



**Australian Government**

**NHMRC National Institute for Dementia Research**

## **NNIDR Expert Advisory Panel Meeting – 24 September 2019**

### **COMMUNIQUE**

**The Expert Advisory Panel met in Sydney and via Videoconference on 24 September 2019, immediately prior to the Alzheimer’s Association International Conference (AAIC) Satellite Symposium (25-27 September 2019). This Communique updates stakeholders on meeting deliberations across key strategic areas.**

The Expert Advisory Panel (EAP) endorsed NNIDR’s work plan through to June 2020, with a focus on NNIDR membership activities, special interest groups, consumer involvement and preparing recommendations on optimal future arrangements for advancing dementia research in Australia. This will include considering how to take forward the important research outcomes from the five year, \$200 million Boosting Dementia Research Initiative (BDRI), as well as identifying priorities for future investment across the priority areas identified in the 2019 Strategic Roadmap for Dementia Research and Translation.

Noting the Cognitive Decline Partnership Centre (CDPC) was nearing the end of its funding period, EAP members congratulated CDPC Director, Professor Sue Kurrle, and the research teams on the impressive body of translational research that had been advanced by the Centre, with active participation from consumers and industry partners. EAP members agreed that knowledge translation activities are key to ensuring a strong benefit from the CDPC investments, and that ways to take forward the research program, including through the DCRC, should be explored.

#### **Funding Rounds Update**

Members welcomed the announcement in July 2019 of the two grant rounds below, committing the final tranche of BDRI funding:

- [Priority round 5: Implementing Dementia Risk Reduction and Prevention](#) (\$18.26 million invested over 5 years, 11 grants awarded)
- [Priority round 6: Improving dementia data and methods](#) (\$2.77 million invested over 2 years, 2 grants awarded)

EAP members recommended a coordinated approach among Priority round 5 grant recipients to: support generation of strong evidence for risk reduction and prevention interventions; help to increase impact of the funding Round; and fast track future knowledge translation activities. NNIDR will work with new and existing Prevention grant recipients and the DCRC to identify opportunities to standardise approaches and pool research results. Members also highlighted there were opportunities to link with international clinical trials, and that it was important for Australian researchers to align their work with international approaches.

On Priority round 6, Dementia Data and Methods, the EAP noted it would be important to include and combine data from multiple sources, including the Australian Dementia Network (ADNeT), population studies relevant to dementia, and primary health networks.

#### **NNIDR Membership**

The EAP welcomed finalisation of NNIDR’s revised membership and engagement plan. The plan will guide NNIDR activities to continue to expand its membership, particularly among allied or health professionals, care service providers and consumers to place NNIDR as a truly national body that includes and involves all Australians interested in dementia research. Members suggested improving the linking of existing datasets of funded dementia researchers to help achieve this.

On broader sector coordination, EAP noted that the Council of Australian Governments' (COAG) national framework for dementia is to be reviewed, representing an opportunity for the Commonwealth to work with State and Territory governments to coalesce efforts and develop a consistent national response to dementia. EAP members also emphasised the importance of the Commonwealth collaborating with primary health networks, including in dementia research and for data gathering.

### **Special Interest Groups**

The EAP commended NNIDR on the development of its Special Interest Groups (SIGs), formed to provide leadership opportunities to NNIDR Development Fellows, and encourage coordination and collaboration on emerging research topics. Members viewed the SIGs as an important asset for the dementia research sector, and supported NNIDR's focus in the coming year to work with SIG convenors to develop work programs and identify areas for NNIDR support.

### **Aboriginal and Torres Strait Islander Roadmap for Dementia Research and Translation**

EAP members warmly welcomed the finalisation of the Aboriginal and Torres Strait Islander Roadmap for Dementia Research and Translation, and associated Action Plan and Consultation Report. All three documents have been developed over the past year with extensive nationwide community consultation. EAP members agreed the Roadmap is well-timed, with the continued high prevalence of dementia in Aboriginal and Torres Strait Islander communities. The EAP recommended the Action Plan be put forward for Government consideration in the broader context of national ageing, and ongoing government focus on closing the current gap between health outcomes for Aboriginal and Torres Strait Islander Australians and the population as a whole. The Roadmap will be publicly launched in the coming months.

### **Culturally and Linguistically Diverse (CALD) Action Plan**

The EAP also welcomed finalisation of the Culturally and Linguistically Diverse (CALD) Dementia Research Action Plan, developed in partnership between NNIDR and the National Ageing Research Institute (NARI), and following national consultations with 19 CALD communities, and industry and research stakeholders. NNIDR will convene a Special Interest Group to help drive Action Plan implementation.

EAP members discussed the issue of ongoing under-representation of CALD Australians in clinical trials, and welcomed plans by ADNeT to consider and seek to proactively address language, ethnicity and cultural diversity issues in its clinical trials and clinics programs.

### **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 at all levels. The EAP extended a warm welcome to Ms Isabelle Burke, who joined the EAP as a formal member (consumer adviser) at this meeting.

NNIDR's Community and Consumer Involvement Program Reference Group (CCIRG) is meeting regularly to progress the consumer involvement work plan. With NNIDR's national role of helping researchers to work with consumers, a key output by June 2020 will be the production of a toolkit on consumer involvement in research. NNIDR is also working closely with ADNeT to look at novel ways of involving consumers and the public, including leveraging the already extensive consumer engagement programs being run by universities and medical research institutes across Australia.

### **Australian Dementia Forum 2020 (ADF2020)**

The EAP welcomed the announcement of ADF2020, which will be held on 31 May – 2 June in Adelaide. The theme for ADF2020 is 'Dementia research: innovation, discovery and translation,' and four international and Australian [keynote speakers](#) confirmed, Professor Gill Livingston (UK), Dr Suvarna Alladi (India), Assistant Professor Shane Liddelow (US), and Dr Eddy Strivens (Australia). [Call for Abstracts and applications for travel awards](#) are open, with a closing date of Friday, 14 February 2020. Registrations will open on Thursday, 14 November 2019.

**We welcome your enquiries on, and input to, NNIDR's strategy and programs. Email: [nnidr@nnidr.gov.au](mailto:nnidr@nnidr.gov.au).**