

Members acknowledged that the evidence base on dementia risk reduction is incomplete and that consequently they were not well placed at this time to highlight any particular risk factors over others. However, members did note existing evidence that strongly suggests cognitive decline at the population level can potentially be affected by behaviour changes acting on cardiovascular risk factors (albeit with more evidence required as to the real potential to have an effect on dementia).
The Council agreed further discussions before, and at, the next meeting, were required before we could collectively make a public statement in this area.

However, as Hilary Doxford endorsed, with no cure currently in sight, risk reduction was considered by the Council to be a critical element of the global dementia agenda. We therefore agreed to make dementia risk reduction the WDC’s fifth priority.

6. **Continuity**

We agreed that there was a need to have clear plans by the fourth WDC meeting, with the aim of securing political agreement in the margins of the final Legacy Event in March 2015.

The UK Government stressed the need to cement progress in 2014/15 and they are considering options to achieve this once it relinquishes its G7 stewardship role in 2015. The UK had been working closely with WHO to develop a framework document, an iterative embodiment of the global work being done at any given time, that countries, and organisations, could align with and commit to.

The UK Government, with WHO Director General Margaret Chan’s support and working closely with G7 partners, is drafting the first outline of the framework which it would share with other G7 countries and WDC members for comment in the coming weeks. Agreement of a new framework would signal a significant step forward from the 2013 Declaration.

The UK Government is also exploring the launch of an international entity or hub to support the framework and facilitate global work beyond the G7. The continuity plan as a whole aims to ensure continued global leadership and coordination of the GAAD agenda.

**Key topics for the 4th World Dementia Council meeting on 11th February 2015**

At its fourth meeting, it is intended that the Council will:

- Welcome the new member who is living with dementia and therefore brings their personal perspective to the work of the World Dementia Council.
- Be updated on the continuing work of the Integrated Development initiative.
- Receive an update on the progress made on the setting up of the Pre-Clinical Fund agreed at this meeting.
- Assess progress made in Open Science and Data work, including consideration of what longer term platforms may look like and the role of citizen science in improving research, prevention, diagnosis and care.
- Decide what public statement might be appropriate for the Council to make on Risk Reduction, and re-consider our role and ambitions for this work.
- Receive an update on progress against the OECD/WHO dementia care framework.
- Seek WDC agreement on the best option for continuity of the global action against dementia programme, including taking forward the Council’s priorities.