

MID-TERM REPORT 2016



COGNITIVE
DECLINE
PARTNERSHIP
CENTRE

THERE SHOULD BE NOTHING ABOUT US, WITHOUT US.

The Cognitive Decline Partnership Centre has been at the forefront of engaging consumers in the research. I was honoured to be involved in a number of its projects, particularly the Confused Hospitalised Older Persons Study and the Implementation of Vitamin D in Residential Care.

I was one of around 20 consumers from the Alzheimer's Australia Consumer Dementia Research Network, who were involved right across the work of the CDPC. We were seen as experts in dementia, either through the lived experience as a person with dementia, or as a person who is caring or has cared for someone with dementia.

Rather than only being subjects of research, we were active in high-level priority setting and funding decisions, as well as on steering and advisory committees, and project teams. We were also involved in review of proposals for relevance and priority, assistance with recruitment, and with dissemination of outcomes.

Consumers sought to create a better future for ourselves and for all those coming after us. Such concerns very much influenced my inputs to the CDPC projects, as I drew on my own lived experience. I believe consumers brought a unique perspective to the research in which we were involved.

There is much that consumers can offer to research: our involvement in making an impact on the direction of that research is a social and human rights issue. We want to create a better future for ourselves and for all those coming after us.

There should be nothing about us, without us.

Christine Bryden
September 2016

MID-TERM REPORT 2016

The CDPC is improving the care for people with dementia by creating and disseminating knowledge about improving best practice in Australia. We work with our partner organisations to leverage this knowledge into industry to create positive change in the lives of people with dementia and in systems, services, and the workforce.

THESE ARE THE STORIES
OF THE EMERGING IMPACT
OF THE COGNITIVE DECLINE
PARTNERSHIP CENTRE.

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COGNITIVE
DECLINE
PARTNERSHIP
CENTRE



OUR VISION IS TO
IMPROVE THE LIVES
OF PEOPLE WITH
DEMENTIA.

OUR MISSION IS
TO DEVELOP AND
COMMUNICATE
RESEARCH TO
IMPROVE THE CARE
OF PEOPLE WITH
DEMENTIA.

DIRECTOR'S REPORT

The CDPC has come a long way since our first meeting in June 2012 when we came together to develop the Work Plan for the following years. That was almost four and a half years ago and in that time there has been an enormous amount of energy and enthusiasm expended in carrying out the CDPC Activities, several of which have now been successfully completed with findings that are already being translated into practice. It has been wonderful to watch the CDPC grow from the original team of 17 Lead Investigators with 14 Activities, to now having over 200 members involved across 33 Activities, with a busy Directorate of five staff to keep everything rolling along.

As Director and Chief Investigator of the CDPC it has given me much pleasure to speak to the broader community about the work we are doing to improve the care of people living with dementia. In particular it has been the involvement of our consumers in the development of our research program, and their continued involvement at all levels of the CDPC that has made the CDPC a unique and relevant Centre for research and implementation. Our consumers are both people with a diagnosis of dementia or someone who has or is caring for a person with dementia and they all have made, and continue to make, a significant contribution.

We have a further two and a half years to complete our current Work Plan and this mid-term report reflects our progress to date. We are now focusing on the impact of our work, and how the outcomes and outputs from completed Activities are making a difference for people with dementia and their carers.

We have an external evaluation of the CDPC occurring later this year. This will assess our progress and the extent to which we have met NHMRC's objectives, and also possibly consider an extension of the CDPC beyond early 2019. There is much for us to do!



Professor Susan Kurrle

CDPC Director and Chief Investigator



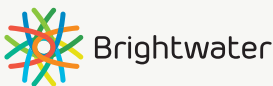
THE NHMRC PARTNERSHIP CENTRE ON DEALING WITH COGNITIVE AND RELATED FUNCTIONAL DECLINE IN OLDER PEOPLE



Australian Government

National Health and Medical Research Council

**UNDERSTAND ALZHEIMER'S
EDUCATE AUSTRALIA**
FIGHT DEMENTIA.ORG.AU



Brightwater



Helping Hand
new aged care



An independent Christian charity

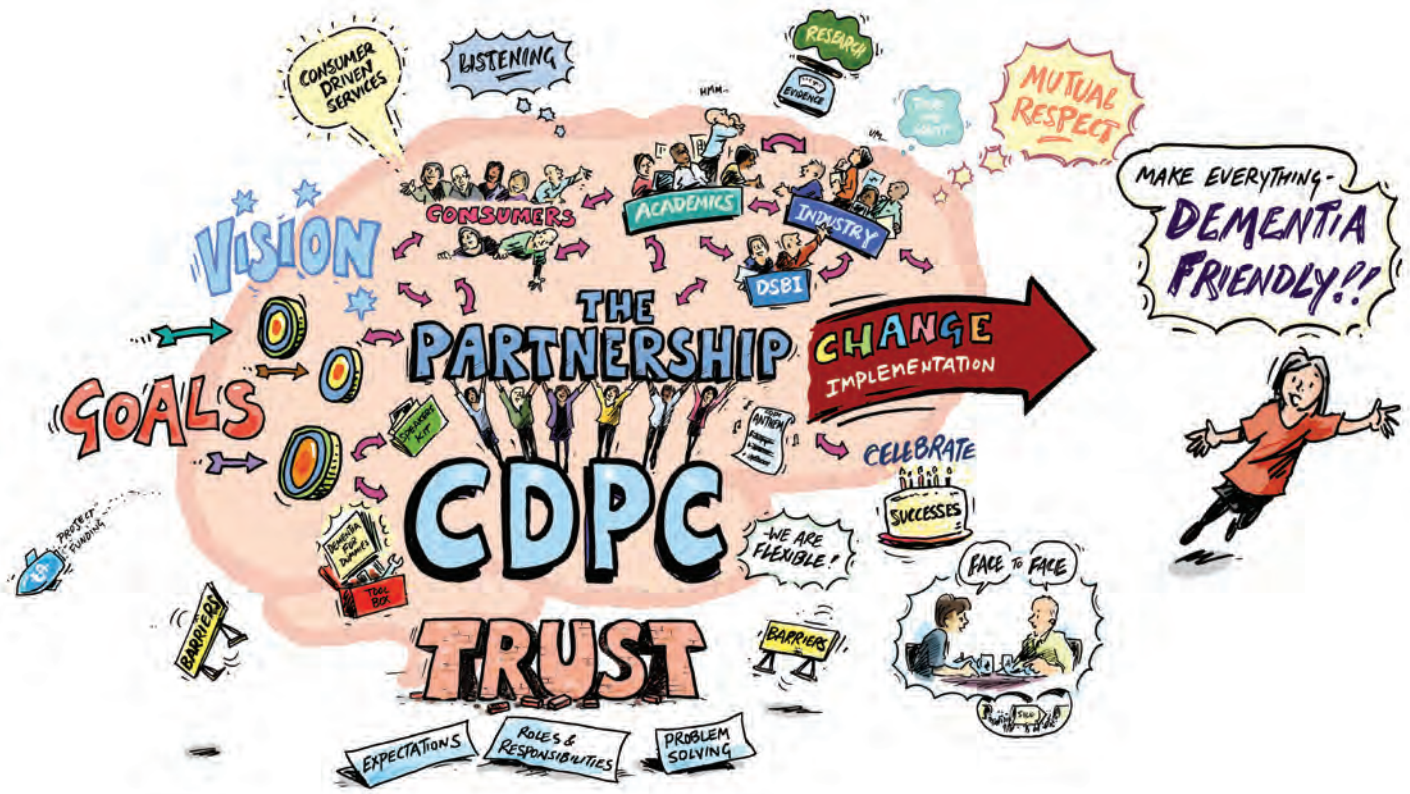
In April 2013 Australia's first Partnership Centre on the theme of 'Dealing with Cognitive and Related Functional Decline in Older People' was launched by the then Minister for Health and Ageing, Mark Butler. This funding initiative by the National Health and Medical Research Council (NHMRC) is part of the Partnerships for Better Health Program and was created with the aim to provide clinicians, service providers, and policy makers with quality research evidence to guide their decisions on improving the health and health care of Australians.

The \$25 million NHMRC Cognitive Decline Partnership Centre (CDPC) is co-funded by the NHMRC, Alzheimer's Australia, and three innovative Australian aged care organisations, Brightwater Care Group (WA), HammondCare and Helping Hand Aged Care (SA) all of whom shared a vision to deliver real improvements for people living with cognitive decline and their carers.

With dementia recognised as a National Health Priority Area, the CDPC has developed an extensive program of work aimed at improving the care of older people with dementia and their carers and providing better evidence and information about best practice in dementia care. We also work towards empowering people to make evidence based change in their practice/s. The CDPC Work Plan, initiated in January 2014, is aligned to eight key themes identified by the CDPC Governance Authority and Executive Committees; in the areas of service model options, pathways and navigation, planning for later life, attitude and culture, workforce development and education, medication management, clinical guidelines, and functional decline.

Now comprising more than 30 research activities spread across Australia, the CDPC is a virtual centre that brings together the skills and experiences of multi-disciplinary researchers, industry experts, policy-makers, clinicians, and consumers to address complex issues around cognitive and related functional decline. Over the last two and a half years the CDPC research portfolio has shown continued growth and it is positioning itself as a leader for delivering evidence based research outcomes that will improve the care of people living with dementia, their carers and families.

CDPC PARTNER ORGANISATIONS



For the Partner Organisations, being part of the CDPC has not only included encouraging research to occur within our services it has also meant identifying DSIBs (Designated System Based Investigators) to speak into the activities and to be a conduit of information back to the Partners. Brightwater Care Group, HammondCare and Helping Hand Aged Care have initiated, developed, advised, supported and enabled a variety of activities to occur within our services. In this we have worked alongside researchers, specialists in a variety of fields and consumer representatives.

The change from standard research practices to the current model has necessitated a huge commitment of time and energy, as we have developed relationships, translated and managed expectations, and communicated results back into our services in persuasive and relevant ways.

We have seen Activity teams engage with people with dementia in person, rather than only with carers and staff. We have seen researchers involve existing staff as agents in the research process, enriching both the research and building capacity. People living and working in our aged care services have so much to contribute!

These differing perspectives must be considered by skilled researchers in the formulation and conduct of activities, so that what is produced is relevant and applicable. As we look towards the next two and a half years, it will become ever more important that the members of the CDPC work together towards outputs and outcomes which make a concrete difference to people living with cognitive decline, whether in residential and community care, the health system or in the wider Australian community.



SERVICE MODEL OPTIONS

Understanding long-term care services for older people with cognitive decline in Australia

Aged care providers are striving to plan and deliver services that provide the best quality care for people with dementia. In order to achieve this there needs to be an understanding of what high quality care means to a person with dementia; however, very little published research details which approaches deliver the best outcomes.

A major project being undertaken in the NHMRC Cognitive Decline Partnership Centre is the INSPIRED study (Investigating Services Provided in the Residential care Environment for Dementia in Australia), which commenced in 2015 aiming to identify and describe different models of care for people with dementia and the consumer outcomes associated with these models. Researchers from Flinders University collected data in 17 residential care facilities from five not-for-profit organisations in four states of Australia (SA, NSW, QLD and WA). These organisations included funding partners HammondCare, Helping Hand Aged Care and Brightwater Care Group.

Through one-on-one interviews, residents and their families have been asked to identify aspects of residential care they value most. Information about the model of care provided in these facilities and the resource usage required to provide this care was also collected from each facility.

The feedback indicated the face-to-face interview process provided many residents with an opportunity to not only give feedback on what it is like to live in residential care but to tell their stories. Many people commented they were happy to contribute to something that will benefit older people in the future.

“ I hope that the facilities for dementia care can be improved and dementia specific facilities are available for all that need them. It is a disease that affects all family members, not just the person with dementia.”

Family member

“ Impressed with the authenticity of the whole project and the work which has gone into it.”

Aged Care Resident

The next phase of the work involves collating and analysing the data and synthesising it with information from State and Commonwealth health systems. It is anticipated that reports on the study findings will be released in mid-2017.

Researchers: Prof Maria Crotty

DSBIs: Megan Corlis (Helping Hand Aged Care), Meredith Gresham, Rebecca Forbes (HammondCare), Wendy Hudson (Brightwater Care Group)

Enabling sub-units: Health Economics, Management of Change and Workforce, Policy and Legislation

Alzheimer's Australia Consumer Network: Tony Ramshaw, Louise Heuzenroeder, Elaine Todd, Kathy Williams

Implementing the Confused Hospitalised Older Persons Study (CHOPS) model to improve outcomes for people with cognitive decline.

The Care of the Confused Hospitalised Older Persons Program (CHOPS) aims to improve responses to delirium and dementia within the hospital system by:

- Improving care and reducing harm for older people and their carers
- Giving health professionals the skills and confidence in caring for people with cognitive impairment
- Supporting system and cultural changes to make hospitals safer places for people with cognitive impairment

Implementation has occurred in 12 healthcare facilities including; Prince of Wales Hospital, Gosford Hospital Lismore Base Hospital, Wollongong Hospital, Broken Hill Base Hospital, Nepean Hospital, Springwood Hospital, Orange Base Hospital, Maitland Hospital, Hornsby Ku-ring-gai Hospital, Fairfield Hospital and Coffs Harbour Hospital.

The CHOPs Program supports training in clinical redesign, program management and change management skills. The Agency for Clinical Innovation provided assistance with data collection, analysis support and evaluation. The CHOPs website and online tools were developed to focus on supporting site staff to implement the CHOPs program.

“ ... the whole environment is quiet and calm. People who are used to visiting periodically are seeing what an amazing difference it is. We have murals on the walls that promote that sense of calmness.”

Hospital staff member

Strong linkages have been made with the Clinical Excellence Commission initiatives, Top 5 and Falls Prevention Programs, NSW Health Dementia Competency and Training Network, Australian Commission on Safety and Quality in Healthcare initiatives, Better Way to Care, Cognitive Impairment Campaign and Delirium Clinical Care Standards and the National Safety and Quality Health Service Standards.

Formative evaluation results demonstrate that the model is able to be successfully adapted across a number of sites.

Researchers: Prof Susan Kurrle, Anne Cumming, Cath Bateman

DSBIs: Wendy Hudson(Brightwater Care Group), Colm Cunningham, Rebecca Forbes, Catriona Lorang (Hammondcare), Jan Van Emden (Helping Hand Aged Care)

Alzheimer's Australia Consumer Network: Christine Bryden, Louise Heuzenroeder, Jennifer Henderson, Anne Turner

EMERGING IMPACT

1

National Partnership

Our structure is unique because we build national partnership through involving consumers and partner organisations at every stage of the research process. Over the past two and a half years we have built an Australia wide network of researchers and affiliate organisations to leverage the impact of our findings.

THE FACTS:

350K+

PEOPLE IN AUSTRALIA ARE LIVING WITH DEMENTIA

2ND

SECOND LEADING CAUSE
OF DEATH IN AUSTRALIA

1.2 MILLION

PEOPLE WHO CARE FOR A
PERSON WITH DEMENTIA

MORE THAN

50%

OF RESIDENTS IN
AUSTRALIAN GOVERNMENT-
SUBSIDISED AGED CARE
FACILITIES HAVE DEMENTIA

Source: Alzheimer's Australia



The cost-effectiveness of aged care, dementia and dementia management in Australia

This project explored a range of economic modelling methods to assess the cost-effectiveness of the health care system and the impact on constrained resources.

Health care systems have limited resources and require choices to be made regarding their allocation to ensure systems remain efficient and sustainable. Financial resource allocation can be made arbitrarily or they may be guided through formal economic analyses. A simulation economic model has been developed to determine the impact of resource constraints and queuing on the efficiency of the health care system as it pertains to aged care, Alzheimer's and dementia management. When compared to other published results, the simulation model generated valid estimates of dementia prevalence and healthcare resource use.

Researchers: Dr Tracy Comans and Lachlan Standfield

DSBIs: Wendy Hudson (Brightwater Care Group), Rebecca Forbes (HammondCare), Megan Corlis, Jan Van Emden (Helping Hand Aged Care)

Alzheimer's Australia Consumer Network: Louise Heuzenroeder, Elaine Todd, Kathy Williams

25% PEOPLE WITH DEMENTIA REQUIRE HOSPITAL TREATMENT

20% OF PATIENTS IN HOSPITAL OVER THE AGE OF 70 HAVE DEMENTIA

50% OF PATIENTS IN HOSPITAL OVER THE AGE OF 90 HAVE DEMENTIA

TOTAL DIRECT HEALTH AND AGED CARE SYSTEM EXPENDITURE ON PEOPLE WITH DEMENTIA WAS

\$4.9 BILLION IN 2009

Source: Australian commission on safety and quality in health care www.safetyandquality.gov.au/abetterwaytocare

A person centered volunteer program to improve the care and outcomes for older people with dementia and/or delirium in acute settings

This project will train volunteers to provide practical assistance and emotional support for people with dementia and/or delirium admitted to rural and regional hospitals.

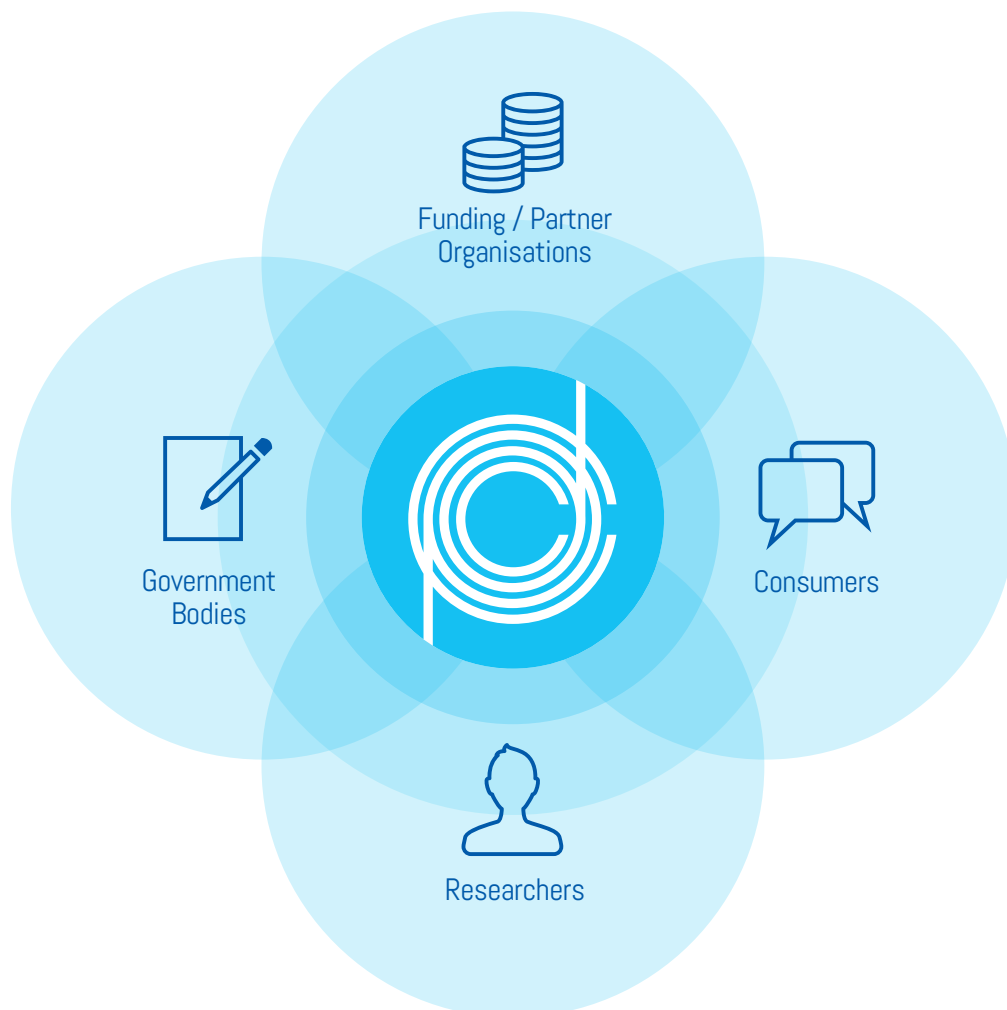
Volunteer Programs may offer significant savings for the acute care setting and significant benefits to patients with dementia and their carers. A pilot program showed acceptance by staff and volunteers and a trend towards reduction in falls in the intervention group. This study is replicating the program across seven Southern NSW Local Health District hospitals, providing greater power to detect changes in patient outcomes. The clinical outcomes and cost-effectiveness of the program will be evaluated using data from patients, carers/families, volunteers and hospital staff. This model also has potential for translation into other settings such as residential aged care facilities.

Researchers: Catherine Bateman, Dr Katrina Anderson, Annaliese Blair

Alzheimer's Australia Consumer Network: Louise Heuzenroeder, Elaine Todd

The CDPC brings together experts in their field to work towards our vision

The CDPC members are specialists in the fields of dementia care, medicine, nursing, psychology, occupational therapy, pharmacology, physiotherapy, sociology, law, health economics, and aged care service management.



Validating and evaluating a quality of life instrument for people with dementia

This project is the first-ever valuation of dementia health states using the quality of life-Alzheimer's Disease instrument to inform planning and resource allocation for dementia care.

Cost-effectiveness is essential in the decision making process for governments. The most common form of cost-effectiveness analysis used in health care relies on accurate estimates of the quality of life (QOL) of the person receiving

the health care intervention. However, commonly used QOL measurements are not suitable for dementia as they do not capture aspects of quality of life that are important to people with dementia, such as family role and social relationships. Disease specific measures of QOL relevant to people living with dementia have been developed e.g. quality of life-Alzheimer's Disease instrument (QOL-AD), however are not suitable in their usual form for use in economic evaluation. This research is the first in Australia developing utility scales for dementia specific measures.

Researchers: Dr Tracy Comans and Dr Kim-Huong Nguyen

Enabling sub-units: Health Economics

Alzheimer's Australia Consumer Network: Joan Jackman

PATHWAYS & NAVIGATION

The key worker role for people with dementia and their carers

Although there have been a number of support models developed to assist people and their carers navigate the health and aged care system there is currently little information about the effectiveness of the support worker role for people with dementia, their carers and family within Australia.

This two phased project with the NHMRC Cognitive Decline Partnership Centre in collaboration with the Royal District Nursing Service included a systematic review of the published literature and a qualitative evaluation of dementia support worker type roles currently in operation across Australia. The project assessed how the support worker role could assist people living with dementia in the community and their carers/family and has provided recommendations that can inform policy and provide a framework for further implementation within advocacy organisations, community groups and other partner organisations.

The findings support the continuation and expansion of the dementia support worker role and support further exploration of how the role can be incorporated within consumer directed care. To continue the provision of the dementia support worker role and to address the current limitations, the recommendations relevant for service development, research and policy development include:

- 1 Explore options for increasing access to the dementia support worker role within consumer directed care
- 2 Trial and align the dementia support worker model with Primary Health Networks to encourage early intervention and increase geographic coverage, particularly rural and remote
- 3 Address the issues of accessibility for diverse groups within existing and future service models

- 4 Undertake a cost effective analysis of dementia support models
- 5 Ensure continuous service improvement for existing services and new services
- 6 Investigate the reasons why people with dementia and/or their caring unit fail to seek help, fail to engage with services, or withdraw from services
- 7 Improve the options for emotional, physical and social care for both people with dementia and their carers
- 8 Provide adaptable funding structures that allow support across the continuum
- 9 Apply the framework as a human resources recruitment, service review and service development tool
- 10 Actively include people with dementia in service development

Researchers: Dr Susan Koch and Dr Dianne Goeman

DSBIs: Megan Corlis (Helping Hand Aged Care) and Wendy Hudson (Brightwater Care Group)

Enabling sub-units: Policy and Legislation

Alzheimer's Australia Consumer Network: Ian Gladstone, Val Jenner/Bob Page, Kate Swaffer, Jane Thomson

Summary report: What is the effectiveness of the support worker role for people with dementia and their carers/family living with dementia. <http://sydney.edu.au/medicine/cdpc/documents/resources/key-worker-report.pdf>

Prototyping alternative respite models for older people with cognitive decline and their carers

This project examined Weavers as an alternate model of support for carers living with dementia that aims to reduce the stress of caring and increase Carer wellbeing.

The Weavers model was developed by the Australian Centre for Social Innovation in response to evidence that existing respite programs for the carers of people with dementia often fail to meet the needs of carers. Weavers peer-to-peer model was prototyped working with carers at home, in collaboration with Helping Hand Aged Care (SA). Following this phase the Weavers model was evaluated with outcomes identifying increased confidence, social benefit and reciprocity. Proposed mechanisms for these Weaver outcomes include feeling valued for their role as a carer and the recognition that they too would have appreciated such support during their caring role.

Researchers: Dr Susan Koch

DSBIs: Megan Corlis (Helping Hand Aged Care)

Enabling sub-units: Health Economics

Alzheimer's Australia Consumer Network: Val Jenner/ Bob Page, Ron Sinclair, Elaine Todd

Weavers Evaluation Report: <http://sydney.edu.au/medicine/cdpc/documents/resources/weavers-evaluation-report.pdf>

The psychosocial impact on the young people having a parent with younger onset dementia (YOD)

The purpose of this research was to develop an understanding of the experiences of young people having a parent with YOD.

Very little research about the impact on the young person having a parent with YOD has been published. This study provided an understanding on societal influences experienced by these young people and highlighted a lack of education tools or support available from health and social care service providers. A workshop also provided a platform for cross-sectorial collaboration and networking for key stakeholders. The research confirmed more opportunities need to be available for young peoples'

engagement within health and social services and a need for greater understanding of their roles within families. This research project has now been converted in to a PhD project to assist in the development of preventative and supportive interventions and strategies for families.

Researchers: Prof Susan Kurrle, A/Prof Christopher Roberts, Karen Hutchinson

DSBIs: Megan Corlis (Helping Hand Aged Care) and Wendy Hudson (Brightwater Care Group)

Alzheimer's Australia Consumer Network: Christine Bryden, Nadine Hedger, Joan Jackman, Kate Swaffer

Understanding the Journey Better: An exploration of the current "state of play" of the health care journey experienced by people living with cognitive decline and their carers

The project will provide a snapshot of the 'current' state of play in the consumer journey through the health care system for those living with cognitive decline and their carers.

While health care costs are rising exponentially there is an increased need for health care organisations to deliver efficient services. Programs of research that have resulted in cost efficiencies as well as producing quality care for patients are programs that have examined patient journeys, with particular success in health care systems. This project is providing the 'pre' study to how the journey is experienced at present (current state) and how consumers would like to experience it (future or ideal state). The current state information can be used as a baseline measure to indicate at what points of the journey the CDPC is impacting those living with cognitive decline and their carers, and where research efforts might focus in future years.

Researchers: Prof Anneke Fitzgerald and Dr Joanne Curry

DSBIs: Megan Corlis (Helping Hand Aged Care)

Enabling sub-units: Management of Change and Workforce

Alzheimer's Australia Consumer Network: Joan Jackman and 26 members of the Alzheimer's Australia Consumer Network in focus groups



PLANNING FOR LATER LIFE

Systematic review and scoping study for the implementation of a national approach to dementia specific advance care planning

Many people with dementia live for a significant time after diagnosis, and many lose the ability to make decisions and choices that are important to them. Advance Care Planning (ACP) provides a mechanism that increases compliance with individual's end of life wishes.

A study within the NHMRC Cognitive Decline Partnership Centre with researchers from HammondCare examined how ACP systems can be improved to meet the needs for people with dementia and other forms of cognitive decline. The project reviewed current literature and resources, and interviewed more than eighty practitioners representing a variety of sectors across Australia with a view to identifying key issues and successful approaches that might inform the development of a national model.

Seven key findings to improve the uptake and quality of ACP for people with dementia were supported in the final report with some specific recommendations and actions for government, organisations and individuals:

- 1 ACP should cover an extended period of time and include a wide range of issues
- 2 Individuals should receive a timely diagnosis of dementia and information about the potential prognosis
- 3 ACP should be done as soon as possible after diagnosis of dementia, if not done previously

- 4 Effective ACP requires conversations that focus on understanding a person's values and beliefs, and what is important to them
- 5 The appointment of one or more substitute decision-makers is critical
- 6 They should be involved in discussions and decision-making as much as possible
- 7 Particular care is needed with transfers between health and care settings

A consumer representative from Alzheimer's Australia's Consumer Network, Kathy Williams, who supported the findings explained,

“ For the people I know who have dementia, what's really important to them is that they have some control over what might happen to them, and that's not just about their medical condition, it's about where they're going to live, who's going to be caring for them, what kinds of activities they still want to participate in, who can visit.

The project will now focus on using and building on what is already in place for ACP with effort focussed on filling gaps or seeking to have current resources adapted to align with the findings on why ACP needs to be different for those with dementia.



EMERGING IMPACT 2

Building Collaboration

The CDPC builds collaboration between consumers, researchers, and partner organisations.

“ I think that this whole experience has changed attitudes. I have seen a lot of respect for consumers, and their thoughts, and actually listening to them instead of saying ‘we’re the researchers, we’re the academics, we know what’s what’. I see a change in respect for consumers and their input and how valuable it is.”

Susan Koch (CDPC Researcher)

“ I am not a researcher by trade, so I am learning a huge amount from the academics I’m working with. The researchers are allowing us to look at things a little differently.”

Megan Corlis (CDPC Researcher; CDPC Partner Organisation, Helping Hand Aged Care)



241

ACT	29
NSW	87
NT	1
QLD	19
SA	53
TAS	3
VIC	19
WA	24
INTERNATIONAL	6

WE ARE INCREASING OUR COLLABORATIVE TIES

Researchers: Prof Meera Agar

DSBIs: Catriona Lorang and Angela Raguz (HammondCare) and Jan Van Emden (Helping Hand Aged Care)

Enabling sub-units: Health Economics and Management of Change and Workforce

Alzheimer’s Australia Consumer Network: Jennifer Henderson, Kathy Williams

Interim Report: Future planning and advance care planning: Why it needs to be different for people with dementia. <http://sydney.edu.au/medicine/cdpc/resources/advance-planning.php>

The policies and practices of financial institutions around substitute decision making

This project investigated the policies and practices of financial institutions with regards to powers of attorney and the consumer experience.



With an ageing population there is a growing need to consider the appointment of substitute decision makers to protect the interests of vulnerable Australians for financial matters. The research involved in-depth interviews with attorneys, financial institutions and government bodies and inquired into their knowledge with regards to financial substitute decision making. The findings highlighted a number of issues experienced by attorneys and banks and also fundamental problems with legislation, lack of harmonisation between the jurisdictions, absence of any form of registration process and the general lack of awareness associated with substitute decision making. The final report includes eight key recommendations for consumer and financial institutions, and based on findings, an education package was developed reviewed and endorsed by the Australian Bankers' Association.

Researchers: Sue Field

DSBI: Jan van Emden (Helping Hand Aged Care)

Alzheimer's Australia Consumer Network: Janet Brennan, Tony Ramshaw, Elaine Todd

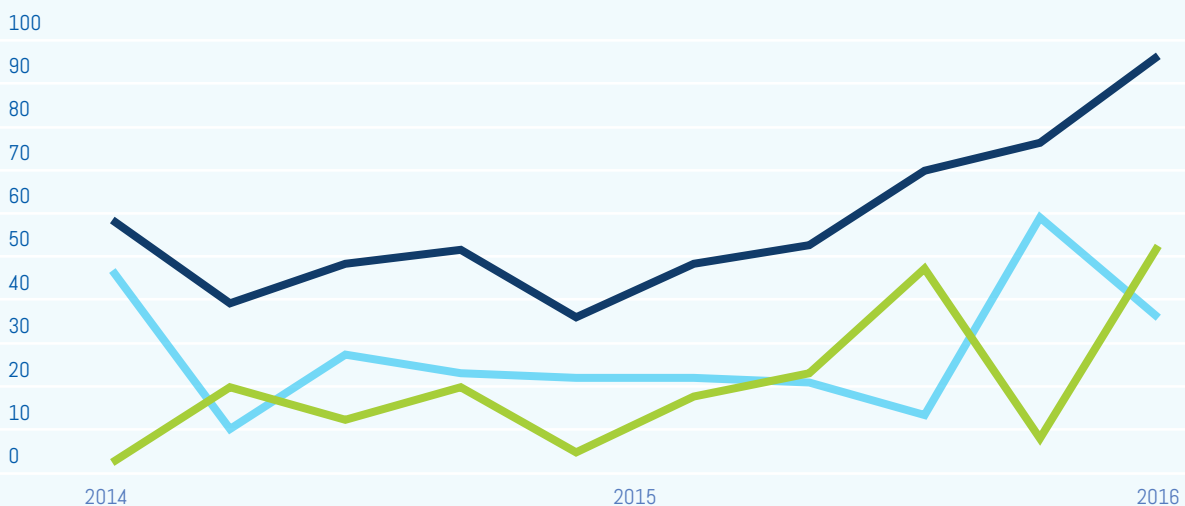
Final report link: <http://sydney.edu.au/medicine/cdpc/documents/about/final-report-policies-practices-of-financial-institutions.pdf>

Increased awareness of CDPC research enhances the opportunity for application of results in policy and practice

The number of outlets where CDPC research findings have been delivered has increased over the life of the CDPC

- Traditional
- Non-traditional
- Total

Note: Traditional: journal articles (refereed, scholarly); conference paper (abstract, poster); conference presentation/workshop. Non-Traditional: all other outputs eg. media interviews, editorials





EMERGING
IMPACT

3

Implementing
“Best Practice”

Optimising advance care planning in dementia through supported decision making: An exploratory mixed methods study of community perceptions and law reform challenges in Australia

This project investigates community perceptions towards supported decision-making in the context of cognitive impairment.

Supported decision making aims to assist people with cognitive impairment to maintain involvement in decision making. The aim of the study is to develop educational materials and practical resources to assist community members and healthcare providers to support decision-making among people with cognitive impairment. Key stakeholders including people with dementia, family caregivers, health providers are being interviewed to assess community perceptions and identify barriers to implementation. Working groups of clinicians, consumers and policy makers are meeting to identify areas of current best practice, and establish strategies for broader implementation in each state. Existing laws, court cases and tribunal hearings across three Australian states (New South Wales, Western Australia and South Australia) are also being studied to identify areas for future law reform.

Researchers: Prof Meera Agar, Sue Field, Dr Craig Sinclair, Prof Susan Kurrle

DSBIs: Megan Corlis (Helping Hand Aged Care) and Meredith Gresham (HammondCare)

Enabling sub-units: Policy and Legislation

Alzheimer’s Australia Consumer Network: Joan Jackman and Kathy Williams

CDPC researchers are passionate about improving “best practice” in caring for people with dementia, and sharing that knowledge with consumers, the public, partner organisations, researchers, and policy makers.

“ Through the strategies we have developed, we will be bringing primary care providers expert information at a relatively low cost.”

Prof Len Gray (CDPC Researcher)

“ I have done a huge amount of media in relation to my project, and I think this has had the effect of raising consumer awareness generally about powers of attorney and the pitfalls of them – not all banks automatically recognize them!”

Sue Field (CDPC Researcher)

ATTITUDE & CULTURE

The effects of regulation on aged care services for people with cognitive decline

This project is the first of its kind to examine the role of regulation in the aged care sector and the impact on the care of people living with dementia.

To identify key areas where regulation affects the quality of care for people living with dementia, interviews with policy experts and aged care staff, including senior managers, facility managers and direct care workers, have been conducted. This research seeks to inform government policy makers, industry stakeholders and regulatory bodies of the benefits and adverse effects of regulation on aged care services, primarily in residential care settings, but with implications for policy developments in community care. The project will provide evidence and suggestions for effective approaches to regulation that are better able to facilitate high quality care for people with dementia.

Researchers: Prof Simon Biggs

DSBIs: Wendy Hudson (Brightwater Care Group), Meredith Gresham, Rebecca Forbes and Catriona Leong (HammondCare), and Megan Corlis (Helping Hand Aged Care)

Enabling sub-units: Research Methodologies, Policy and Legislation, Health Economics

Alzheimer's Australia Consumer Network: Janet Brennan, Joan Jackman, Tara Quirke

Living with Dementia in the Community: Assessing the risks

A risk assessment tool has been developed to help the person living with cognitive decline assess and manage physical and psychosocial risks.

People living with cognitive decline in the community are exposed to a number of risks associated with daily living, and many decisions are made that may impact their quality of life and independence. A risk assessment framework with a checklist of activities would assist people in the community in making decisions about care for people with cognitive decline. The current project is adapting a UK risk assessment framework for use in Australia, and exploring its applicability for people with cognitive decline who live in the community. Once finalised, the risk assessment tool will be made available for people living with cognitive decline, their carers and professionals who work in the area of community aged care.

Researchers: Prof Dimity Pond

DSBIs: Wendy Hudson (Brightwater Care Group), Megan Corlis, Jan Van Emden (Helping Hand Aged Care)

Enabling sub-units: Management of Change and Workforce, Health Economics, Policy and legislation

Alzheimer's Australia Consumer Network: Christine Bryden, Mick Carmody, Ian Gladstone, Danijela Hlis, Joan Jackman, Ron Sinclair

Dementia in the public domain: attitudes and interventions

This project examines current public perceptions of dementia and will develop an evaluation of national and international strategies for greater awareness of key issues.

As community based care becomes a popular personal and policy option, the visibility of people with dementia in public will become increasingly common. Analysis of the implementation and effectiveness of public education will be key in influencing positive identities and empathy of people with dementia and their carers. The project brings together existing evidence and activities tailored to the specific needs and context of dementia; new research data on the overlap and gaps between professional and consumer attitudes and expectations; critical mapping of national and international public health campaigns used to influence attitudes; and recommendations to improve future public health and interest group campaigning. It will also contribute to the development of appropriate tools for future policy and practice.

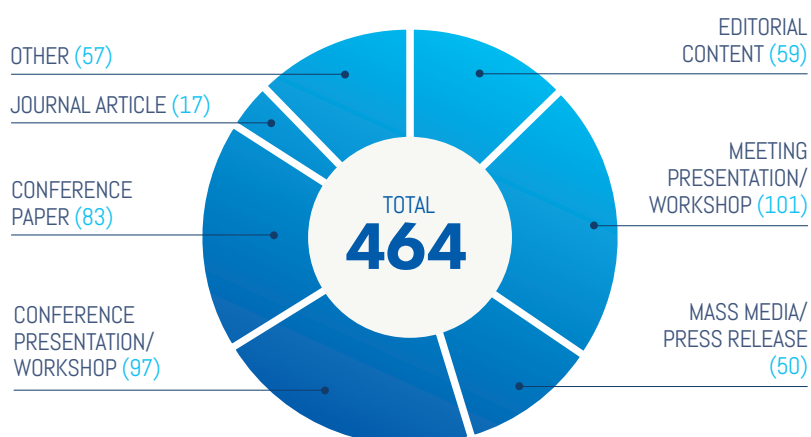
Researchers: Prof Simon Biggs

DSBIs: Meredith Gresham (HammondCare)

Alzheimer's Australia Consumer Network: Danijela Hlis, Joan Jackman, Tara Quirke, Tony Ramshaw

Distribution of results across multiple formats improves audience engagement

Distribution of Output formats



EMERGING IMPACT 4

Improving Quality of Life

Improving quality of life for people with dementia is the underlying goal of ALL CDPC research. Some CDPC projects are already having a direct impact on the lives of people with dementia.

“ You can see that Confused Hospitalised Patients project (CHOPS), at a service level, is changing the way care is delivered to older people in hospitals and it's not just happening within the twelve hospitals originally part of the project that CDPC funded”

Prof Susan Kurrle (CDPC Director, CDPC Researcher)

WORKFORCE DEVELOPMENT & EDUCATION

Evaluating the outcomes of interprofessional education (IPE) programs in residential aged care

(Project Extension: Developing and implementing an IPE toolkit in residential aged care to better support the care the care needs of people with cognitive and functional decline)

The creation of a sustainable workforce that is well trained and competent is crucial if aged care organisations are to provide quality care for older Australians living with cognitive and related functional decline. NHMRC Cognitive Decline Partnership Centre funding partners, Brightwater Care Group and Helping Hand Aged Care, have developed interprofessional student placement programs in their residential aged care facilities that provide training for students from a diverse range of disciplines, including medicine, dietetics, direct care workers, pharmacy, physiotherapy, occupational therapy, nursing and speech pathology. This CDPC funded project evaluated the interprofessional education programs within Brightwater Care Group (WA) and Helping Hand Aged Care (SA) to determine what the benefits of an IPE program are in residential aged care.

“ I have found it really helpful. They [students] have been amazing with the information they've given us, as far as looking after the residents is concerned”

Staff Member

Outcomes of the evaluation included:

- 1 Residential aged care provided an optimal environment for interprofessional student placements
- 2 Residents received additional care improving their physical and emotional wellbeing
- 3 Students changed their views on residential aged care following the placement and became more likely to work in aged care in the future
- 4 Current facility staff improved their skills and knowledge during the programs

As a result of the evaluation findings an interprofessional education resource toolkit, specifically for residential aged care, is being developed within the CDPC. The toolkit will enable staff to support interprofessional education and facilitate interprofessional student placements to improve the care and wellbeing outcomes for people with cognitive and functional related decline. The online toolkit will soon be available to all aged care organisations within Australia.

Researchers: Karla Seaman

DSBIs: Megan Corlis (Helping Hand Aged Care)

Enabling sub-units: Health Economics

Alzheimer's Australia Consumer Network: Tony Ramshaw, Louise Heuzenroeder, Elaine Todd, Kathy Williams

Final Report: Evaluating the outcomes for Interprofessional Education Programs in Residential Aged Care.

<http://sydney.edu.au/medicine/cdpc/resources/ipe-consumer.php>

Improving quality of residential dementia care and promoting change by supporting and caring for staff

This systematic review examined the relationship between staff characteristics, quality of care, and broadly-defined quality of life for residents in long-term facilities.

Two systematic reviews were conducted based on the published scientific literature over the last 20 years. The project aimed to provide more information about the relationships between staff, quality of care, and quality of life for residents and the interventions that have been used with staff to try to improve quality of care and quality of life. Some findings indicated high quality programs improve the way staff interact with residents with effects maintained over the long term. This study may improve the way the aged care sector understands what training, education and skills are required to enhance care of their residents with dementia.

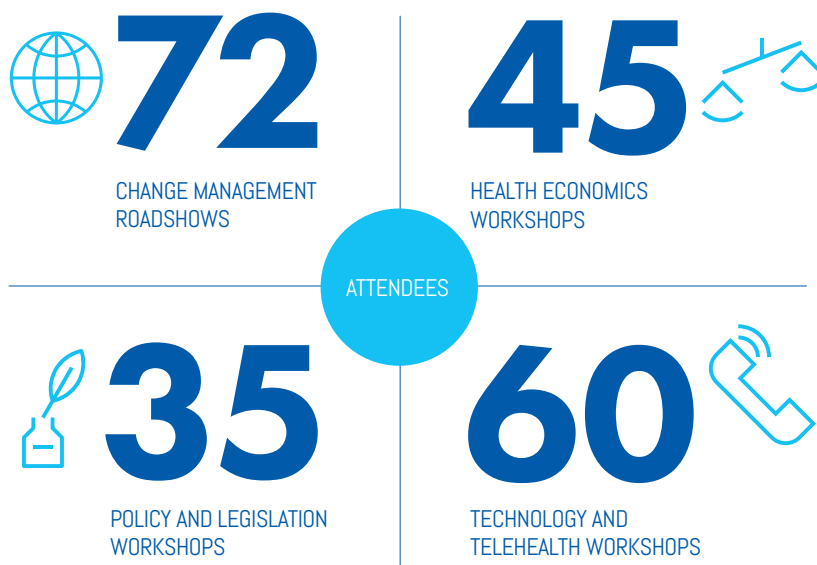
Researchers: Dr Katrina Anderson, Dr Mike Bird, Annaliese Blair, Dr Sarah Macpherson

DSBIs: Meredith Gresham (HammondCare) and Jan Van Emden (Helping Hand Aged Care)

Enabling sub-units: Management of Change and Workforce

Alzheimer's Australia Consumer Network: Jennifer Henderson, Danijela Hlis, Val Jenner/Bob Page, Ron Sinclair

CDPC Internal Workshops support a collaborative learning environment



EMERGING IMPACT 5

Empowering Implementation of Proven Models

The CDPC structure enables unique working relationships to form between partner organisations and researchers, to improve research translation.

“ The Interprofessional Professional Education project has definitely made an impact in our organisation and in Helping Hand, and we are implementing the toolkit at 2 other organisations in Perth and another organisation in SA. We are expanding our reach to make the toolkit as applicable across Australia as possible.”

Karla Seaman (CDPC Researcher; CDPC Partner Organisation, Brightwater Care Group)

CONSUMER INVOLVEMENT IN THE PARTNERSHIP CENTRE



The CDPC has supported CDRN members to attend conferences and workshops around Australia



Consumer involvement in research for many is still a new idea. It was new, if not novel in the dementia research area, four and a half years ago when the CDPC formed and commenced work on the short-list of fourteen major projects, under the banner of the *Partnership Centre for Dealing with Cognitive and Related Functional Decline in Older People*.

As a Funding Partner, Alzheimer's Australia committed its Consumer Dementia Research Network (CDRN) to the CDPC's research in the shape of a part-time funded Consumer Investigator position, supported by a sub-group of six voluntary Consumers and further assisted by approximately twenty voluntary members of the CDRN working across the CDPC projects.

These Consumers have brought a varied mix of personal and professional backgrounds to the CDPC, but above all they have brought a passion and determination to be actively involved, with project team members, to make a difference to the lives of people with dementia and the people who share their lives.

“Initially it was likened to embarking on a 'Magical Mystery Tour'! Prof. Kurrle invited our input into the shortlisting of the first fourteen Projects to be undertaken. From the outset we offered Consumer alignment to all Activities.

The Consumers had to learn more about the processes of research and working within research teams and the researchers had to learn about what the Consumers could contribute and how to work in partnership to achieve the intended outcomes.

Half-way through this five year term of funding the Consumers have experienced significant growth in their skills and understanding of research, together with a stronger appreciation of how, as Consumers, they be of assistance to the CDPC. The research teams have developed a respect for the unique perspective of Consumers and their potential for further sensitising the relevance of projects to the needs of people with dementia and the people who support them.

External consumer engagement enhances capacity

- ✓ Board of the NNIDR
- ✓ NNIDR Expert Advisory Panel
- ✓ DSS National Carer Gateway Advisory Group
- ✓ ACSQHC Cognivite Impairment Advisory Group
- ✓ ACSQHC Cognivite Impairment Roundtable
- ✓ ACSQHC Delirium Care Standards Working Group
- ✓ ACT Dementia Services Advisory Group

This has been achieved through active Consumer involvement from the Consumer Enabling Sub-Unit, in all aspects of the CDPC, including the Executive Committee; the Scientific Sub-Committee; the Project Steering/Advisory Committees; the Annual Meetings – including Presentations; Workshops; Evaluation processes and periodic reporting requirements.

Importantly, Consumers have been invited to contribute to the development of proposed projects from the conceptual stage through to final approval. Additionally we have seen two CDRN members invited onto Governance structures within the NHMRC National Institute for Dementia Research (NNIDR), Dr Jane Thompson, NNIDR Board Member and Louise Heuzenroeder, Expert Advisory Panel Member. We have also seen six of the CDRN members awarded in 2016 for their extraordinary advocacy for people with Dementia and the people who support them, Christine Bryden, AM and Dr Ron Sinclair, OAM. Internal evaluation of Consumer involvement to the end of 2015 showed a high level of satisfaction across the CDPC.

Half-way through this five year funding term Alzheimer's Australia continues to support Consumer involvement in the CDPC through its new 'National Consumer Network' (March 2016), with approximately 16 Consumers consistently involved in CDPC projects and also broader Consumer participation when needed, through this National Network.

With the support of Alzheimer's Australia we look forward to the second half of this five year term in further strengthening this collaboration between Consumers and Researchers; in seeing the impact of our involvement on research outcomes and seeing the difference they are making to the lives of people living with the impact of dementia – our goal in partnership together.

Appreciation is extended to each Consumer who has generously committed their time, effort and energy to the work of the CDPC and to the CDPC for actively supporting and encouraging our continued involvement into this second half of the five year term.

RESEARCH FOR US – WITH US!

Joan Jackman

EMERGING IMPACT

6

Future Workforce Development

The CDPC supports development of the future workforce by introducing new and established researchers into the field of dementia. All CDPC projects have at least one team member who is new to the field of dementia.

“ Before moving into research, I felt as though my impact was very minimal and that I only dealt with people on an individual level. I feel that, in moving into research, I am making a bigger impact at a broader community level. I think that doing research in industry and in the community gives you a completely different perspective on research”

Karla Seaman (CDPC Researcher; CDPC Partner Organisation, Brightwater Care Group)

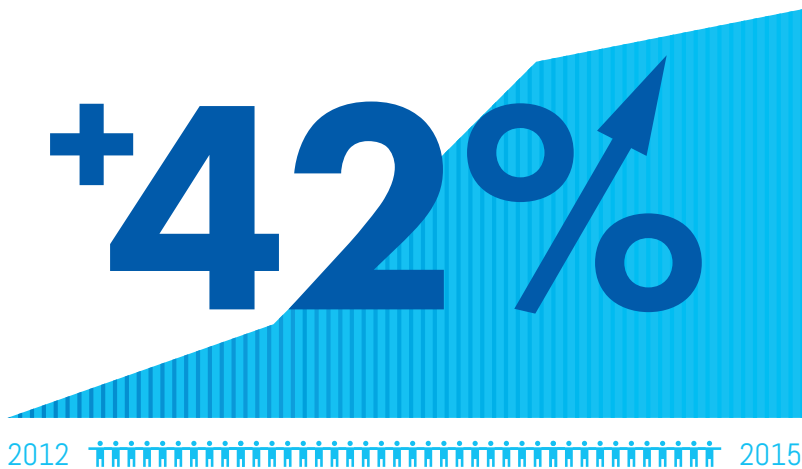
Healthy Ageing in Australian Physicians

This qualitative project aimed to understand the ways in which Australian doctors experience and adapt to the ageing process including changes in cognition.

By collecting information through interviews and focus groups from doctors, other health professionals and the patients of older doctors this research team aimed to understand and document ways in which doctors experience the ageing process. A particular focus was the changes in cognitive and physical function and consequently how that affects their patients. The goal of the project has been to develop a healthy ageing toolkit for older doctors, an evidence based approach to maintaining healthy, safe and sustainable medical practice. This continues in development with other research groups working on pre-retirement planning.

Researchers: Prof Susan Kurrle and Dr Narelle Shadbolt
DSBIs: Jan Van Emden (Helping Hand Aged Care)
Alzheimer’s Australia Consumer Network: Joan Jackman, Elaine Todd (+4 non-CDRN Consumers)

Increase in Annual Meeting Attendees



MEDICATION MANAGEMENT

Optimising the quality use of medicines for people with cognitive and related functional decline

In 2013 the Medication Safety in Australia Review found that up to 50 per cent of people with dementia in residential aged care facilities are taking a potentially inappropriate medication and that adverse drug events are still common. There has been a rapid increase in polypharmacy (multiple medicines use) in Australia with consequences such as adverse drug reactions, which may be misattributed to ageing or dementia.

The primary aim of this project is to optimise the quality use of medicines (QUM) in people with cognitive and related functional decline through gaining an increased understanding of what are the most effective tools in guiding medication selection and what facilitates QUM.

Work during the first two and a half years of this five year project has focused on strengthening the evidence base for implementation of QUM. A questionnaire (DeprescriBe) examining the beliefs and attitudes of people with cognitive decline and their carers towards medication use has been developed and validated, with input from consumers and DSBI representatives. The data obtained from this questionnaire will further enhance our understanding of the potential barriers perceived by patients, carers and health professionals in relation to optimising medication use. Additionally, the team has evaluated the effects of polypharmacy and Drug Burden Index (DBI) on frailty transitions and death. The main findings from this analysis were that each additional medication and unit increase in DBI was associated with a greater risk of transitioning from a status of robustness to death.

A National Stakeholders Meeting was convened in August 2015, in partnership with NPS MedicineWise, to discuss strategies to improve quality use of medicines for older Australians, with an emphasis on avoiding the harms of multiple medicines use. Representatives including consumers, clinicians, academics, policy makers, and health and aged care professionals attended the meeting and identified strategic areas, released in an Outcomes Statement, including policy change, increased education and awareness of consumers and clinicians on the benefits of quality use of medicines, use of technology and eHealth. This work was continued at a workshop at the National Medicines Symposium in Canberra in May 2016. Working groups have now come together to develop a Strategic and Action Plan that will provide a way forward to achieve a reduction in the prevalence of harmful or unnecessary medication in older Australians.

This information will inform the implementation of appropriate QUM tools in a variety of settings across three states in Australia, including both metropolitan and regional locations during the final two years of the project.

Researchers: Prof Sarah Hilmer and A/Prof Simon Bell

DSBIs: Colm Cunningham, Rebecca Forbes, Dr Catriona Lorang (HammondCare), Megan Corlis (Helping Hand Aged Care)

Enabling sub-units: Policy and Legislation, Technology and Telehealth

Alzheimer's Australia Consumer Network: Tara Quirke and Joan Jackman

EMERGING
IMPACT

7

Policy and
Systems Change

Making lasting improvements in the care of people with dementia requires more than increasing knowledge and changing attitudes. The CDPC's long term goal is promoting broader policy and systems change.

“A great thing about the Partnership Centre is that our work provokes discussion and change.”

*Prof Maria Crotty
(CDPC Researcher)*

“We are trying to achieve a ‘fundamental attitude change and empowerment from a consumer perspective and this is not easy to implement.’”

*Prof Meera Agar
(CDPC Researcher)*

Focus on the implementation of the use of Vitamin D supplements in Australian residential Aged Care Facilities (RACFs)

This project is examining the implementation of vitamin D supplements in RACFs to reduce falls.

Research has shown that most people living in residential aged care facilities don't have enough vitamin D and as a result are at higher risk of falls and fall related injury. A program in New Zealand has proven that it is possible to provide people living in residential aged care facilities with monthly doses of vitamin D to reverse the deficiency. This strategy is being examined in the Australian aged care context in about 40 Australian residential aged care facilities. Implementation is facilitated largely by providing information and education in a variety of formats to multiple stakeholder groups. Following this, locally identified strategies will be implemented at each site to help enhance and sustain the implementation of vitamin D supplement use.

Researchers: Prof Ian Cameron

DSBIs: Megan Corlis, Jan van Emden (Helping Hand Aged Care)

Enabling sub-units: Management of Change and Workforce, Research Methodologies

Alzheimer's Australia Consumer Network: Tara Quirke, Joan Jackman, Les Leckie

Telehealth enabled systems to improve medicines use among persons with cognitive impairment and dementia in residential aged care facilities

This project will develop and test telehealth strategies to improve the timeliness and efficiency of medication review.

Those responsible for prescribing, dispensing and administering medicines can be assisted through reviews conducted by specialists, namely Geriatricians and Pharmacists. However, because visits by specialists are infrequent and expensive, reviews may not occur consistently, nor do they usually occur simultaneously among General Practitioners (GPs), Geriatricians and Pharmacists. Through telehealth strategies developed in this project specialist medication review will become available for more people more promptly, including those in rural and remote communities. In turn, more appropriate prescribing among people with dementia will result in fewer symptoms and side effects.

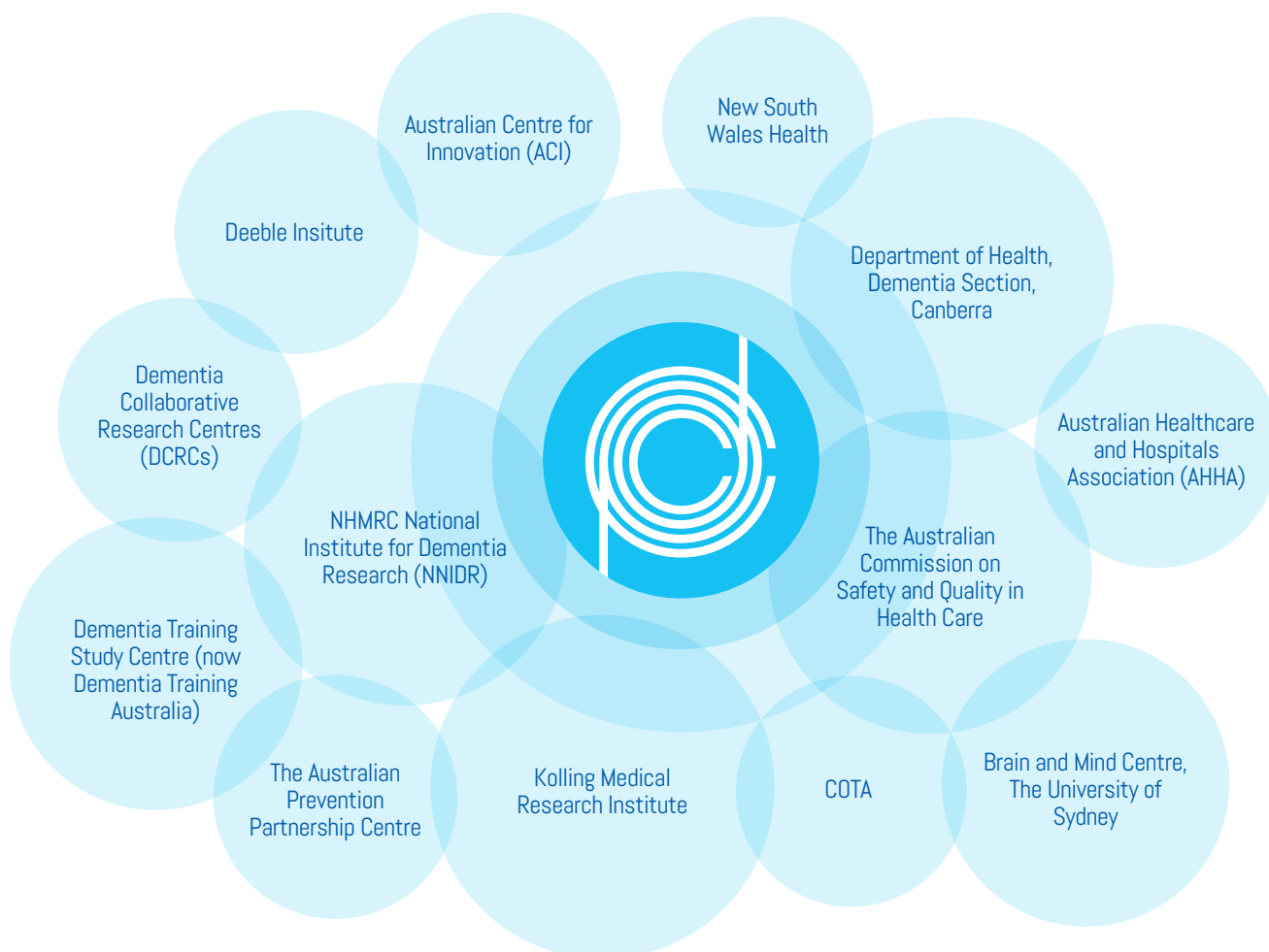
Researchers: Prof Len Gray, Prof Sarah Hilmer, A/Prof Simon Bell

Enabling sub-units: Policy and Legislation, Technology and Telehealth

Alzheimer's Australia Consumer Network: Tara Quirke and Joan Jackman



Strategic linkages with influential organisations strengthens CDPC collaboration and partnerships



CLINICAL GUIDELINES

New clinical practice guidelines and principles of care for people with dementia in Australia

Previously Australia did not have national clinical practice guidelines for people with dementia. Identified as a National Health Priority due to the increasing prevalence of dementia in Australia, the NHMRC Cognitive Decline Partnership Centre funded a multidisciplinary Guideline Adaptation Committee to review international clinical practice guidelines and adapt existing guidelines to new clinical practice guidelines for dementia in Australia.

The Clinical Practice Guidelines and Principles of Care for People with Dementia in Australia (http://sydney.edu.au/medicine/cdpc/documents/resources/CDPC-Dementia-Guidelines_WEB.pdf), released in March 2016, provide doctors, general practice nurses, primary care and allied health professionals, working with people with dementia in community, residential and hospital settings with access to recommendations reflecting current evidence on dementia care to better respond to the needs and preferences of the person living with dementia. The Guidelines are also important to consumers and their care providers as they detail what should be expected with regards to best practice care.

Mr John Quinn, who helped launch the Guidelines and is living with dementia said,

“ These guidelines will help people better understand the specific needs that we as people living with dementia are faced with every day.”

There are 109 recommendations in the guidelines which have the potential to transform dementia care in Australia and include:

- Person-centred individualized care responding to the needs and preferences of people with dementia and their carers
- Timely diagnosis, meaning that early signs of dementia such as memory loss are not dismissed as normal ageing and should be investigated
- Living well with dementia, which highlights the importance of good nutrition, enjoyable exercise, staying involved with work or other mental activity, and remaining as independent as possible
- Appropriate training of staff working with people with dementia, which has been shown to reduce symptoms such as agitation, reduce the use of physical restraints, and improve quality of care

The Guidelines are currently being implemented through: development of Health Pathways; inclusion in undergraduate teaching and professional development short courses, and government organisation student/staff training programs.

Researchers: Prof Maria Crotty and A/Prof Craig Whitehead

DSBIs: Jan Van Emden (Helping Hand Aged Care)

Enabling sub-units: Management of Change and Workforce and Policy and Legislation

Alzheimer's Australia Consumer Network:

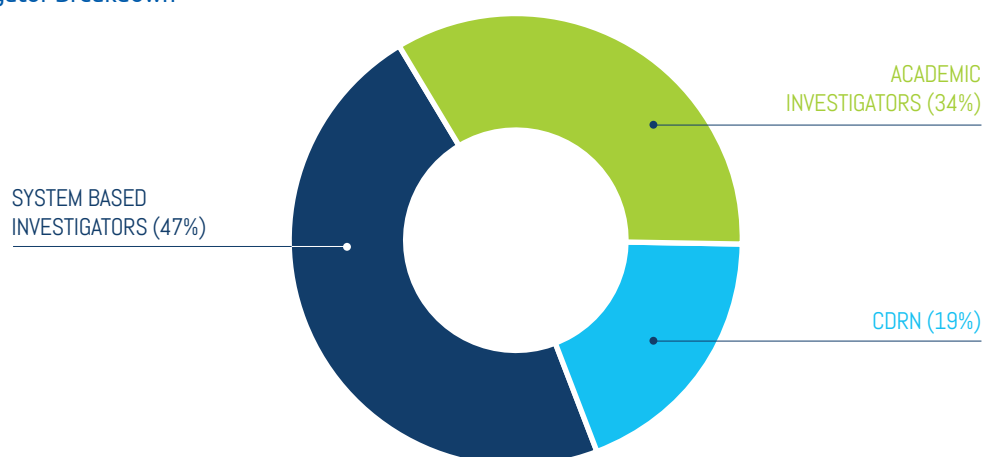
Christine Bryden, Louise Heuzenroeder, Joan Jackman, Jane Thompson, Kate Swaffer

The Clinical Practice Guidelines and Principles of Care for People with Dementia: <http://sydney.edu.au/medicine/cdpc/resources/dementia-guidelines.php>



The CDPC values the diversity of expertise and experience of academic and non-academic investigators

CDPC Investigator Breakdown



Development and implementation of a consensus guide on dementia in primary care

This project will provide General Practitioners (GPs) with up to date 'Care of patients with dementia in general practice' guidelines.

GPs often see dementia diagnosis as a specialist domain however there are scenarios where GPs are required to communicate a diagnosis of dementia, for instance when access to a specialist is difficult or when explaining the diagnosis with their patient and their family or carer. This project is reviewing international GP dementia guidelines and current literature to identify gaps in the 2003

guidelines, and has involved consumers, carers and experts in the field of dementia. Following the production of new GP dementia guidelines the team will select demonstration practices throughout Australia for a targeted dissemination, and then work with those practices on the implementation of the guidelines.

Researchers: Prof Dimity Pond

DSBIs: Jan Van Emden (Helping Hand Aged Care)

Alzheimer's Australia Consumer Network: Louise Heuzenroeder, Danijela Hlis, Joan Jackman, Kathy Williams.



FUNCTIONAL DECLINE

Understanding risk and preventing falls and functional decline in older people with cognitive impairment

This project explores the association between physical and cognitive performance, function, frailty and falls in older people with cognitive impairment.

Approximately 60 per cent of people with dementia fall annually and these falls are more likely to result in death and institutionalisation. Preventing falls in cognitively impaired older people will reduce the cost from falls to the individual and the health care system. Currently there are

no successful fall prevention trials in community-dwelling cognitively impaired older people. The study will improve our understanding of the relationship between cognitive and physical function and falls risk in older people with cognitive impairment, investigate the relationship between falls and both cognitive and physical decline over time in people with cognitive impairment and investigate new and novel approaches to falls prevention in dementia.

Researchers: Prof Jacqui Close, Dr Morag Taylor, Prof Susan Kurrle

DSBIs: Jan Van Emden (Helping Hand Aged Care)

Alzheimer's Australia Consumer Network: Kate Swaffer, Ian Gladstone, Joan Jackman, Elaine Todd

Implementing care of older persons with dementia in their environments in the Australian health context

This project will integrate the Care of Older Persons with Dementia in their Environments (COPE) within existing health systems in Australia.

Functional decline is one of the core features of dementia and is associated with reduced quality of life, considerable impact on carers and can lead to institutionalisation. COPE is a bio-behavioural program designed to improve function,

reduce dependency and increase engagement of the person with dementia and in improving carer. This project will translate COPE to the Australian context within not for profit, private and government care systems and will examine facilitators and barriers at therapist, organisation and policy levels, explore funding models and build in features of sustainability.

Researchers: Prof Lindy Clemson, Prof Susan Kurrle

DSBIs: Meredith Gresham (HammondCare)

Enabling sub-units: Health Economics

Alzheimer's Australia Consumer Network: Danijela Hlis, Joan Jackman, Glenys Petrie, John Quinn, Jane Thompson

Improving cognitive and functional capacity of older people with dementia in residential aged care through an exercise prescription approach

This project will examine functional and cognitive capacity of residents before and following exercise prescription interventions, as well as the impact on the staff and families of residents.

The positive effect of exercise on health and to prevent, or delay cognitive decline in older adults is well documented. Helping Hand has implemented an Exercise Physiologist (EP) to provide group based exercise for residents who have significant dementia and other chronic conditions. The project involves integrating Exercise Physiology interventions into the ongoing care for residents. This evidence-based evaluation project will consider and report on factors that may influence successful implementation of

these interventions including level of cognition, functional abilities, and well-being of residents before and following EP interventions, as well as staff cooperation/perception, and the perceptions and impact of the program on the families of residents.

Researchers: Megan Corlis and A/Prof Gaynor Parfitt

DSBIs: Meredith Gresham (HammondCare) and Wendy Hudson (Brightwater Care Group)

Enabling sub-units: Health Economics and Management of Change and Workforce

Alzheimer's Australia Consumer Network: Ian Gladstone and Ron Sinclair

Understanding the impact of socialisation robots on the social engagement of older adults with cognitive decline

This study aims to improve the social engagement of older adults with cognitive decline by exploring the use of a humanoid socialisation robot within Australian aged care facilities.

The increasing sophistication of robotic engineering and the corresponding ease of access to devices that can perform complex tasks yet are simple to program and affordable to purchase has led to the development of the next generation of robots to support people with cognitive decline, particularly in the area of social engagement. By comparing group activity programs using the Zorobot, a socialisation robot with standard activity programs, the study team is examining the social engagement of older adults with cognitive decline and exploring staff attitudes to the use of socialisation robot technology within the Australian residential aged care context.



Researchers: Karla Seaman, Brett Robinson

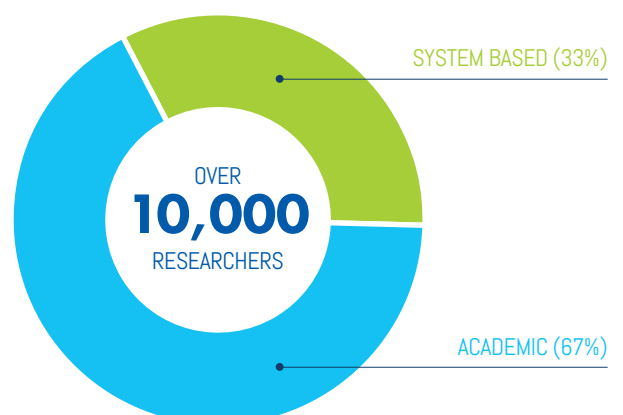
DSBIs: Wendy Hudson (Brightwater Care Group)

Enabling sub-units: Management of Change and Workforce and Research Methodology

Alzheimer's Australia Consumer Network: Val Jenner

Influencing external practitioners and academics

The CDPC delivers quality research evidence to drive informed change. Over the first two and a half years of the CDPC over 10,000 influencers in the field of dementia care have been exposed to our research findings.



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CONFERENCE PRESENTATIONS

Pennington, A. (2016, July). Changing hearts and minds: Strategies to improve exercise perceptions and behaviours. Presented at World Congress on Active Ageing, Melbourne VIC

Biggs, S., & Carr, A. (2016, July). The role of regulation in policy for Australian dementia care. Presented at International Federation on Ageing 13th Global Conference "Disasters in an Ageing World"

Field, S. (2016, July). Policies and practices of financial institutions relating to substitute decision making instruments. Presented at International Federation on Ageing 13th Global Conference

Field, S. (2016, July). Policies and practices of financial institutions relating to substitute decision making instruments. CDPC Symposium "Living well with dementia: Programs to support older Australians." Conducted at International Federation on Ageing 13th Global Conference, Brisbane, QLD.

Biggs, S., & Carr, A. (2016, July). "In case of emergency break glass": Fire safety, environmental design and the dilemmas of dementia care. CDPC Symposium "Living well with dementia: Programs to support older Australians." Conducted at International Federation on Ageing 13th Global Conference, Brisbane, QLD.

Thompson, J. (2016, July). Current challenges in the acute care environment in caring for people with cognitive impairment or confusion. CDPC Symposium "Living well with dementia: Programs to support older Australians." Conducted at International Federation on Ageing 13th Global Conference, Brisbane, QLD.

Goeman, D. (2016, July). Evaluation of the effectiveness of the key worker support role - Activity 3. CDPC Symposium "Living well with dementia: Programs to support older Australians." Conducted at International Federation on Ageing 13th Global Conference, Brisbane, QLD.

Biggs, S., & Lowenstein, A. (2016, July). Using generational intelligence in social policy. Symposium "Inter-generational relations: conceptual and practical developments" Conducted at The

23 Nordic Congress of Gerontology, Tampere, Finland.

Haapala-Biggs, I., & Biggs, S. (2016, July). Generational Intelligence, Community Engagement and Intergenerational Training. Symposium "Inter-generational relations: conceptual and practical developments" Conducted at The 23 Nordic Congress of Gerontology, Tampere, Finland.

Biggs, S. & Carr, A. (2016, July). The role of regulation in policy for Australian dementia care. Presented at The 23rd Nordic Conference of Gerontology, Tampere, Finland.

Field, S. (2016, July). Policies and practices of financial institutions relating to substitute decision making instruments. Presented at the International Dementia Conference, Grand Designs "Are we there yet?" Sydney, NSW.

Laver, K. (2016, July). Clinical Practice Guidelines and Principles of Care for People with Dementia. Presented at the International Dementia Conference, Grand Designs "Are we there yet?" Sydney, NSW.

Milte, R. (2016, July). Quality in residential care from the consumer perspective of people living with dementia: The importance of personhood. Presented at the International Dementia Conference, Grand Designs "Are we there yet?" Sydney, NSW.

Yapp, G. (2016, July). Advance Care Planning for People with Dementia: What needs to be different? Presented at the International Dementia Conference, Grand Designs "Are we there yet?" Sydney, NSW.

Biggs, S., & Carr, A. (2016, July). Regulating care spaces: risk, protection and degrees of freedom in residential care. Presented at the International Dementia Conference, Grand Designs "Are we there yet?" Sydney, NSW.

Taylor, M., & Close, J. (2016, July). Relationships between executive function, physiological performance, medication use and falls in older people with cognitive impairment. Presented at The Australian and New Zealand Society for Geriatric Medicine Annual Scientific Meeting, Cairns, QLD.

Kurrle, S., Cumming, R., Laver, K., Whitehead, C., & Crotty, M. (2016, July). Clinical Practice Guidelines for Dementia in Australia. Presented at the Australian and New Zealand Society for Geriatric Medicine Annual Scientific Meeting, Cairns, QLD.

Carr, A., & Biggs, S. (2016, May). Dementia and the social model of disability: what are the conceptual, policy and research implications?. Presented at the Forever Young: Better Health and Wellbeing for our Cultural Diverse Older Australians, Multicultural Advisory Service (MAS), Ethnic Communities Council of Queensland and Diversicare, Cairns, QLD.

Taylor, M., & Close, J. (2016 May). Home-based exercise improves balance in older people with dementia. Presented at NSW Falls Prevention Network Forum, Wesley Convention Centre, Sydney, NSW.

Hilmer, S., Bell, S., & Heaney, A. (2016, May). Improving quality use of medicines by older Australians: outcomes of a national stakeholders' meeting and development of a strategic plan. Presented at National Medicines Symposium 2016, Canberra, ACT.

Farrer, O., Yaxley, A., Walton, K., Milte, R., Miller, M. (2016, May). The 'diabetic diet': a web based survey for determining the incidence, rationale, composition and implications in Australian residential aged care facilities. Presented at the Dietitians Association of Australia Conference, Melbourne, VIC.

Thompson, J.F., Todd, E., Kurrle, S., Jackman, J., & Grosvenor, S. (2016, May). Consumer "tokenism" is not enough.... Presented at the ARCS Australia Scientific Congress, Randwick, NSW.

Kurrle, S., Beattie, E., Draper, B., Thompson, J., & Sanson-Fisher, R. (2016, May). Panel session: Innovations in care research. Conducted at NHMRC National Institute for Dementia Research Forum, Brisbane, QLD.

Kurrle, S., (2016, May). Improving the quality of care for people with dementia. Presented at the NHMRC National Institute for Dementia Research Forum, Brisbane, QLD.

Milte, R., Bradley, C., & Crotty, M. (2016, April). Food service provision in residential aged care facilities in Australia: How are dementia specific units catering for residents with dementia? Presented at the 31st

- International Conference of Alzheimer's disease International Dementia: Global Perspective - Local Solutions, Budapest, Hungary.
- Gaynor, P. (2016, April). The role of accredited exercise physiologists in dementia care. Presented at the Exercise and Sports Science Australia Annual Conference, Adelaide, SA.
- Kurrle, S. (2016, March). Clinical Practice Guidelines and Principles of Care for People with Dementia. National Dementia Conference, Brisbane, Qld.
- Field, S. (2016, March). Policies and practices of financial institutions relating to substitute decision making instruments. Presented at the National Dementia Conference, Brisbane, QLD.
- Field, S. (2016, February). Policies and practices of financial institutions relating to substitute decision making instruments. Presented at the 4th National Elder Abuse Conference, Melbourne, VIC.
- Jamsen, K., Bell, S., Kirkpatrick, C., Iiomaki, J., Le Couteur, D., & Gnjjidic, D. (2016, January). A multi-state model multiple medication use and Drug Burden Index in frailty state transitions and death: the CHAMP study. Presented at the Population Approach Group of Australia & New Zealand, Melbourne, VIC.
- Goodwin-Hawkins, B., & Carr, A. (2016, December). Vulnerable and Voiceless? Dementia from the Margins. Presented at the Conference of the Cultural studies Association of Australasia, Melbourne, VIC.
- Shekhar, R., & Vueti, V. (2015, December). CHOPS: Care of the confused hospitalised older person – Quality project at Fairfield Hospital. Presented at the Aged Care and Rehabilitation Conference: Partnerships in Care, NSW.
- Carr, A. (2015, December). Regulating dementia care: formalising obligation and the moral imperative. Presented at the Australian Anthropological Society Conference, The University of Melbourne, Melbourne, VIC.
- Reeve, E. (2015, December). Older adult and carers attitudes towards deprescribing. Presented at the Society of Hospital Pharmacists of Australia Conference, Melbourne, VIC.
- Reeve, E., Low, Lee-Fay., & Hilmer, S. (2015, December). Older adults' and carers' beliefs and attitudes towards deprescribing. Presented at the Australasian Pharmaceutical Science Association-Australasian Society of Clinical and Experimental Pharmacologists and Toxicologists (APSA-ASCEPT) Hobart, TAS.
- Anderson, K., Bird, M., MacPherson, S., & Blair, A. (2015, November). Improving quality of residential dementia care and promoting change by supporting and caring for staff: What can we learn from the literature? Presented at the RANZCP Faculty of Psychiatry of Old Age and APS Psychology and Ageing Special Interest Group Joint conference, Adelaide, SA.
- Cameron, I., Miller-Amberber, A., & Barnett, P. (2015, November). Approach to Implementation of Vitamin D Supplements in Australian Residential Aged Care Facilities. Presented at the 12th Australasian Injury Prevention & Safety Promotion Conference, Sydney, NSW.
- Reeve, E., Gnjjidic, D., Long, J., & Hilmer, S. (2015, November). A systematic review of the emerging definition of "deprescribing" with network analysis: implications for future research and clinical practice. Presented at the Gerontological Society of America Annual Scientific Meeting, Orlando, Florida.
- Reeve, E. (2015, November). Patient Autonomy in Deprescribing: A Qualitative Study of the Beliefs of Older Adults and Caregivers. Presented at the Gerontological Society of America Annual Scientific Meeting, Orlando, Florida.
- Anderson, K., Bird, M., & MacPherson, S. (2015, November). Improving residential dementia care through staff interventions: A systematic Review. Presented at the 48th Australian Association of Gerontology National Conference, Session 6C "Cognitive Impairment in Older People", Alice Springs, NT.
- Renehan, E., Goeman, D., & Koch, S. (2015, November). Key Worker models for people with dementia and their carers/family. Presented at the 48th Australian Association of Gerontology National Conference, Session 6C "Cognitive Impairment in Older People", Alice Springs Convention Centre, Alice Springs, NT.
- Cameron, I., Miller-Amberber, A., & Barnett, P. (2015, November). ViDAus: Implementing Vitamin D to reduce falls in Australian residential aged care. Presented at the 48th Australian Association of Gerontology National Conference, Alice Springs Convention Centre, Alice Springs, NT.
- Bateman, C. (2015, November). Dementia and delirium care with volunteers: From strength to strength. Presented at the 48th Australian Association of Gerontology National Conference, Session 6C "Cognitive Impairment in Older People", Alice Springs Convention Centre, Alice Springs, NT.
- Thompson, J., Heuzenroeder, L., Jackman, J., Bryden, C., Swaffer, K., Laver, K., Crotty, M., & Whitehead, C. (2015, October). Partnering with consumers to develop the Australian Clinical Guidelines for dementia in Australia. Presented at the 4th Annual NHMRC Symposium on Research Translation, Sydney, NSW.
- Seaman, K., Hurrup-Gregory, J., Saunders, R., Loffler, H., & Lawrence, J. (2015, October). Interprofessional education in residential aged care: Optimising care and workforce possibilities. Presented at the International Association of Gerontology and Geriatrics Regional Congress Chang Mai, Thailand.
- Field, S. (2015, October). Powers of Attorney: Are they worth the paper they are written on?, 2nd International Conference on Capacity with IPA International Congress, Estrel Berlin Hotel and Convention Center, Berlin, Germany.
- Goeman, D., Renehan, E., & Koch, S. (2015, October). Key Worker roles for people with Dementia: A Systematic Review. Presented at the International Association of Geriatrics and Gerontology Congress, The International Convention and Exhibition Center Commemorating His Majesty's 7th Cycle Birthday Anniversary, Chiang Mai, Thailand.
- Seaman, K., Hurrup-Gregory, J., Saunders, R., Lofler, H., Singer, R., & Lawrence, J. (2015, October). Interprofessional education in residential aged care: Translating knowledge into practice in the care of older adults. Presented at the Interprofessional Health, Education & Practice International Conference, Melbourne, VIC.

- Seaman, K., Harrup-Gregory, J., Saunders, R., Lofler, H., Singer, R., & Lawrence, J. (2015, September) Exploring an interprofessional education program in residential aged care. Presented at the 5th European Conference on Interprofessional Practice and Education, Nijmegen, The Netherlands.
- Thompson, J., Heuzenroeder, L., Jackman, J., Bryden, C., Swaffer, K., Laver, K., & Whitehead, C. (2015, September) Incorporating consumer preferences and values into the new Australian clinical practice guidelines for dementia. Presented at the National Dementia Research and Knowledge Translation Forum, Science and Practice: The Big Questions, Sydney, NSW.
- Bateman, C., Anderson, K., & Blair, A. (2015, September) Dementia and delirium care with volunteers program: Translation, partnerships and continuation. Presented at the National Dementia Research and Knowledge Translation Forum, Science and Practice: The Big Questions, Sydney, NSW.
- Seaman, K., Harrup-Gregory, J., Saunders, R., Lofler, H., Singer, R., & Lawrence, J. (2015, August). Interprofessional education and residential aged care: Multifaceted outcomes for residents and students. Presented at the European Forum for Primary Care, Amsterdam, The Netherlands.
- Pond, D. (2015, August). Cognitive Testing for Memory Loss/Dementia (NCD) in Older People. Presented at the Hunter Postgraduate Medical Institute, Newcastle, NSW.
- Seaman, K., Harrup-Gregory, J., Saunders, R., Lofler, H., Singer, R., & Lawrence, J. (2015, July). Working towards a sustainable aged care workforce through interprofessional education. Presented at the PHCRIS Concurrent Papers 12 "Education and Training" Adelaide Convention Centre, Adelaide, SA.
- Whitehead, C., Laver, K., Dyer, S., & Cumming, R. (2015, July). A case for national clinical practice guidelines for dementia in Australia. Presented at the Occupational Therapy Australia (OTA) 26th National Conference and Exhibition, Melbourne Convention and Exhibition Centre, Melbourne, VIC.
- Bell, S. (2015, May). Pain management in residential aged care facilities. Presented at the Australian Association of Consultant Pharmacy (AACP) 11th Annual Consultant Pharmacy Seminar, Melbourne, VIC.
- Kurrle, S. (2015, May). Dementia: The Australian perspective. Presented at the 25th Anniversary of the Indonesian Academy of Sciences (AIPI), AIPI-NHMRC Workshop on Lifestyle Diseases, Jakarta, Indonesia.
- Thompson, J., Swaffer, K., & Ramshaw, T. (2015, April). Consumer involvement in dementia research in Australia. Presented at the 30th International Conference of Alzheimer's Disease International, Session 'Engaging People Living with Dementia', Perth, WA.
- Hutshinson, K., Roberts, C., & Kurrle, S. (2015, April). Young people collaborating for social change so they no longer feel alone in the journey with their parent's dementia. Presented at the 30th International Conference of Alzheimer's Disease International, Session 'Engaging People Living with Dementia', Perth, WA.
- Seaman, K., Harrup-Gregory, J., Saunders, R., & Lawrence, J. (2015, April 16) Residential aged care: Stagnant or stimulating for future graduates? Presented at the 30th International Conference of Alzheimer's Disease International Session 'Preparing a Sustainable and Educated Workforce', Perth, WA.
- Whitehead, C., Laver, K., Dyer, S., & Cumming, R. (2015, April). A case for national clinical practice guidelines for dementia in Australia. Presented at the Australian and New Zealand Society for Geriatric Medicine (ANZSGM) Annual Scientific Meeting, Perth, WA.
- Seaman, K., Harrup-Gregory, J., Saunders, R., & Lawrence, J. (2015, March). Residential aged care: Stagnant or stimulating? Presented at the Creating a workforce for the future by changing students' perceptions, Aged and Community Services Western Australian Conference, Connolly, WA.
- Dimity, P. (2015, March). Dementia: do we need to make the diagnosis? and if so how? And what are we going to do about it? Presented at the The Royal Australian College of General Practitioners Conference, Newcastle, NSW.
- Temple, A., Moehead, a., Dillon, R., Bateman, C. (2015, March). A collaborative approach to planning and delivering care for confused older people in hospital. Presented at the Australian Association of Gerontology (NSW Division) (AAG) and Aged & Community Services of NSW & ACT (ACS), Batemans Bay, NSW.
- Anderson, K. (2015, March). What does good quality residential dementia care really look like? A systematic review of the evidence. Presented at the Australian Association of Gerontology (NSW Division) (AAG) and Aged & Community Services of NSW & ACT (ACS) Regional Conference, Batemans Bay, NSW.
- Hilmer, S. (2014, December). Prescribing considerations for people with dementia. Presented at the Australasian Society of Clinical and Experimental Pharmacologists and Toxicologists (ASCEPT) and the Molecular Pharmacology of GPCRs (MPGPCR) Joint Scientific Meeting, Melbourne Convention Centre, Melbourne, VIC.
- Fitzgerald, A., Hayes, K., & Radford, K. (2014, December). Working together for a common goal: Lessons for governance structure from a quadruple helix organisation. Presented at the 28th Australian and New Zealand Academy of Management Conference 2014, University of Technology, Sydney NSW
- Carr, a., & Biggs, S. (2014, November). Theorising Dementia-friendly environments: the relationship between care, space and regulation. Presented at the Australian Association of Gerontology (AAG) 47th National Conference, Adelaide Oval, Adelaide, SA.
- Kurrle, S. (2014, November 21). NHMRC Partnership Centre on Dealing with Cognitive and Related Functional Decline in Older People. Presented at the QLD State wide Dementia Network Forum, Brisbane, QLD.
- Reeve, E., Hilmer, S., & Gnjjidic, D. (2014, November). Emerging Definition of Deprescribing: Implications for Research and Practice in Older Adults. Plenary Session 6, New Horizons 2014, St Leonards, NSW.
- Kurrle, S. (2014, November). Emerging issues in dementia care and research. Presented at the Batemans Bay Southern NSW Dementia Network Symposium, Batemans Bay, NSW.

- Reeve, E. (2014, November). Development and application of a patient-centred deprescribing process. Presented at the Gerontological Society of America's 67th Annual Scientific Meeting, Washington, DC, USA.
- Hilmer, S. (2014, November). Understanding associations of medicines with geriatric syndromes: Implications for prescribing and deprescribing. Presented at the Gerontology Society of America Annual Scientific Meeting, Washington, DC, USA.
- Kurrle, S. (2014, October). Living with dementia, Dementia Forum. Presented at the Charles Perkins Centre - University of Sydney, Sydney, NSW.
- Field, S. (2014, September). The policies and practices of financial institutions in respect of substitute decision making instruments, The policies and practices of financial institutions in respect of substitute decision making instruments. Presented at the 1st Annual International Capacity Conference 'Capacity, Ethics and the Prevention of Abuse', Hong Kong.
- Kurrle, S. (2014, September). Physical Comorbidities of Dementia. Presented at the 22nd Annual Scientific Meeting of the Australasian Faculty of Rehabilitation Medicine (AFRM), Adelaide, SA.
- Harrup-Gregory Jane, Seaman, K., Pratt, K., Hallsworth, A., Gall, K., & Elliot-Davies, L. (2014, September). An interprofessional experience that will change lives and shape the future. Presented at the Health Interprofessional Education (HIPE) Conference, Curtin University, Perth, WA.
- Reeve, E. (2014, August). What are the barriers to and enablers of deprescribing: the patient perspective. Presented at the Guideline International Conference, Melbourne, VIC.
- Kurrle, S. (2014, August). Dementia Research Funding & Priorities for Philanthropy. Presented at the The Wicking Symposium - Panel Session, Melbourne, VIC.
- Hutchinson, K., & Roberts, C. (2014, August). The empowerment of young people to rise above societal marginalisation who have a parent with dementia: A social model perspective. Presented at the Lifespan Postgraduate Symposium, Westmead, NSW.
- Pond, D. (2014, July). What do I do when the risk is high? New guidelines for assessment and management of dementia in general practice. NHMRC Cognitive Decline Partnership Centre Morning Concurrent Session E, International Dementia Conference - Risky Business 2, Hilton Hotel, Sydney, NSW.
- Hilmer, S., Bell, S., & Reeve, E. (2014, July). Optimising medicines in older people with dementia: Understanding risks, benefits and translation. Presented at the International Dementia Conference - Risky Business 2, Hilton Hotel, Sydney, NSW.
- Temple, A. (2014, July). Reducing the risks for confused older people in acute care. Presented at the International Dementia Conference - Risky Business 2, Hilton Hotel, Sydney, NSW.
- Field, S. (2014, July). Powers of Attorney: Are they worth the paper they are written on Presented at the International Dementia Conference - Risky Business 2, Hilton Hotel, Sydney, NSW.
- Kurrle, S. (2014, July). NHMRC Cognitive Decline Partnership Centre: reducing the risks for people with cognitive and related functional decline Presented at the International Dementia Conference - Risky Business 2, Hilton Hotel, Sydney, NSW.
- Temple, A. (2014, July). Care of Confused Hospitalised Older Persons Program (CHOPs), Pre-Risky Business 2 Conference presentation to Singapore Delegates
- Kurrle, S. (2014, July). Keynote presentation, Risks and benefits: balancing care in cognitive decline. Presented at the International Dementia Conference - Risky Business 2, Hilton Hotel, Sydney, NSW.
- Hilmer, S. (2014, July). Deprescribing for Frail Older People in Hospital. Presented at the Acute Care of the Frail Elderly Seminar, Melbourne, VIC.
- Shadbolt, N. (2014, May). Adapting to Ageing for Doctors. Presented at the 1st International Meeting on Wellbeing and Performance in Clinical Practice (Well-Med) Workshop (W7), Alexandroupolis, Greece.
- Temple, A. (2014, May). Care of the confused hospitalised older person program (CHOPs). Presented at the Delirium Clinical and Research Day, Parkville, VIC.
- Hilmer, S. (2014, May). What is the evidence for deprescribing in older people? Presented at the Australian National Workshop in Deprescribing, St Lucia, QLD.
- Reeve, E. (2014, May). The patient perspective: What are the barriers to and enablers of deprescribing? Presented at the Australian National Workshop in Deprescribing, St Lucia, QLD.
- Jamsine, K., Turner, J., Shakib, S., Singhal, N., Hogan-Dorna, J., Prowse, R., Johns, S., & Bell, S. (2014, May). Analgesic use and pain in robust, pre-frail and frail older people with cancer. Presented at the Australasian Society of Clinical and Experimental Pharmacologists and Toxicologists (ASCEPT) Clinical Pharmacology Weekend, Pharmacoeconomics Symposium, Darlinghurst, NSW.
- Edwin, T., Jokanovic, N., Koponen, M., Thomas, D., Hilmer, S., & Bell, S. (2014, May). Prevalence of analgesic use in people with and without dementia in aged care facilities. Presented at the Australasian Society of Clinical and Experimental Pharmacologists and Toxicologists (ASCEPT) Clinical Pharmacology Weekend, Pharmacoeconomics Symposium, Darlinghurst, NSW.
- Temple, A. (2014, April). CHOPs Care of the Confused Hospitalised Older Person Study, Presented at the Sydney Local Health District Falls Forum, NSW.

CDPC GOVERNANCE AUTHORITY

The Governance Authority members are responsible for the performance of the CDPC against NHMRC objectives, and ensure the portfolio of research Activities reflect the desires of funding partners.

CURRENT MEMBERS



Dr John McCallum (Chair – independent)

Dr John Mc Callum has previously held positions as Director of the NHMRC National Institute for Dementia Research Head of the Research Translation Group at NHMRC, University management including Deputy Vice Chancellor (Educational Programs) and Director TAFE at Victoria University 2004–2010 and Executive Dean of Health at Western Sydney University 1995–2004.



Ms Carol Bennett (Alzheimer's Australia)

Carol Bennett, the Chief Executive Officer of Alzheimer's Australia (2015–Aug 2016), has over the past fifteen years, worked at a senior executive level in peak national and state health organisations, most recently for five years as CEO of the Consumers Health Forum of Australia. Carol has been appointed as a council member of the National Health and Medical Research Council, and a Board Director of the International Alliance for Patients Organisations.



Dr Jennifer Lawrence (Brightwater Care Group)

Dr Jennifer Lawrence is the Chief Executive Officer at Brightwater Care Group. Before being appointed CEO and as part of the Executive at Brightwater, Jennifer managed the business operations of services for older people and people with disabilities, was responsible for overseeing the build of two aged care facilities and a \$20m rebuild of the Oats Street Rehabilitation service. Jennifer has also established the Brightwater Research Centre, Brightwater's research arm, and has published and presented research internationally.



Prof Christopher Poulos (HammondCare)

Prof Chris Poulos is the Foundation Hammond Chair of Positive Ageing and Care with the University of New South Wales (Australia) and a rehabilitation physician with over 25 years clinical experience. He is also the Immediate Past President of the Australasian Faculty of Rehabilitation Medicine, former chair of the Australasian Rehabilitation Outcomes Centre Management Advisory Committee, and Visiting Principal Fellow with the Australian Health Services Research Institute, University of Wollongong.



Mr Ian Hardy (Helping Hand Aged Care)

Ian Hardy is the Chief Executive Officer of Helping Hand Aged Care in South Australia. Ian is a former President of the national aged-care peak body, Aged and Community Services Australia (ACSA), and has served as a member of the Board of the Adelaide Northern Medicare Local, the Repatriation General Hospital in Adelaide, the International Association of Homes and Services for the Ageing, the South Australian Ministerial Advisory Board on Ageing and the State Disability Advisory Board. He was recently appointed as Chair of the Strategic Review Panel of the Wicking Trust.



Mr Alan Singh (NHMRC)

Alan Singh is the Executive Director of Research Policy and Translation. Alan Singh has worked on issues in the Health portfolio for 20 years, including three years at PM&C. He led the policy taskforce at the Department of Health for Health Reform Mark 1 (under Prime Minister Rudd), and also steered through a \$1.5 billion package for mental health reform in the 2011–12 Budget. In his current role he is responsible for the Structural Review of NHMRC's Grant Program, the Research Translation Faculty, Advanced Health Research and Translation Centres, and Partnership Centres.



Dr Christopher Pettigrew (NHMRC)

Dr Christopher Pettigrew is Acting Deputy Director, NHMRC National Institute for Dementia Research (NNIDR). After receiving his PhD Christopher worked as a post-doctoral research fellow at University College Cork (Ireland) then moved to Boston (USA), working first at the Boston Biomedical Research Institute and then the University of Massachusetts Medical School. Before joining the NNIDR Christopher was editor of "Trends in Molecular Medicine", also contributing to "Trends in Parasitology" and aiding the launch of "Trends in Cancer". He has also worked extensively in science communication on blogs, podcasts and radio.

PREVIOUS MEMBERS



Mr Glenn Rees AM (Alzheimer's Australia)

Glen Rees AM was CEO of Alzheimer's Australia from 2000–Dec 2014 and currently holds the position of Chair of Alzheimer's Disease International. Glenn has worked at senior levels in the British and Australian Public Services. In Australia since 1976 he has worked in program and policy areas including Prime Minister and Cabinet, Employment and Training, Aged Care, Disabilities, Housing and the Aboriginal and Torres Strait Islander Commission. He was Chair of the Nursing Homes and Hostels Review in 1986 and was involved in implementing the first wave of aged care reforms.



Dr Steven Judd (Hammond Care)

Dr Steven Judd is the Chief Executive Officer of HammondCare, regarded nationally and internationally as one of Australia's most innovative health and aged care providers. Stephen has been actively involved as a lead and contributing author for several books on dementia care, aged care design and the role of charities in contemporary Australian society. He currently serves on the Board of the Community Council for Australia and is a member of the Commonwealths' Minister's Dementia Advisory Group.



Dr Penny Flett

Dr Penny Flett was CEO of Brightwater Care Group until mid-2015. Penny graduated in Medicine from the University of Adelaide, and has worked in geriatric medicine, and long term care, and for the last 20 years in management and leadership. Her postgraduate qualifications include Geriatric Medicine, and Fellowship of the Royal Australian College of Medical Administrators. Penny has been involved in aged care in Victoria, and in WA, has been President of the WA Chamber of Commerce and Industry, and holds appointments as Pro-Chancellor at the University of Western Australia, Chair of the WA Aged Care Advisory Council, and Chair of Council at Methodist Ladies College.

CDPC Executive Committee

The Executive Committee is responsible for monitoring the progress of the CDPC's activities, as well as making key decisions regarding the approval of new research projects and the allocation of resources.



Prof Susan Kurrle (CDPC Chief Investigator and Director)

Professor Susan Kurrle was selected to lead the CDPC Investigator Team in 2012 and as the Chief Investigator and Director of the Centre is responsible for leading the Investigator teams. Susan holds the Curran Chair in Health Care of Older People in the Faculty of Medicine at the University of Sydney and works as a specialist geriatrician in both hospital and community at Hornsby Ku-ring-gai Hospital, and at Batemans Bay Hospital in Southern NSW. She has a visiting academic appointment at the Leyden Academy of Vitality and Ageing, University of Leiden, The Netherlands.



Prof Simon Biggs

Professor Simon Biggs is Professor of Gerontology & Social Policy in the School of Social & Political Sciences at the University of Melbourne. He has participated in numerous European, Australian and Canadian government briefings on topics such as population ageing, dignity in later life and elder protection, and is a member of the World Economic Forum's Global Agenda Council on Ageing Societies. His research interests include the relationship between social identity and adult ageing, changing adult life-course, and social and personal experiences of ageing.



Prof Maria Crotty

Professor Maria Crotty is a rehabilitation physician and Director of the Rehabilitation Studies Unit at Flinders University, based at Repatriation General Hospital in Adelaide. Maria also sits on the Executive of the Fragility Fracture Network (FFN) an international group dedicated to improving care of older people with hip fractures. Maria has expertise in multidisciplinary research focused on the implementation of rehabilitation programs for older people, particularly those with dementia.



Prof Anneke Fitzgerald

Professor Anneke Fitzgerald contributes extensive expertise to the CDPC in the research fields of organisational behaviour in health care, organisational culture, professional identity, process innovation and dissemination and knowledge transfer. Based within Griffith Business School at Griffith University she brings more than 20 years of experience in the health industry, including roles as a Nurse Unit Manager and Health Services Manager in the acute hospital setting.



Ms Joan Jackman

Joan Jackman is the CDPC Lead Consumer of the Consumer Enabling Sub-Unit. Joan has been actively involved in consumer advocacy activities with Alzheimer's Australia since 2007, including participation in the first Alzheimer's Australia National Younger Onset Dementia Summit in Canberra held in 2009.

**Dr Susan Koch**

Dr Susan Koch has previously held the positions as Director of the Royal District Nursing Service (RDNS) Institute, Adjunct A/Prof at La Trobe University of A/Prof of Gerontic Nursing and Director of Postgraduate, Research and Higher Degrees for the La Trobe University's Australian Centre for Evidence Based Aged Care (ACEBAC), and has served as President for Alzheimer's Australia's Victoria. Susan is currently the Chair of the Commonwealth's Minister's Dementia Advisory Group and a Fellow of the Royal College of Nursing and Australian Association of Ageing.

**Jan Van Emden**

Jan is currently the Designated System Based Investigator representative on the Executive Committee. Jan holds the position of project manager for research and student participation at Helping Hand Aged Care, working closely with local and national universities, vocational training providers and secondary schools to provide the opportunity for over 1000 students annually to gain invaluable hands on experience in age care. Jan has a background in physiotherapy service provision, management and education. He has worked within acute health care facilities as well as aged care residential and community based settings, within urban metropolitan areas as well as rural and remote locations in Australia and the USA.

Affiliated organisations

Agency for Clinical Innovation	Royal District Nursing Service Limited	University of Sydney
Flinders University	Southern New South Wales Local Health District	University of Queensland
Griffith University	University of Melbourne	University of Western Australia
Monash University	University of Newcastle	Western Sydney University

CDPC Scientific Sub-Committee members (2014–2016)

Prof Ian Cameron (Chair) – The University of Sydney; CDPC Research Methodologies Enabling Sub-Unit Lead	Karla Seaman (2014, 2015, 2016) – Brightwater Care Group, DSBI	Megan Corlis (2014) – Helping Hand Aged Care, DSBI
Prof Meera Agar (2014, 2015, 2016) – University of Technology, Sydney	Ron Sinclair (2014, 2015, 2016) – AANO Consumer Dementia Research Network (CDRN)	Dr Hiltse Heemskerk (2014) – University of Sydney
A/Prof Caroline E Bulsara (2014, 2015, 2016) – University of Notre Dame Australia	Elaine Todd (2014, 2015, 2016) – Consumer Dementia Research Network (CDRN)	Leo White (2014) – Consumer Dementia Research Network (CDRN)
Dr Liz Gill (2014, 2015, 2016) – John Walsh Centre for Rehabilitation Research; Sydney Medical School Northern; The University of Sydney; Kolling Institute of Medical Research	A/Prof Simon Bell (2014, 2015) – Monash University	Dr Kathryn (Kate) Hayes (2015) – Griffith University; Western Sydney University
Dr Dianne Goeman (2014, 2015, 2016) – Royal District Nursing Service Institute	Christine Bryden (2014, 2015) – Consumer Dementia Research Network (CDRN)	Dr Kate Laver (2015) – Flinders University
Prof Leonard Gray (2014, 2015, 2016) – The University of Queensland, CDPC Technology & Telehealth Enabling Sub-Unit Lead	Tracy Comans (2014, 2015) – Griffith University, CDPC Health Economics Enabling Sub-Unit Lead	Dr Janet Long (2015) – Macquarie University
	Prof Anneke Fitzgerald (2014, 2015) – Griffith University, CDPC Management of Change & Workforce Enabling Sub-Unit Lead	Catriona Lorang (2015) – HammondCare, DSBI
	Meredith Gresham (2014, 2015) – HammondCare, DSBI	Kate Swaffer (2015) – Consumer Dementia Research Network (CDRN)
		A/Prof Katrina Anderson (2016) – Aged Care Evaluation Unit, Southern NSW Local Health District

Enabling Sub-Unit Leads

Enabling sub-Units provide advice to CDPC research teams in their area of expertise.

Prof Ian Cameron (Research Methodologies)	Ms Megan Corlis (2013–15)	Prof Anneke Fitzgerald (Management of Change and Workforce)
Dr Tracy Comans (Health Economics)	Ms Rebecca Forbes (2016) (Designated System Based Investigators)	Ms Joan Jackman (Consumer Enabling Sub-Unit)
Ms Anne Cumming (Policy and Legislation)	Prof Len Gray (Technology and Telehealth)	

Designated System Based Investigators

The Designated System Based Investigators (DSBIs) are senior staff members of the Funding Partners who support Lead Investigators in knowledge translation, dissemination and implementation of activity outputs.

Brightwater Care Group

Ms Wendy Hudson
Ms Karla Seaman

HammondCare

A/Prof Colm Cunningham
Ms Meredith Gresham
Ms Rebecca Forbes
Dr Catriona Lorang
Prof Chris Poulos
Ms Angela Raguz

Helping Hand Aged Care

Ms Megan Corlis
Mr Jan Van Emden
Ms Samantha Giorgatzis
Ms Helen Loffler
Ms Helen Radoslovich

Alzheimer's Australia Consumer Dementia Research Network (2013–mid-2016)

The CDRN ensures consumer input and representation across all of the research activities of the CDPC. The below members have had consistent contributions and involvement with CDPC activities with involvement from the broader consumer network when required.

Joan Jackman
Janet Brennan
Christine Bryden
Ian Gladstone
Nadine Hedger
Jennifer Henderson
Louise Heuzenroeder

Danijela Hlis
Val Jenner
Les Leckie
Bob Page
Tara Quirke
Tony Ramshaw
Ron Sinclair

Kate Swaffer
Jane Thompson
Elaine Todd
Anne Turner
Kathy Williams

Original CDPC Lead Investigators

A/Prof Meera Agar
Cath Bateman
A/Prof Simon Bell
Prof Simon Biggs
Dr Michael Bird
Prof Ian Cameron

Dr Tracy Comans
Prof Maria Crotty
Anne Cumming
Sue Field
Prof Anneke Fitzgerald
Dr Liz Gill

Prof Len Gray
Prof Sarah Hilmer
Dr Susan Koch
Prof Dimity Pond
A/Prof Craig Whitehead

CDPC Operations Team

Jennifer Thompson,
Operations Manager

Rebecca Tam,
Finance Officer

Alexandra Nikitas,
Project Administrator

Sally Grosvenor,
Communications Officer

Candida Blows,
Director Personal Assistant

CDPC Evaluation Team

Dr Shannon McDermott
Research Fellow, Evaluation

Alexandra Nikitas



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