NHMRC Dementia Key Stakeholder Forum

On 20 June 2014, NHMRC hosted a forum for key stakeholders in dementia research to help inform implementation of the $200 million Boosting Dementia Research initiative announced as part of the 2014 Budget.

The forum was a productive and valuable opportunity to seek attendees’ views on Australia’s research strengths and challenges in relation to dementia research; objectives of the new NHMRC National Institute of Dementia Research and ways to dramatically expand dementia research capacity.

Sixty participants including neuroscientists, psychiatrists, population health and health services researchers, health professionals, policy makers, consumer representatives and representatives from not for profit organisations attended the workshop. Comments provided by participants will be used to guide implementation of the Boosting Dementia Research initiative.

Overarching principles for the Initiative

Attendees put forward suggestions to frame the Boosting Dementia Research initiative. They proposed that the Initiative needs to:

- **Provide a lasting legacy to have substantial **sustainable impacts** beyond the life of the five year measure;**

- **Engage consumers strongly throughout the research prioritisation, development and translation processes (noting that this is more inclusive than simple consultation);**

- **Drive national **collaboration** across sectors and research disciplines to formulate and answer the key questions for dementia research;**

- **Ensure that the research is translated to induce **systemic change** in the health system and make a significant difference for dementia patients and carers;**

- **Prioritise** research including by maintaining appropriate balance between building on current research strengths and identifying gaps in Australia’s research capacity;

- **Engage clinicians and providers, so that research findings are **translated** to inform practice and practice informs further research;**

- **Include research on mixed and other forms of dementia and ageing in addition to Alzheimer’s disease;**

- **Include a focus on** early diagnosis **and lifestyle intervention and identify population health measures to reduce the risk and prevent dementia; and**

- **Include **discovery** research on normal brain function to inform dementia prevention, diagnosis and treatment.
NHMRC National Institute for Dementia Research

A new NHMRC National Institute for Dementia Research is being established to synthesise, focus and translate the Australian research effort in dementia. The Institute will be allocated $50 million over five years. Attendees discussed the objectives of the new NHMRC National Institute of Dementia Research and suggested that the Institute needs to:

- Show strong leadership of dementia research in Australia and articulate this through a clearly defined mission;
- Track and actively coordinate current research across Australia including by harmonising, standardising and maximising linkages and feedback across clinical and translation projects;
- Engage a network of researchers, consumers, clinicians and other key stakeholders across Australia in the research and translation processes;
- Drive integration with international efforts and ensure Australia is part of the momentum of the global focus on dementia research;
- Form a focal point for developing new partnerships, including with industry and primary care and leveraging additional funding;
- Identify and promote best practice translation through a range of innovative methods;
- Track what works and undertake large scale projects to make strong and lasting impacts for dementia patients and carers and reduce stigma; Maximise linkages and access to big data and essential research infrastructure; and
- Operate transparently particularly for the prioritisation processes, progress of the research and how it is being translated.

Attendees also made suggestions for projects that the Institute could consider funding. These included:

- Coordination of large scale cohort studies and analytical epidemiological studies, including phenotype and genotype characterisations;
- Funding essential research facilities, including brain imaging, biobanks and data linkage studies;
- Providing a focal point for patient recruitment into preclinical and clinical trials; and
- Driving translation of research into tangible outcomes across primary and secondary prevention, treatment and care in the community, aged care and end of life stages of dementia patients and carers.

Ways to expand research capacity

The Boosting Dementia Research initiative includes $46 million of NHMRC and ARC funding which will be allocated to dramatically expand research capacity in dementia research and build the future research workforce.

The $26 million ARC component needs to ensure that research takes into account the social, economic and cultural impacts and complex consequences of dementia.

Attendees, including researchers funded by ARC, suggested the following ways to boost research capacity:

- Development of a framework to boost cross disciplinary research by facilitating co-location of different disciplines including clinical bioinformatics, health economics, mathematics and discovery research;
- Establish dementia research networks for allied health and primary care researchers;
• Direct funding support for research and priorities established by clinicians and allied health professionals;
• Fellowships for researchers focusing on dementia models of care, design and other related areas;
• Develop clinical registries and large scale epidemiological datasets that are widely accessible to all dementia researchers;
• Allocate seed funding for novel and transformative early stage research; Promote initiatives that facilitate research exchange/secondments between industry and academic research;
• Allocate longer term five year funding to attract and retain the best and brightest researchers in priority areas of dementia research; and
• Increase training and mentoring for professionals from allied health and related disciplines to increase their research scientific capability.

What next?

NHMRC will continue to consult with key stakeholders to develop the details of this initiative, including in the community sector, research and government. As details are further developed, NHMRC will keep stakeholders advised, for example through NHMRC Research and Health Trackers and the NHMRC website.