World Dementia Council

Statement of Purpose

Dementia is a ticking bomb. The world’s ageing population is driving the problem to critical levels: the World Health Organization (WHO) estimated that 36 million people worldwide were living with dementia in 2010 and that Alzheimer’s Disease and other dementia cases will nearly double every 20 years. A large proportion of this increase will be in middle income countries.

WHO also estimated that the global cost of dementia care in 2010 was U.S$604 billion—that’s 1.0% of global GDP. By 2030, the cost of caring for close to 90 million dementia patients could be a staggering U.S$1.2 trillion or more. This is unsustainable and investment is needed, if we are to avert this economic and social disaster.

This is not an acceptable situation. Something fundamental has to change. We need a concerted effort to mobilise a global assault on dementia, in the way we attacked HIV/AIDS in the 1980s and 90s.

We need to deliver accurate and early diagnosis, effective treatment and better care and support.

We believe current research and development is not making sufficiently rapid progress. Conventional drug development approaches have made limited headway. Our understanding of dementia and our diagnostic tools are still in their infancy. There have been multiple clinical trial failures, often in the late stages of development, at large cost to investors and the pharmaceutical industry. Too much experimental science is left on the laboratory shelf with no prospect of financial support to enable further development. We believe the current ratio of risk to reward in dementia research and development is not attractive to investors. The lead times are long and the chances of failure are very high. We need to change that equation.

The World Dementia Council has been formed at the invitation of the UK Government to support the World Dementia Envoy in his role of championing
the cause of innovation in dementia across diagnosis, treatment and care and by focusing on how we can unlock far greater amounts of investment.

Members of the Council come from different backgrounds and different nations but we are united in our passion to make an urgent and fundamental breakthrough in the diagnosis, treatment and care of people with dementia.

Our aim is to stimulate innovation, development and commercialisation of life enhancing drugs, treatments and care for people with dementia, and in protection of those at risk of dementia, within a generation.

We will do this by providing independent advocacy and global leadership. The views we express will be independent of any particular interest group or Government policy. We will speak freely and clearly as to what we believe needs to change. We will be radical in our thinking, but always based on the best evidence and sound science.

The Council will work towards a framework to enable and incentivise the ecosystem around dementia and a ten year plan to achieve our goals. We are determined that we will make progress.

The G8 Declaration set the goal that we will have found a cure or a disease modifying therapy by 2025. To this end, we will aim that within seven years we should have delayed the onset and progress of the disease by at least one quality-adjusted life year. By 2025, we expect this to have risen to at least two added years.

We cannot achieve these ambitions alone. There is already important work going on around the world. We want to create an environment in which this work can expand, extend and succeed.

Over the next year we have agreed to work to achieve meaningful and specific changes in the following priority areas:

- **Finance** – to propose new incentives and financial structures that drive new investment by lowering risk and increasing reward.

- **Research collaboration** - to develop incentives that would catalyse new research partnerships between government, academia and industry, with an emphasis on entrepreneurial effort and a patient-focussed research approach
• **Regulation and trials** - to seek to harmonise the regulatory pathway and find other ways to make it more flexible and efficient, in order to accelerate drug development.

• **Sharing knowledge** - we will put our weight behind global efforts to build single inventories of research activity and databases. In addition, we will address disincentives for collaboration in both industry and academia and seek to increase opportunities to share data and establish networks and platforms for synthesising and disseminating knowledge to different stakeholders.

• **Health and care** - to identify and disseminate innovative practice in the care of people with dementia and make these and existing practices available to those with dementia throughout the world, as well as their families and other carers.

• **Awareness** - to raise public awareness of the scale of the economic and social challenge we face and the urgency of the need for a radical global response, with a view to changing policies and practice to increase diagnosis rates and to improve the treatment and care of those with dementia.

We will be open and transparent in the way that we go about our work. We want to engage with as many interested parties as possible and we will establish a comprehensive digital platform to facilitate our communication.

In the coming weeks we will agree a work programme for the next twelve months which will show how we intend to make early progress on these priority areas as we move towards our objectives. We will share this widely and would welcome comment and debate.

We also encourage you to respond to this first Statement. What do you want the Council to prioritise? What priority areas are missing? What could make the most difference?

We look forward to working with you.

*The World Dementia Council*
*May 2014*