



Australian Government

NHMRC National Institute for Dementia Research

NNIDR Expert Advisory Panel Meeting – 27 February 2019

COMMUNIQUE

The Expert Advisory Panel met face-to-face in Canberra on 27 February 2019 for a one day meeting. This Communique updates stakeholders on meeting deliberations across key strategic areas.

With the Australian Government's Boosting Dementia Research Initiative (BDRI) investment in its final year, Expert Advisory Panel (EAP) members met to discuss progress achieved to date, future directions for dementia research, and advise on current and new NNIDR initiatives.

EAP members welcomed the upcoming release of a revised Strategic Roadmap for Dementia Research and Translation for consultation before a public launch mid-year. The new Strategic Roadmap will set the direction for dementia research based on the new strengths and knowledge generated by the BDRI. The new Roadmap will continue to recognise the need to address all aspects of the challenge, from prevention to cure and care, while placing increased emphasis on improving outcomes for Aboriginal and Torres Strait Islander Australians, and retaining and developing the new research capacity introduced to the sector since 2014.

Aboriginal and Torres Strait Islander Strategic Roadmap for Dementia Research and Translation

Dr Kate Smith and Professor Dawn Bessarab, co-chairs of the Working Group developing the Aboriginal and Torres Strait Islander Roadmap for Dementia Research and Translation, briefed EAP Members on development of the draft Roadmap. They outlined the extensive community consultation process, which included 26 face-to-face consultations with urban, rural and remote communities across Australia, and a call for written submissions. Dr Smith and Professor Bessarab noted that research priorities in the draft Roadmap have come from the community, and highlighted that there is currently a lack of culturally safe services for older Aboriginal and Torres Strait Islander Australians, especially those with dementia.

Once finalised, the Roadmap and supporting Action Plan will guide the work of NNIDR and the broader dementia research sector, to help reduce the gap between dementia incidence, prevalence, and health and wellbeing outcomes for Aboriginal and Torres Strait Islander peoples compared with the population as a whole.

CALD Dementia Research Action Plan

NNIDR has partnered with the National Ageing Research Institute (NARI) and key stakeholder representatives to develop an Action Plan to address culturally and linguistically diverse (CALD) Australians and communities' dementia research needs. Progress to date has included an initial stakeholder consultation workshop in Melbourne with clinicians, researchers, service providers and community representatives, and the commencement of up to 14 consultations with ethnic communities across Australia. An online survey targeting service providers and researchers will be released in April. EAP members noted that the collaborative approach between NNIDR and NARI to explore CALD research needs was working well and is a sound model for future work.

Consumer Involvement in Dementia Research

EAP members continued to underline their support for active involvement of people living with dementia, their carers and families, in dementia research. NNIDR's Consumer Involvement Program aims to increase the capacity of consumers to be involved in research and influence the research agenda. Training for consumers and researchers is a priority, with the Consumer Involvement Program Reference Group holding its second meeting in early April to discuss dementia-specific components needed for learning and training materials.

Brain Banking

EAP members welcomed the March 2019 planned commencement of a consultancy to review brain banking arrangements for Australian dementia research. The Brain Banking initiative is investigating sustainable brain

banking arrangements in Australia that can meet the needs of Australian researchers wanting access to brain tissue resources for dementia research. NNIDR has established a Reference Panel to closely monitor progress of the project and has approved the engagement of a consultant to assist with the project. The completion date is scheduled for June 2019. The EAP advised it will be important that the case for brain banking is able to inform the Department of Education and Training's National Collaborative Research Infrastructure Strategy (NCRIS) planned review of biobanking, which is tentatively scheduled to commence in mid-to late 2020.

Progress reports from BDRI Team Grant and JPND Collaboration Grant Holders

The BDRI Team Grants:

Through the Boosting Dementia Research Initiative (BDRI), six large collaborative team grants¹ were funded in 2015 for a five year period. With these entering their final year of funding, Chief Investigators from each of the team grants were invited to participate in a facilitated Team Grants Workshop to assess progress, new areas of collaboration, and to propose areas for new dementia research investment. Chief Investigators presented to the EAP on their research to date, to communicate early outcomes and outline the extent of collaborations fostered through the investment. There were a number of common themes arising from the presentations including:

- All CIs demonstrated significant progress in capacity building, collaboration and translational impact in their programs of work to date.
- Integrating emerging researchers into large projects (e.g. NNIDR fellows) is critical to achieve dementia outcomes progress.
- The grants have brought new people into the field of dementia research.
- Team grants support multi-disciplinary research (incorporating non-traditional disciplines) as this "disrupts" traditional thinking; enabling new thinking and ideas to emerge.

Team Grant holders and the EAP noted:

- Long term follow up of longitudinal studies is essential given the nature of disease.
- The importance of ensuring platforms developed in the projects endure beyond the life of the grants for the national benefit.
- There are opportunities to leverage the establishment of the Australian Dementia Network (ADNeT) in pursuing emerging project directions. Improved access to neurological testing, and access to and linking of cohorts as and where appropriate, are two new opportunities arising.

European Union Joint Programme – Neurodegenerative Disease Research (JPND) Grants:

Professor Perminder Sachdev presented on progress of two grants awarded in 2015 to enable Australian participation in international JPND collaborations. The first saw an Australian team form part of the BRIDGET Consortium, with data now shared across countries and the Australian group participating in many of the analyses. The second program allows Australian participation in the EADB Consortium, the major aim of which is to create a large database/biobank comprised of Alzheimer's disease cases and controls with genetic data.

The EAP noted the importance of international collaborations and discussed the value of Australian researchers pursuing further international collaboration opportunities, particularly with the US National Institutes of Health.

Australian Dementia Forum 2019 (ADF2019, Hobart, 13-14 June 2019)

The EAP will next meet in a combined meeting with the NNIDR Board just prior to NNIDR's annual research symposium, ADF2019, which will be held in Hobart on 13-14 June. The theme of this year's Forum is *Shining a Light on the Impact of Dementia Research*. EAP members encourage broad participation from researchers, health and care professionals, and people living with dementia, their carers and families.

Enquiries on NNIDR's strategy and programs should be directed to nnidr@nnidr.gov.au.

¹ The six grants are: Vascular mechanisms of neurodegeneration: drivers and determinants of dementia (CIA A/Prof Amy Brodtmann, The Florey Institute), An Australian community of practice in Research in Dementia (ACCORD) to improve health outcomes for people with dementia and their carers (CIA Prof Rob Sanson-Fisher, University of Newcastle), Maintain Your Brain (CIA Prof Henry Brodaty), Non-Alzheimer's disease degenerative dementias: Identifying prodromal genetic/familial phenotypes, modifying factors, and protein variations involved in progression (CIA Prof Glenda Halliday, University of Sydney), Developing insight into the molecular origins of familial and sporadic frontotemporal dementia and amyotrophic lateral sclerosis (CIA Prof Ian Blair, Macquarie University), Prospective Imaging Study of Ageing: Genes, Brain & Behaviour (CIA Prof Michael Breakspear, University of Newcastle)