



# Australian Government

## NHMRC National Institute for Dementia Research

### NNIDR Collaboration and Coordination Framework

December 2016

#### Background:

There is a need for enhanced collaboration and coordination in Australian dementia research. This has been clear for some time in a broader health and medical research setting, and was summarised in the recently released "Review to strengthen Independent Medical Research Institutes:

*The need for collaboration has been reflected in the findings of major reviews such as the 1999 Wills Review, the 2009 Zerhouni Review of NHMRC, the 2008 Cutler Review of the nation's innovation system, the Australian Government's 2009 Innovation Agenda, Powering Ideas, and most recently, the 2013 McKeon Strategic Review of Health and Medical Research.*

*The McKeon Review noted that the Australian health care system, and in particular the HMR sector, is a highly fragmented landscape that involves various government departments and agencies at both the Federal and State and Territory level; a large number of stakeholders with different priorities and capabilities; and a range of research disciplines. Collaboration is therefore required not only to form a cohesive system and align research goals, but also to leverage the different skills, knowledge bases and resources of stakeholders; to ensure that research is effectively translated into clinical practice and health service delivery; and for Australia to remain a significant global contributor to health and medical research.*

Enhancing the coordination and building collaborations in Australian dementia research was a key component of Alzheimer's Australia's Expression of Interest for the provision of services for the Dementia Institute.

- *Bring together Australia's dementia research; including existing NHMRC dementia related programs and other national initiatives, to ensure stronger coordination and collaboration.*
- *Synthesise information provided from current research and develop strong linkages with community groups, practitioners and other service providers to rapidly and flexibly translate research outcomes.*
- *Develop partnerships between researchers, industry and philanthropic organisations to help embed dementia research into the health system and stimulate the translation and implementation of research findings into policy and practice.*
- *Ensure Australian participation in major international collaborations relevant to dementia research.*

*Alzheimer's Australia has brought together a compelling research community that includes Australia's leading dementia researchers. These partners share a commitment to build on existing consortia and collaborations to synthesise research efforts and orchestrate a more ambitious and impactful research agenda.*

*This recognises that researchers, teams and organisations working alone will never be able to achieve the social impact that they could by working together. Collaboration and open innovation are imperative if we are to drive improvement and unlock value. In noting this, it is acknowledged that this is not yet the dominant paradigm in Australia. The sector sees the Institute as a unique opportunity to think and act differently.*

These documents highlight the importance and need for collaboration and coordination in Australian dementia research, and the critical role of the Dementia Institute in driving the necessary culture change. The Institute has an opportunity to create a new model and paradigm for successful research and translation outcomes through a collaborative and coordinated approach.

The NHMRC National Institute for Dementia Research (NNIDR) collaboration and coordination framework has been developed using the “NHMRC National Dementia Research & Translation Priority Framework” (Priority Framework) as a basis. The Priority Framework was developed through extensive and diverse stakeholder consultations, and informs NNIDR strategy and activities.

The key objectives of Institute include:

- Bring together Australia’s dementia research, including existing National Health and Medical Research Council (NHMRC) dementia-related programs and other national initiatives, to ensure stronger coordination and collaboration.
- Develop strong linkages with community groups, practitioners and other service providers.
- Develop partnerships between researchers, industry and philanthropic organisations.

These objectives are mirrored in the Director’s key duties, as outlined in the Dementia Institute services contract between Alzheimer’s Australia and the NHMRC:

- *Driving stronger co-ordination and collaboration of Australia’s dementia research effort, managing and facilitating co-operative relationships with government agencies and key stakeholder groups.*
- *Developing strong linkages with researchers, community groups, practitioners and other service providers.*
- *Developing partnerships between researchers, industry and philanthropic organisations.*

Actions taken by the Institute within this framework are already underway, and will be reported as necessary to relevant Institute stakeholders.

### **Collaboration and Coordination in context: the NHMRC National Dementia Research and Translation Priority Framework**

The Priority Framework developed themes for collaboration and coordination.

Aligned priorities: priorities and efforts of investigators, governments, service providers and consumers are aligned through a shared *narrative of change for consumer outcomes*.

Powerful partnerships: *cross-sector, cross-domain and cross-disciplinary partnerships*, thought leadership and the inclusion of different sectors of research inform the design of vital new research projects and new approaches to research.

Coordinated programs of research with continuity: *programs of research* provide a framework to draw Australian dementia research together. Programs of research harness the synergy of different types of knowledge and experiences; provide continuity of research; and foster cycles of continuous learning and increasing levels of engagement.

The NHMRC National dementia research & translation priority framework calls for nationally coordinated programs of research across 5 research theme priorities:

1. Living with dementia
  - Consumers are included in co-design of research and service solutions
  - Increased participation in clinical trials allowing earlier access to innovative treatments and care
  - Model for collaborative care decision making

2. Prevention
  - Coordinate and share data: baseline of community knowledge of risk factors; gaps in knowledge; coordinated strategy for new collecting data; existing/ongoing longitudinal studies
  - Translate knowledge to population level strategies
3. Diagnosis
  - Collaborative programs in basic science to inform diagnosis.
  - Collaborative partnerships that lead the development and coordination of a recognised and consistent pathway from diagnosis to care are established
  - Data relevant to early assessment and diagnosis are coordinated and shared
  - Services are co-designed with consumers
  - Coordinate existing biomarkers and integrate new biomarkers as they are identified and validated
4. Intervention/Treatment
  - Collaborative programs in basic science to inform treatment development.
5. Care
  - Develop programs of research that: consolidate evidence from research to inform frameworks that change practice; establish partnerships that are able to lead change and translation in complex environments of care; develop a research program in complex systems of care that can demonstrate the impact and viability of quality of care that supports quality of life.
  - Sustainable cross sector innovation leadership partnerships that bring together innovation leaders in policy, facility directors, clinicians and care providers.

### **The NHMRC National Institute for Dementia Research (Dementia Institute) Collaboration and Coordination Framework**

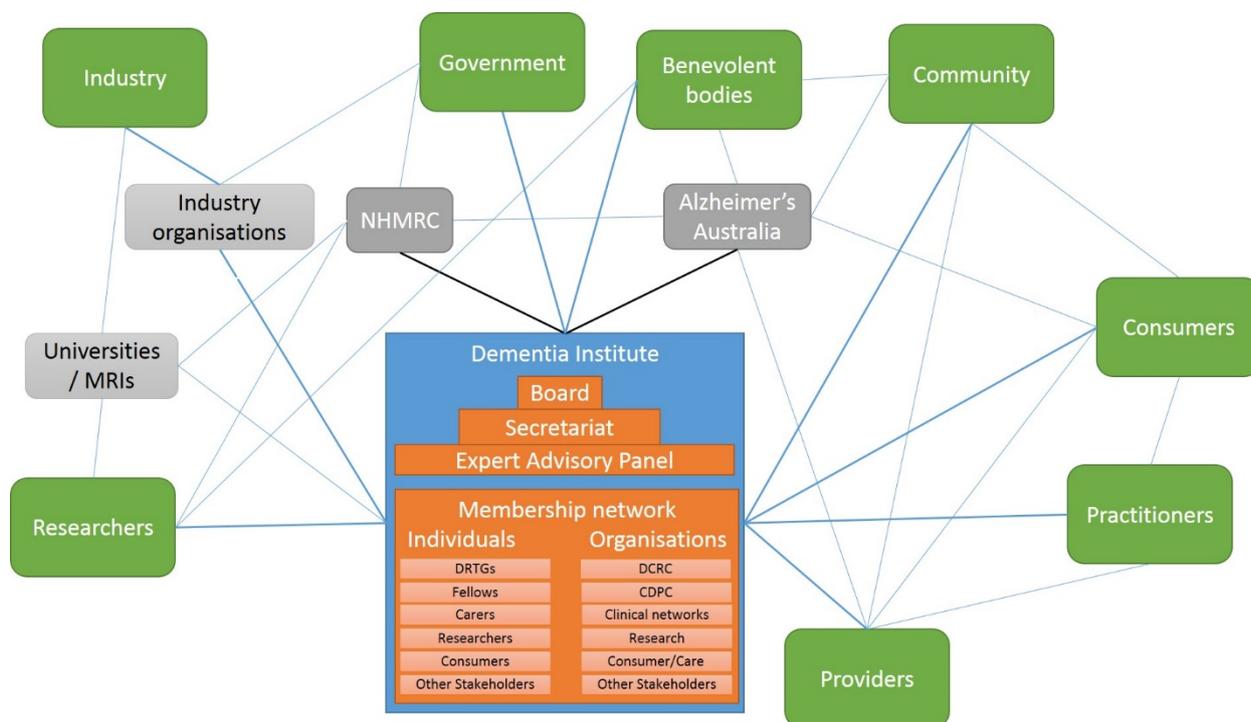
**Key element 1:** *Aligned priorities: Dementia Institute engagement of stakeholders through a shared narrative of change for consumer outcomes*

Delivering genuine outcomes for consumers is dictated by what is possible in the short and the long term. A shared narrative for change can be established by drawing attention to the interdependent relationship between short, medium, and long term outcomes in each research thematic domain.

The implementation of priority research and translation outcomes will require the coordinated effort of a whole ecosystem of stakeholders who are impacted by dementia and dementia research (*see Figure 1*), including:

- Consumers
  - Contribute to disease understanding and co-design programs of research, service solutions and approaches to the way consumers live with care
- Researchers
  - Coordinate research to optimise strengths, and identify gaps and opportunities for new thinking. Structure research with a long-term vision that can also deliver short-term outcomes across thematic domains (living with dementia, prevention, treatment, diagnosis and care)
- Medical practitioners
- Aged care providers
  - Drive the urgent need for innovation to increase quality of care and quality of life for people with dementia and to reduce the cost of service delivery. Will partner with researchers to design, validate and translate innovation.
- Government, social services, health agencies
  - Collaborative partners in development of a knowledge translation strategy and alignment of funding, regulatory frameworks and policy to deliver priority outcomes

- Dementia Institute
  - o Select priorities for action, facilitate coordination of research and establish programs of research in each thematic domain.



*Figure 1: The Dementia Institute forms the centre of the collaboration and coordination framework network. Abbreviations: NHMRC, National Health and Medical Research Council; MRIs, Medical Research Institutes; DCRC, Dementia Collaborative Research Centre; CDPC, Cognitive and Related Decline Partnership Centre; DRTGs, Dementia Research Team Grants.*

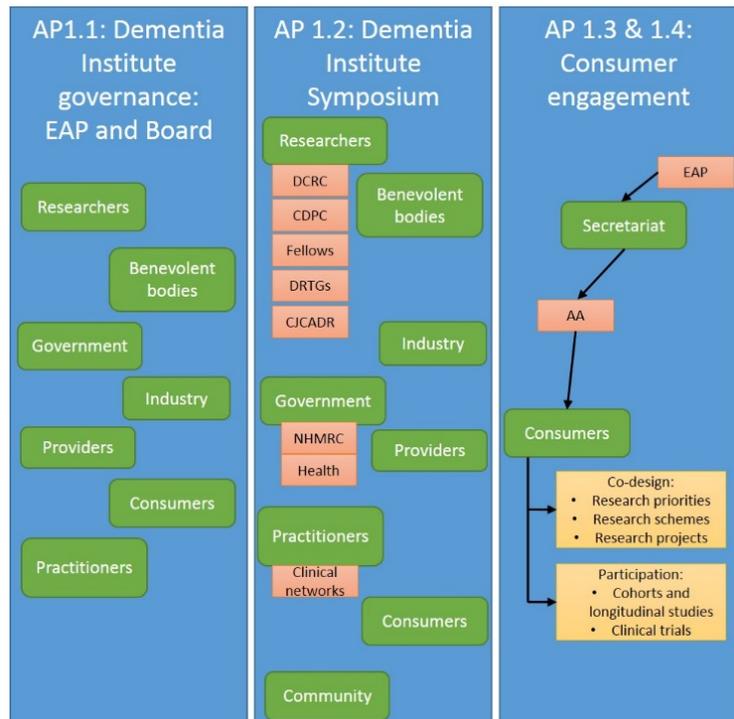
The Dementia Institute will engage all stakeholders and focus them toward collaborations to change consumer outcomes. Representatives from each group of stakeholders are present on the Dementia Institute Expert Advisory Panel. In addition, stakeholders will also be present on theme-oriented expert subcommittees. The Dementia Institute will be the fulcrum of the shared narrative for change, and will use Expert Advisory Panel members as well as the Membership network as agents for this shared narrative for change.

The Dementia Institute Symposium, to be held in May 2016, will be critical point in forming the joint narrative of change for consumer outcomes. The Symposium will bring together all parts of the Dementia Institute membership network and stakeholders, and provide opportunities for all parties to interact and discuss opportunities for cross-sector and cross-discipline collaboration and coordination. It is planned that the Symposium will also include international research leaders as Keynote/Plenary speakers. Joint Australia Research Council (ARC)-NHMRC Dementia Research Fellows, Dementia Research Team Grants (DRTGs) and centres of

dementia research excellence will be expected to attend and form the majority of presentations at the symposium.

### Consumers

The Dementia Institute will work with Alzheimer’s Australia, the NHMRC and the Consumer Dementia Research Network (CDRN) and other relevant consumers and consumer representatives to develop a robust consumer engagement strategy. Consumer engagement may include co-design of research programs, and active involvement in research on living with dementia, and care/service solutions. Consumers may also be involved in the formation and registration of ready cohorts for clinical study and trials.

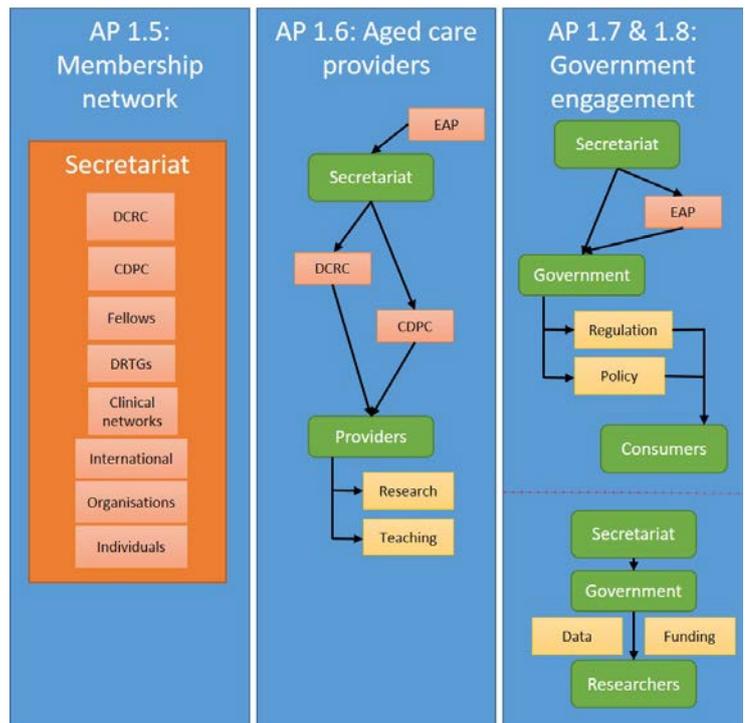


### Researchers

The Dementia Institute will work with Dementia researchers in each of the thematic priority areas. Investigators from the six Team Grants, as well as the 76 joint ARC-NHMRC Fellows, will form the core membership network of the Dementia Institute, along with researchers from the Clem Jones Centre for Ageing Dementia Research (CJCADR), Dementia Cooperative Research Centres (DCRCs; note the three DCRCs are being combined into a single research program, with the Program Director to be advised by the Dementia Institute Expert Advisory Panel) and the NHMRC Cognitive and Related Decline Partnership Centre (CDPC; note the Dementia Institute Director is Chair of the CDPC governance authority). Successful grant holders from relevant future national and international (e.g. JPCofuND; Joint Programme in Neurodegenerative Disease) funding rounds will also be included in the Dementia Institute membership. Additional individual and organisation memberships will be assessed on an application basis. The Dementia Institute membership network will establish and strengthen connections between Australian dementia researchers, and aid in coordinating research collaborations.

### Aged Care Providers

Care providers will be engaged via the existing CDPC and DCRC activities, through their incorporation into the Dementia Institute. To increase awareness and capability, and to deliver quality care outcomes, the Dementia Institute will support teaching aged care facilities, and research-ready aged care facilities.



Government, Social Services and Health Agencies

Government engagement will be key to the translation of knowledge arising from research into a regulatory framework and policies to deliver outcomes for consumers. The Dementia Institute will also need to work with National and State and Territory governments to align funding. For example, the QLD government has matched funding for the CJCADR, and Dementia Institute is currently engaging NSW and VIC governments to match support for the Team Grants.

Appropriate Government agencies may also be engaged as contributors. For example, the Australian Institute of Health and Welfare (AIHW) on epidemiology data, Australian Commission on Safety and Quality in Health Care (ACSQHC) on guidelines and standards of care, among others.

Conversations have been initiated by the NHMRC with state governments regarding the inclusion of existing clinical networks within the Dementia Institute membership network. This will strengthen practitioner engagement by the Dementia Institute.

**Key element 2: Powerful partnerships: co-design of new projects by cross-sector/domain/disciplinary partnerships, different sectors informing research project design and approaches**

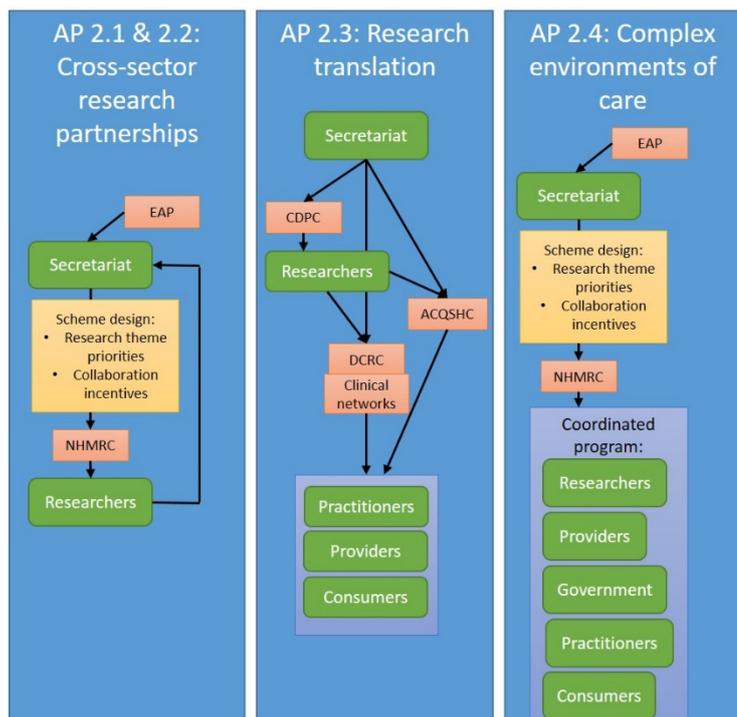
In the short term improving quality of care and quality of life for people with dementia and support for care providers will continue to be a priority for Australian research. With the right partnerships, it will be possible to make significant improvement in the experience of living with dementia, diagnosis and care. Long term intervention outcomes will also be facilitated and accelerated with the right partnerships.

Powerful partnerships will provide thought leadership to envisage change from multiple perspectives. Cross-disciplinary and cross-sector partnerships will optimise innovation, enable research in complex care environments, and support and promote translation.

Research Partnerships

Establishing the Dementia Institute membership network will facilitate and strengthen connections between all sectors of Dementia research in Australia. The network will facilitate and coordinate new research collaborations. The Dementia Institute Symposium will also assist the formation of new research partnerships.

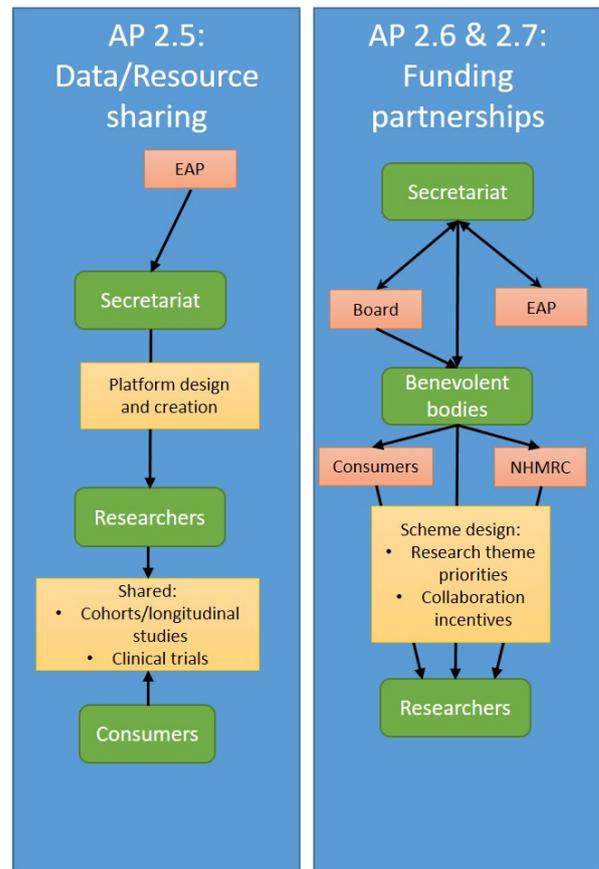
In basic research, cross-sector partnerships lead to innovation and translation. The Dementia Institute will call for projects that are aligned with research theme priorities, and provide funding incentives for participation by different research groups that can contribute different knowledge to the same challenges but with the same goals. With the existing Dementia Research Team Grants already awarded by the NHMRC, the Dementia Institute has engaged these research groups in identifying further opportunities to collaborate with other teams and centres for research excellence. A meeting of all Team Grant investigators, representatives



from the Dementia Institute and Dementia Institute Expert Advisory Panel who also will represent centres of excellence in dementia research has already been held. Business cases are currently being prepared based on the outcomes of the meeting.

### Research and Translation Partnerships

To enable research in complex environments of care, partnerships with hospitals, communities and residential care providers need to be established to lead coordinated programs focusing on translating outcomes for patient care. It is envisaged that the Dementia Institute, particularly through the CDPC and DCRC, can play a lead role in developing these translation partnerships. The CDPC will coordinate translatable research partnerships, while the DCRC and clinicians networks will coordinate translating research for medical practitioners and carers. The DCRCs will also co-ordinate translating research on dementia risk reduction and population modelling of the impact of dementia and projected prevalence. Government organisations such as the ACSQHC will also contribute to translating research into patient outcomes through preparation and implementation of guidelines and standards.



A program of research will provide the structure for dialogue and innovation between policy makers, facility directors, health professionals, clinicians, care providers, and people with dementia. A call for participation in research will be made, with funding incentives and competition for participation. Research developing scalable innovative care solutions will be prioritised.

A further mechanism available for the Dementia Institute to enhance collaborative and coordinated research is through data and resource sharing. The Dementia Institute secretariat will explore opportunities to enable collaborative longitudinal frameworks. A common platform to combine multiple existing cohort studies to enable the sharing of data and analysis is needed, and would provide a gateway to draw more consumers to participate in cohort studies and clinical trials. Significant infrastructure and processes will be required to achieve and coordinate this, and incentives will be used for existing studies to pool their data, and funding schemes may be needed to support the generation, pooling and analysis of data. Collaboration would be a key criteria of a call for such research grant applications.

### Funding Partnerships

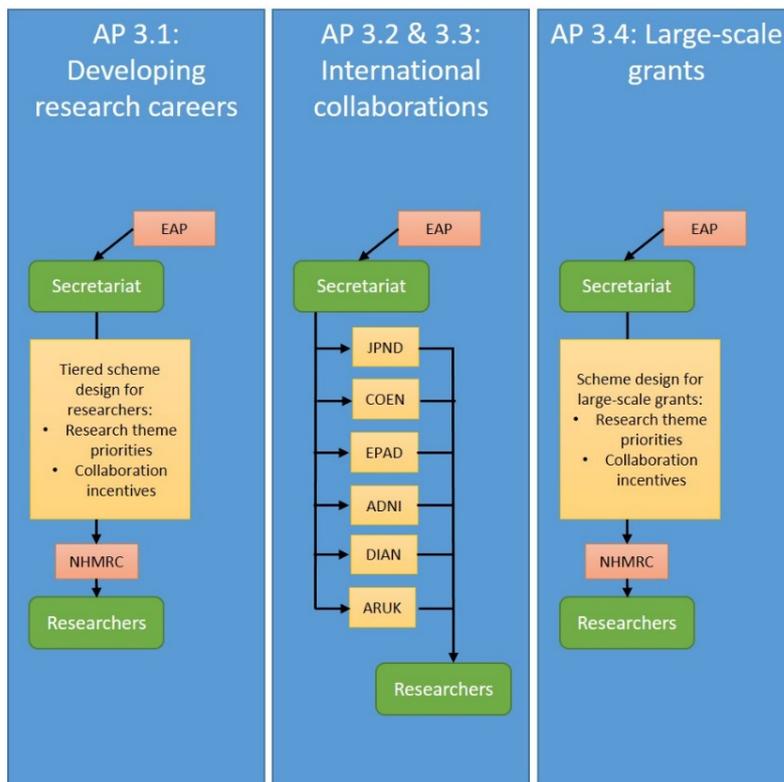
The Dementia Institute is also currently exploring Public-Private partnership models, and has had preliminary discussions with the National Institutes of Health (NIH) Foundation. The Dementia Institute Board is also working to identify opportunities for collaboration and partnerships between benevolent bodies, philanthropic organisations, and the Dementia Institute to support dementia research in Australia.

**Key element 3: Continuity:**  
*Coordinated and ongoing (sustainable) research programs for continuity of research, learning and engagement*

The Boosting Dementia Research initiative is a five year program, and during this time it is critical that the Dementia Institute develops a legacy of ongoing research programs, learning and engagement. It is through this legacy that the Dementia Institute will contribute to the long-term outcomes of the Research Translation Priority Framework, which include contributing to the World Dementia Council target of a five year delay in onset of dementia by 2025.

Aligned priorities and powerful partnerships are necessary for coordinated and ongoing research

programs in dementia. For example, the creation and support of teaching and research-ready aged care facilities will enable long-term translation of care research into patient outcomes. The Dementia Institute membership network will create a legacy of connections between dementia researchers, and lasting collaborations. The Dementia Institute will also be supporting the next generation of dementia researchers through the ARC-NHMRC joint fellowships, and training these fellows to be competitive in future national and international funding rounds. To solidify the research legacy of the Dementia Institute it will be critical to convert these early career researchers into established dementia researchers, while concurrently developing the next generation of dementia research leaders from the current mid-level researchers.



Australian dementia research programs must be integrated in global dementia research to be competitive in international funding rounds. The Dementia Institute will generate partnerships to increase access to international funding opportunities for Australian dementia researchers as lead or collaborative investigators. Following participation in a recent funding round, the Dementia Institute has now gained membership of the JPND, which is based in the European Union. This will allow the Dementia Institute to contribute to the JPND priority setting for future funding rounds, and full participation in these rounds. The Dementia Institute has also begun to explore the possibility of membership of the Centres of Excellence in Neurodegeneration Research (COEN), and the Dementia Institute Expert Advisory Panel, Board and the NHMRC CEO will consider whether to lodge an application for membership in 2016. A position paper with respect to additional international collaboration opportunities (with: European Prevention of Alzheimer’s Dementia Consortium, EPAD; Global Alzheimer’s Platform, GAP; Alzheimer’s Research UK, ARUK; Dominantly Inherited Alzheimer Network, DIAN; Alzheimer’s Disease Neuroimaging Initiative, ADNI) is currently being prepared by the Dementia Institute secretariat for evaluation and recommendations from the Dementia Institute Expert Advisory Panel.

Developing successful collaborations and partnerships with industry and benevolent bodies will also help to sustain ongoing dementia research programs as part of the Dementia Institute legacy. Dementia Institute -initiated frameworks for longitudinal studies and large-scale grants will also be aimed to develop ongoing and sustainable research programs.