

WE CAN TACKLE AUSTRALIA'S DEMENTIA EPIDEMIC



A partnership between



AUSTRALIANS LIVING WITH DEMENTIA ARE ASKED TO NAVIGATE A CONFUSING, INCONSISTENT PATHWAY TO DIAGNOSIS AND INTERVENTIONS.

IT'S TIME TO CHANGE THAT.

Imagine a world where dementia can be rapidly detected and treated; where the path to managing dementia is clear and easy to follow and links through to cutting-edge research are easy to find. We believe we can take the first steps towards making this a reality.

AN AUSTRALIAN-FIRST SOLUTION FOR PEOPLE LIVING WITH DEMENTIA

We want to shape a world where people living with dementia only need to go through one door to get an accurate diagnosis and treatment tailored to the specific type of dementia they are facing.

This vision is for world-leading comprehensive dementia diagnosis, care and research centres for Australians - the National Comprehensive Dementia Centre (NCDC) Network - that would provide a urgently needed single door to timely diagnosis, clinical care and treatment, and ongoing support for people with dementia, their families and their carers. For the first time in Australia, the NCDC Network would bring together the efforts of GPs, clinical specialists, health professionals, aged care service providers, dementia advocacy groups and new and existing research programs in a unified approach to supporting people with dementia.

The world-class research taking place onsite across the network, with the expertise of the eight founding partners, would transform the treatment of people with dementia, support independent living and quality of life, and pursue the medical breakthroughs that will one day lead to prevention or cure.

The establishment of comprehensive research and care centres for dementia would place Australia as a global leader in dementia research, treatment, education and care, and would:

- Begin to address a health issue expected to affect up to 6.4 million Australians at a cost of \$1 trillion dollars in the next 40 years.
- Support the National Dementia Strategy to achieve a 5% reduction in the number of people with dementia over the age of 65, leading to a cost saving of \$5.7 billion from 2016-2025 and \$120.4 billion by 2056.
- Improve workforce capacity and training of aged care workers under the National Aged Care Workforce Strategy.
- Improve management of a disease that disproportionately affects Aboriginal and Torres Strait Islander people.
- Help address some of the gaps and limits in care for people with dementia identified by the Royal Commission into Aged Care Quality and Safety.

We are exploring the opportunity to establish three centres in Brisbane, Melbourne and Sydney - the first of what we believe could be a nation-wide rollout of centres across Australia; creating an interconnected network that shares resources and research outcomes for the betterment of all Australians facing dementia.

DEMENTIA - A GLOBAL EPIDEMIC

Dementia is a progressive disease that strips people of their memory, independence and ability to communicate and move. It is degenerative, irreversible and has no cure. It robs individuals of who they are, and families of their loved one.

Worldwide, around 50 million people have dementia and there are nearly 10 million new cases of dementia every year. Alzheimer's disease is the most common form of dementia and may contribute to 60-70% of cases.

Dementia is one of the major causes of disability and dependency among older people worldwide. It has a physical, psychological, social, and economic impact, not only on people with dementia, but also on their carers, families, the health system and society at large.

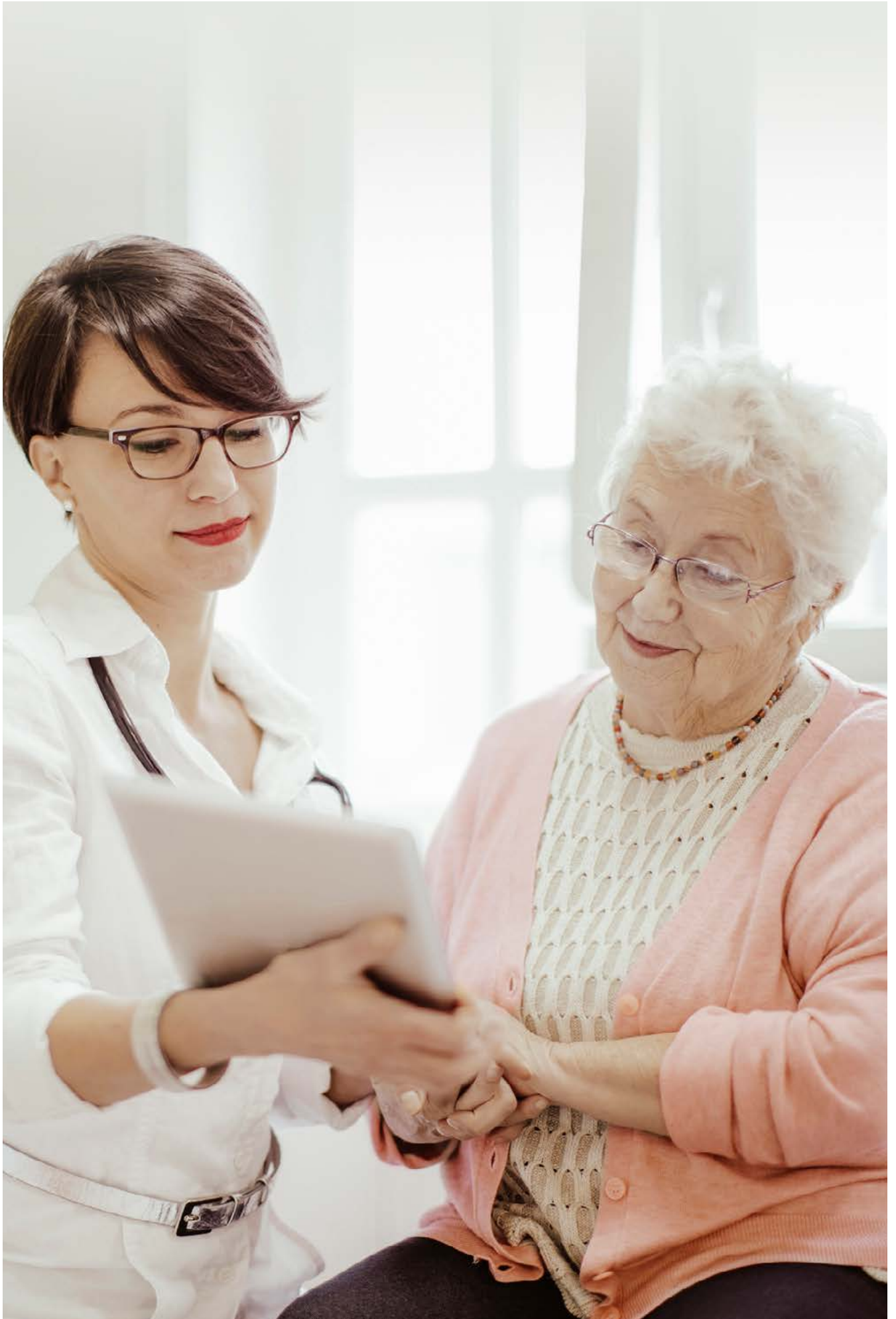
It is universally accepted that Alzheimer's disease will represent one of the major health problems of the 21st century. According to the Global Burden of Disease 2016 study, there were 43.8 million (range 37.8 million to 51.0 million) people worldwide with Alzheimer's disease and other forms of dementia in 2016 (Nichols, E. et al (2018)).

DEMENTIA IN AUSTRALIA

Today, close to half a million Australians live with dementia. It is the leading cause of death in women, the second leading cause of death for Australians overall and likely to become the leading cause of death within five years. This epidemic is set to grow, with numbers predicted to rise to one million by 2058.

Living with dementia isn't the only problem - the current process of diagnosis and treatment only adds to the ordeal of a person with dementia and their family. There is currently no easy way for people to access research that might positively impact their lives.

- 244 people are diagnosed with dementia every day.
- People with dementia make up 53% of those in residential aged care.
- Dementia is the third leading cause of disability burden.
- Dementia disproportionately affects Aboriginal and Torres Strait Islander people, striking at a rate that is 3-5 times higher than non-Indigenous people.
- The individual annual cost of dementia is AUD\$88,000 - almost twice the average lifetime cost of cancer.



ONE HUNDRED DOORS TO TREATMENT - AND YET NO CLEAR HOME

An early diagnosis can provide people with dementia and their families with peace of mind, management plans and access to clinical trials, which can greatly improve quality of life and independence. However, many people living with dementia and their families liken the process of tracking down diagnosis and treatment to trying to navigate their way through 100 different doors.

Much like the disease itself, the path to a dementia diagnosis is painfully muddled. Diagnostic services are dispersed and inconsistent, and people are often bounced between various GPs, clinics and specialists before they secure a diagnosis. Due to the lack of experts who understand the spectrum of dementia symptoms:

- Only a quarter of people with dementia are properly diagnosed.
- From initial symptoms, the average diagnosis takes three years.
- Two-thirds of people with dementia do not see a neurologist or psychologist and are not provided with an appropriate treatment strategy.

Even after a diagnosis is made, people with dementia and their families need to battle with a maze of fragmented care options, delayed services, and a lack of access to clinical trials and new research. Accessing memory and cognitive services can take 6 to 12 months – valuable time for a person experiencing dementia symptoms.

Today, a dementia diagnosis can feel like the end of the road. We want to change this.

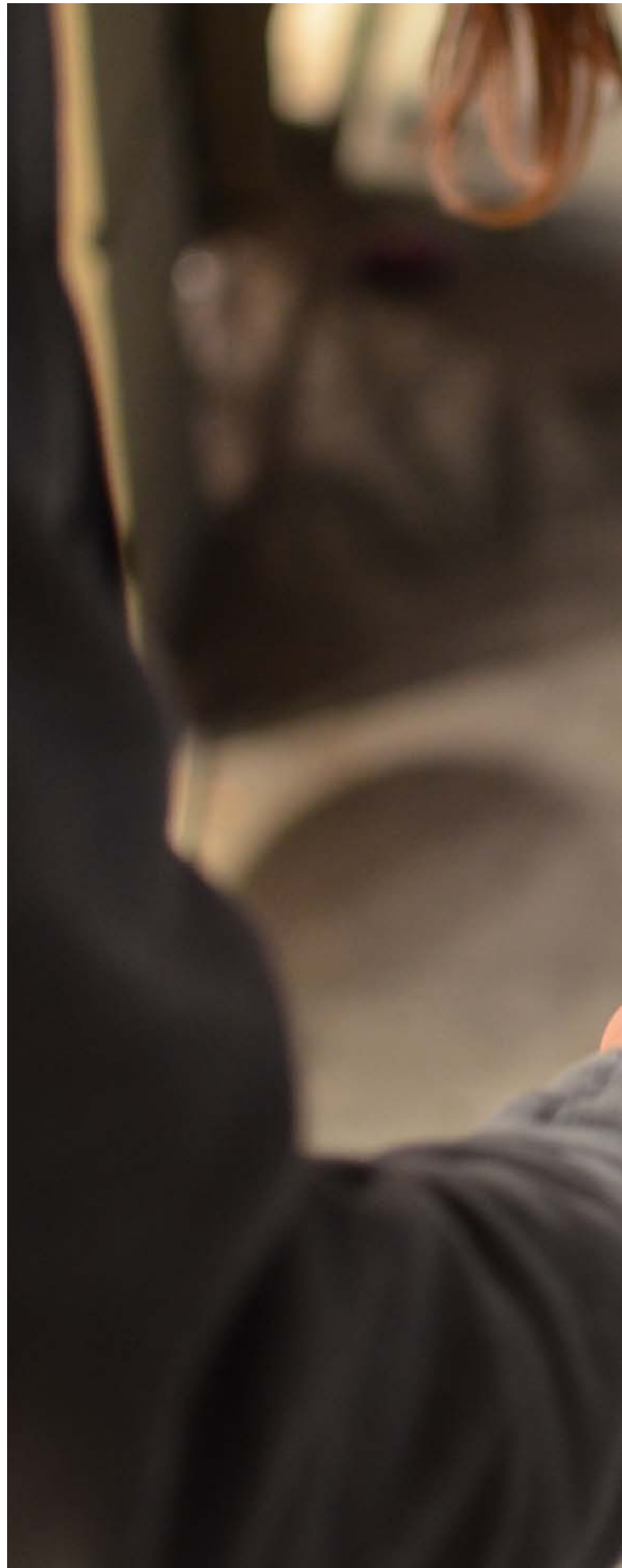
LEARNING FROM CANCER – FROM HOPELESSNESS TO PRECISION

In the 1970s the outlook for an individual diagnosed with cancer seemed hopeless. There were few known treatments, a great deal of stigma surrounded cancer, there was little understanding of the disease and no comprehensive centres for collaborative research, education and care.

Nowadays, cancer is often detected early, prevented, for some it is cured and for many is a chronic disease, not a death sentence. This has been the result of scientific research, clinical research and clinical translation together with advances in imaging and diagnostics. This is our goal for dementia.

Critical to the quantum leaps in cancer treatments and care has been the integration of research, education and care programs. Comprehensive centres for cancer around the world have led the way in breakthrough treatments from the bench to the bedside. The powerful alliance of the 10 leading partners in the Victorian Comprehensive Cancer Centre (VCCC), in particular the University of Melbourne, the Walter and Eliza Hall Institute, the Peter MacCallum Cancer Centre and The Royal Melbourne Hospital, has led the acceleration of translating scientific evidence into patient and community benefit.

Inspired by this model, now is the time to create a comprehensive approach to dementia. We will start with progressing the science with an end goal to integrate research and care for the benefit of the community now and into the future.





TRANSFORMING DEMENTIA DIAGNOSIS, TREATMENT AND CARE

A NETWORK OF COMPREHENSIVE CENTRES FOR PEOPLE WITH DEMENTIA AND THEIR FAMILIES

This new, centralised approach to dementia management will give a sense of hope and peace of mind that is missing in the current fragmented system. It will radically improve the accessibility, consistency and quality of care for people with dementia and their families and will dramatically accelerate research capability.

BENEFITS WOULD INCLUDE:

- One door to a timely diagnosis, management plan and expert dementia specialist care.
- Access to the latest treatment options, clinical trials and enablement and cognitive-maintenance interventions.
- Continuity of clinical care and ongoing monitoring. People with dementia would have access to clinical trials, outpost services and local resources, and revised treatment and service options to correspond with the disease progression.
- Increased research capability

The plight of people living with dementia and their families is currently largely hidden, taking place in the shadows of more high-profile areas of health. These centres would bring the care of people living with dementia forward into the light, delivering the same world-class standard of care that is currently afforded to breast cancer and prostate cancer patients in Australia.

ANATOMY OF A COMPREHENSIVE DEMENTIA CENTRE

With centres in Brisbane, Melbourne and Sydney, the proposed network of centres will offer a personalised experience where world-class diagnosis, clinical care and support services exist alongside training, education services and dementia research.

THE CENTRES WILL OFFER FOUR CORE SERVICES:

1. **First port of call:** The centres will be the first and central point of contact for dementia referrals. A treatment concierge service will provide a systematic pathway for specialist referrals, services and support.
2. **Diagnosis, treatment and services coordination:** People who may have dementia can access early screening services with state-of-the-art diagnostic imaging and testing by dementia specialists. Once diagnosed, they can be monitored and linked to the most appropriate services for their condition. This may include cognitive services to empower independent living and access to new treatments and therapies as they become available. 12 month follow-up and assistance with services will also be provided.
3. **Clinical research platform and workforce training:** People being treated at the centres will have the opportunity to participate in clinical trials and research studies, gaining access to new treatments and assistive technologies. The NCDC network will also provide standardised education and training to GPs and healthcare professionals.
4. **Dementia clinical research and innovation:** By integrating existing research programs with clinical care centres and services, the centre will accelerate the impact and quality of dementia research and care in Australia. The comprehensive centres will co-locate:
 - Clinicians providing expertise and clinical care in diagnosis
 - Dementia Australia delivering ongoing advice, advocacy and support for people and their carers
 - Leading researchers with ability to translate and expedite research to clinical care.

RESEARCH CONDUCTED IN THE CENTRE WILL FOLLOW FOUR KEY THEMES:



Optimising today's care and services: Identifying the services that deliver maximum sustainable benefits to people with dementia and their families and developing standards and guidelines for diagnosis, treatment and care.



Preventative strategies: Identifying risk factors, developing evidence-based strategies to delay the onset and progression of dementia, and building evidence for guidelines and policies.



Early detection, diagnosis and intervention: Improving imaging and diagnostic technologies and tests by applying translational research outcomes, enabling earlier and more accurate diagnosis.



Precision medicine and disease-modifying therapies: Identifying genomic, molecular and pathway drivers of disease to develop new precision medicine treatments to slow or stop the progression of dementia, and ultimately find a cure.



AUSTRALIA - A WORLD LEADER IN DEMENTIA RESEARCH

Australia is among the best in the world when it comes to dementia research. Dementia researchers across the founding partners are recognised as world leaders in the field, with many ranking in the top 1% of highly cited researchers, acknowledging their calibre and research impact:

The research expertise of the founding partners spans

- **The causes of dementia** – from the genetic risk factors to the molecular and cellular changes that underlie the disease
- **Better ways of diagnosing dementia** – including the development of better and more accurate methods of diagnosis through neuroimaging, neuropsychological testing and biomarkers
- **Dementia care** – including the development of better care options to support and improve the quality of life of people with dementia, their families and carers
- **Dementia treatments** – including the development of new medications that modifies or slows the progression of disease, reduces symptoms and improve the quality of life in people.
- **Dementia risk reduction and prevention** – including lifestyle prevention strategies in order to delay dementia onset

Our leading academics in the field of dementia include:

- Professor Christopher Rowe – a world-leader in the field of neuroimaging and Director of the Australian Dementia Network a network of researchers, clinicians and health service providers expediting recruitment of people to clinical trials.
- Professor Colin Masters AO - a giant in the field of Alzheimer's disease and currently leading the world's largest international drug trial aimed at delaying symptoms of the disease.
- Professor Ashley Bush – leading a new research program to stop the degeneration of vulnerable brain cells in people with Alzheimer's.
- Professor Perminder Sachdev AM – an internationally acclaimed leader in the field of healthy brain ageing and better clinical care of age-related brain disorders and co-founder of the Centre for Healthy Brain Ageing.
- Professor Henry Brodaty AO – a pioneer of dementia research in Australia with expertise in prevention of cognitive decline and dementia, and co-founder of the Centre for Healthy Brain Ageing
- Professor Kaarin Anstey - one of Australia's leading researchers in cognitive ageing and dementia and Director of the Ageing Futures Institute.
- Professor Gerard Byrne - Director of the Older Persons' Mental Health Service at the Royal Brisbane and Women's Hospital and leading expert in the neuropsychiatric symptoms of Alzheimer's disease
- Professor Peter Nestor - leading research into how the major forms of dementia affect the brain through novel imaging methods



LOCATION AND SUPPORT

Learning from leading centres around the world (UK Dementia Research Institute in the UK and Aging and Disability Resource Centers in the USA) comprehensive centres must be located in precincts that offer access to the very best dementia research activity; availability of investigative genomic and imaging technology; comprehensive medical care and easy accessibility to individuals and families. On consideration of these factors we are actively reviewing possible sites in Brisbane, Sydney and Melbourne's biomedical precincts, which would be ideal locations to establish the flagship centres to act as exemplars for the national network.

These innovative centres will bring together medical research, medical care and access to social services, closely aligning to available care and use of existing world class technologies to avoid duplication.

We anticipate establishing the NCDC network as a joint venture, backed by the eight founding partners and expanding over time to include additional organisations. The funding model would require a mixture of support from the founding institutional partners, State and Federal Government, industry and philanthropy.



WORLD-CLASS LEADERSHIP AND COLLABORATION

A centre of this calibre requires collaboration between leaders in the field. The NCDC network will be co-led by the University of Melbourne, University of New South Wales and University of Queensland, in collaboration with the Royal Melbourne Hospital, the Royal Brisbane and Woman's Hospital, the South Eastern Sydney Local Health District, the Australian Dementia Network (ADNet) and Dementia Australia. These eight partners are already engaged in making this concept a reality.

THE UNIVERSITY OF MELBOURNE

The University of Melbourne is the top ranked university in Australia and recognised world-wide for expertise in neuroscience. Dementia researchers at the University of Melbourne are recognised as frontiers in multidisciplinary approaches and ranked in the top 1% of highly cited researchers for their calibre and influence on the field.



THE UNIVERSITY OF NEW SOUTH WALES

The University of New South Wales is home to one of the world's top 50 medical faculties, UNSW Medicine.. The faculty is home to the Centre for Healthy Brain Ageing (CHeBA) an international centre of excellence in multidisciplinary research into the ageing brain, which undertakes innovative research and provide the empirical basis to prevent and treat dementia and achieve healthy brain ageing for all Australians.



THE UNIVERSITY OF QUEENSLAND

The University of Queensland is a research-intensive university in the top 50 universities world-wide. The University is home to the Queensland Brain Institute and Clem Jones Centre for Ageing Dementia Research (CJCADR), Australia's first dedicated dementia research centre – home to more than 90 exceptional researchers working to understand what causes dementia and how it can be treated.



DEMENTIA AUSTRALIA

Dementia Australia ties together the collaboration with strong advocacy and community support services. Dementia Australia is committed to representing the more than 400,000 Australians living with dementia, and to 1.5 million people who care for them. It provides advocacy, support, education and information to all people affected by dementia.



THE ROYAL MELBOURNE HOSPITAL

Since 1848 The Royal Melbourne Hospital has been providing outstanding care and treatment to the sickest in our community. A world-renowned institution, the RMH plays a key role in the Victorian health sector as a major Victorian referral service for specialist and complex care being a designated state-wide provider for services. The Royal Melbourne Hospital and the University of Melbourne have had an enduring partnership in place for nearly 150 years, collaborating on the clinical teaching and training of healthcare and research leaders of the future.



SOUTH EASTERN SYDNEY LOCAL HEALTH DISTRICT

The South Eastern Sydney Local Health District (SESLHD) is one of the largest local health districts in Australia, delivering high quality health care to almost 1,000,000 residents. SESLHD, together with UNSW, is a foundation partner of the Randwick Health & Innovation Precinct, where the Prince of Wales Hospital has been caring for the community for more than 160 years. The Precinct brings together world-class education, research and healthcare organisations to address real-world problems across the lifespan, from newborns to centenarians.



THE ROYAL BRISBANE AND WOMEN'S HOSPITAL

Royal Brisbane and Women's Hospital (RBWH) is Queensland's largest hospital and provides outstanding care across an extensive range of clinical areas and is known for its preeminent cancer care, maternity, trauma and burns care. The RBWH has proud partnerships with more than 14 Queensland and national universities. With more than 150 years of caring for Queensland, the modern-day RBWH supports and produces world-leading research and education and is a prominent innovator in the pursuit of ever-improving patient outcomes.



AUSTRALIAN DEMENTIA NETWORK (ADNET)

The Australian Dementia Network (ADNet) is an integrated network of the country's top dementia researchers to create a sustainable, translational research infrastructure to drive ongoing, high quality research and clinical care for Australians living with, or at risk of, cognitive impairment and dementia. Led by Professor Chris Rowe, ADNeT is comprised of 25 investigators, 12 institutions and a broad spectrum of government, clinicians and consumer advisors.



Once established, the NDC will collaborate across other research and clinical centres and, in turn, embrace collaboration across other state-based centres. This will also create a national cohort of volunteers via individual research projects in each state and a mechanism for interconnected research across Australia.

