NHMRC Partnership Centre:
Dealing with Cognitive and Related Functional Decline
in Older People

Annual Report

2014
Director’s Report

I am very pleased to present a summary of the 2014 Annual Report for the NHMRC Partnership Centre on Dealing with Cognitive and Related Functional Decline in Older People (Cognitive Decline Partnership Centre or CDPC).

This is our first annual report and whilst a large part of progress in 2014 has been the finalising of our research projects, employing staff, and obtaining ethics approvals, there have also been a number of other initiatives undertaken. These have included workshops in several states on the Management of Change and Workforce Management, a national workshop held in Sydney on Health Economics, and the Annual Meeting held in Melbourne in November 2014. These meetings have had excellent involvement from CDPC Network Members and have led to the development of important collaborations.

A highlight of 2014 has been the high level of involvement from the Alzheimer’s Australia Consumer Dementia Research Network and our industry partners Brightwater Care Group, HammondCare and Helping Hand Aged Care. Their commitment has been crucial to the success of the CDPC from its inception, and their ongoing contribution is greatly valued.

Our Vision

To co-create and synthesise knowledge that changes policy, systems and practice, improving the lives of people living with dementia and cognitive decline

The CDPC works to embed programs and processes within the Australian health and aged care setting that improve the lives of people living with dementia and their carers.

It is known that poor prevention and treatment of delirium in hospital leads to functional decline, increased morbidity, mortality and adverse events. This results in prolonged hospitalisation as well as a higher risk of admission to residential care. These factors increase cost to the health system, providing a sound rationale for change.

The Confused Hospitalised Older Persons Study (CHOPS) aims to improve responses to delirium and dementia within the hospital system. Initially piloted by the Clinical Aged Health Network of the NSW Agency for Clinical Innovation, the CHOPS enables better identification of older people with confusion in hospital, investigates the causes of confusion and ensures that effective treatment and management strategies are instigated.

Implementation of the CHOPS Program is based around seven Key Principles that were developed in consultation with key stakeholders, including consumers and members from the NSW Local Health Districts.

Specifically, the Key Principles detail the importance of:

- Conducting cognitive screening for confusion of all patients aged over 65 years on admission or within 24 hours of admission using a validated screening tool
- Identifying people at risk of delirium and implementing prevention strategies to manage this risk informing the person’s family, carer and staff involved
- The need to assess older people with confusion in order to determine the cause and appropriate management options
- Ensuring hospitals have programs in place for older people with confusion that align with the Key Principles, and that implementation of such programs is undertaken in partnership with the older person, their carer and family
- The importance of ensuring that communication processes and tools are adopted that support person-centred care during their hospital stay and at the time care is transferred to the community
- Educating staff about how to best care for older people with confusion and supporting these staff in their efforts
- Ensuring that older people with confusion are provided with supportive care environments

Practical measures have been successfully implemented by the three hospitals where the program has been rolled out in 2014 and in 2015, the CHOPS program will be implemented in an additional nine NSW hospitals, including four regional/rural sites.

Other activities within the CDPC that will contribute to change within the aged care sector relate to testing new approaches to respite care, and putting proven strategies for the quality use of medicines into practice.

CHOPS forum at Lismore Hospital, NSW
The CDPC brings together proven, up-to-date research that is both relevant and applicable across the Australian health care system.

Bringing together proven research and providing the evidence to change system-wide practice and policy, which will ultimately improve the lives of people living with dementia, is core to many of the CDPC Activities.

Advance care planning, the role of the key worker in providing care and support for people with dementia and their carers, risk assessment in the community and the development of the first Clinical Practice Guidelines for Dementia in Australia are just some of the activities where the CDPC is acting to inform change.

Another study within the CDPC aims to inform health and care professionals about supporting staff and improving care in long term residential dementia facilities. Many people with dementia will spend the end of their lives in residential care and are dependent on care staff.

One review aims to determine the important individual staff variables or within-facility staff variables associated with quality of care, or quality of life, for people with dementia in residential care.

Another review regarding interventions, which have produced shorter term or long term improvements in quality of life for people with dementia in residential care, will form the second report. This review will help to inform policy makers, external research teams, and individual aged care organisations about methods and techniques, which have and have not worked, and what may be required to improve quality of care.

The CDPC has adopted a collaborative approach to improve the health and health care system for people living with dementia and their carers.

The CDPC brings together clinicians, researchers, industry, consumers and policy makers to investigate new areas of research that will enhance knowledge and understanding. Understanding the true value of delivering quality residential aged care for people with cognitive decline, quality use of medicines, the real impact of regulations in care settings, and the social impact on young people with a parent diagnosed with dementia are all areas where the CDPC is involved.

Another research programme within the CDPC is investigating the policies and practices of financial institutions in NSW with regards to substitute decision making tools in order to recommend policy and procedure changes to create better outcomes for older people.

A diagnosis of dementia does not mean an individual loses the right to make decisions for themselves. However, as the disease progresses, there may be diminished mental capacity, making decisions about personal, health and financial matters difficult. In these instances a person needs to be appointed to make decisions on their behalf, a substitute decision maker.

Consumers regularly report inconsistencies in the policies and practices of financial institutions which often do not recognise existing substitute decision making tools, causing great difficulties for people with dementia and their carers.

During 2014, collaborators from the University of Western Sydney and Council on The Ageing NSW and with representation from consumers and industry partners, undertook interviews and surveys with key stakeholders including:

- Consumers who had acted in the role of Attorney on behalf of a person with a diagnosis of dementia
- Financial Institutions as represented by both the Australian Bankers Association and their Members
- Government Departments including the NSW: Trustee and Guardian, Land and Property Information, Guardianship Division of NCAT, and the Commonwealth Financial Ombudsman Service

The findings of the project highlighted a number of issues relating not only to the problems experienced by the consumers but also the banks.

As result of this study a pilot education package for front line staff in financial institutions has been developed with the aim of assisting staff to understand the relevant instruments used in substitute decision making in respect of financial transactions.

CDPC Network Members at the 2014 CDPC Annual Meeting

CDPC Lead Investigators at the 2014 CDPC Annual Meeting
The CDPC is developing an effective and sustainable workforce by provision of evidence-based knowledge and understanding through education.

The majority of CDPC projects have the potential to deliver a more sustainable health and aged care workforce. In particular the CDPC is specifically evaluating the role of interprofessional education in residential aged care, the importance of supporting and caring for staff, and economic modelling of aged care and dementia management in the Australian health care system.

There is some evidence demonstrating that interprofessional learning programs demonstrate real benefits for students undertaking clinical education placements as well as the residents and staff of residential aged care facilities, however, no rigorous evaluations have been conducted to date.

A CDPC Activity, led by Brightwater Care Group in conjunction with Helping Hand Aged Care and Western Australian universities, is evaluating the impact of an interprofessional education (IPE) program in residential aged care with regard to:

• Students’ perceptions of residential aged care and support for people with cognitive and related functional decline
• Students’ career paths and approach to people with cognitive and related functional decline in their future careers
• The approach, learning and involvement of existing staff
• Resident health outcomes and wellbeing

During 2014, a total of 51 undergraduate students from the University of Western Australia, University of Notre Dame and Curtin University representing the disciplines of dietetics, occupational therapy, speech pathology, nursing, physiotherapy, pharmacy and medicine participated in the IPE Program at a Brightwater Care Group residential aged care facility.

To increase national generalisability of the findings, in 2015 the Brightwater Care Group is working with Helping Hand Aged Care, to allow for joint analysis of objectives and to compare IPE models with the goal of developing a transferable and sustainable IPE model that other aged care organisations can adopt. In addition, Helping Hand Aged Care will be including vocational education students and university students at various tertiary levels to broaden the scope of the potential workforce.

Research for Us-with Us Consumer Report

When Professor Kurrle first presented the proposed CDPC Workplan to the Consumer Dementia Research Network (CDRN) as a group in mid-2012 it was the beginning of exciting and inspirational times to be actively involved in the unique and innovative CDPC.

Alzheimer’s Australia, as one of the Funding Partners, created an opportunity for CDRN Members to bring the consumer voice to the work of the CDPC, including the funding of a part-time Consumer Investigator (CI) position, together with the support of a CDRN Member Sub-Group and the broader membership.

Joan Jackman, Lead Consumer Investigator, represents consumers on the Executive Committee and facilitates, co-ordinates and supports the involvement of consumers in all CDPC Activities, as members of the CDPC. With the support of Professor Kurrle, the Lead Investigators and Alzheimer’s Australia, up to four consumers are now involved in each of the current 17 Activities.

The interest and enthusiasm of the consumers has also extended to contributing to Activity Focus Groups, Reference Groups, and also to the Scientific Sub-Committee, established in 2014, as well as to selectively review Activity Proposals in their formative stages of development.

Extending the involvement of consumers to the CDPC has been an interesting and enlightening learning experience for all involved. Consumer involvement in the CDPC has developed a better understanding regarding the work involved in the complex process of research and as a group has continued to gain respect of the Activity Leads and Project Officers for the experience, skill and expertise consumers bring to the CDPC.

Above all else, the consumers involved in CDPC Activities have had to learn patience and harness passions and energy to contribute effective and vigilant consumer perspectives.

The CDRN members look forward in 2015 to evaluating how effectively this is achieved and how consumers are making a difference to the work of CDPC.

CDRN members Jane Thompson (left) and Tara Quirke
In 2014, the CDPC commenced 17 Activities covering seven thematic areas, with involvement from representatives of four of the Funding Partners: Alzheimer’s Australia, Brightwater Care Group, HammondCare and Helping Hand Aged Care. A number of other initiatives have also been undertaken with the intent of building the skills and capabilities of members in the CDPC Network.

The CDPC adopted the four objectives for the NHMRC Partnerships for Better Health – Partnership Centre Initiative to guide its work, namely:

1. Support implementation of research-informed change in health and health-care systems
2. Synthesis and dissemination of existing research relevant to improving health and health care system performance
3. Undertake collaborative new research to improve health and health care using methods that are cross-sectional, inter-disciplinary, and trans-national in scope
4. Build capacity within the research community to do applied research, and within the system to use research as part of change management

“The ability to involve key stakeholders from the beginning of the CDPC, including people with dementia and their carers, has meant that the CDPC has been able to focus on those issues that we know will have a positive impact on the lives of people living with dementia,” Professor Kurrle, CDPC Chief Investigator and Director

<table>
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<tr>
<th>CDPC Activities</th>
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<tr>
<td>1. Understanding long-term care configurations for older people with cognitive decline in Australia</td>
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<td>2. The care of the Confused Hospitalised Older Persons (CHOPs) Program Implementation*</td>
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<td>3. Evaluating the Dementia Key Worker role</td>
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<td>4. Prototyping an alternative respite model for older people with cognitive decline and their carers</td>
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<td>5. Systematic review and scoping study for the implementation of a national approach to specific advance care planning</td>
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<td>6. The policies and practices of financial institutions around substitute decision making</td>
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<td>7. The effects of regulation on aged care services for people with cognitive decline</td>
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<td>8. Living with dementia in the community: Assessing the risks</td>
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<td>9. Evaluating the outcomes of inter-professional education programs in residential aged care</td>
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<td>10. Improving quality of residential dementia care and promoting change by supporting and caring for staff</td>
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<td>11. Optimising the quality use of medicines for people with cognitive and related functional decline</td>
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<td>12. Focus on the implementation of the use of Vitamin D supplements in Australian Residential Aged Care Facilities (RACFs)</td>
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<td>13. Review international dementia guideline and synthesise to develop national Australian guideline</td>
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<td>14. Development and implementation of a consensus guide on dementia in primary care</td>
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<td>15. Estimation of the cost-effectiveness of aged care, dementia and dementia management in Australia*</td>
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<td>16. Healthy ageing in Australian Physicians*</td>
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<td>17. The psychological impact on the young people having a parent with younger onset dementia</td>
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(*abbreviated Activity title)

**Working together for change**

The CDPC is a multi-disciplinary network of 153 people with specialities in the fields of medicine, nursing, psychology, occupational therapy, pharmacology, physiotherapy, sociology, law, health economics, and aged care service management.

![Geographical distribution of the CDPC Network](image)

**Knowledge sharing**

In 2014 the CDPC has collectively demonstrated the ongoing relevance and importance of the key questions being addressed by the CDPC through the production of evidence based material (Total outputs=129).

![Distribution of output types in 2014](image)

**Strategic Linkages**

Strategic linkages were established with key organisations to maximise the CDPC’s reach including with:

- Dementia Training Study Centres
- Dementia Collaborative Research Centres
- National Ageing Research Institute
- Centre for Education and Research on Ageing
- The Deeble Institute
- Centre for Informing Policy in Health with Evidence from Research
- The Australian Prevention Partnership Centre

**CDPC Performance**

A total of $3,956,220 of an available $5,011,498 in funds was allocated in the Year 1 budget with 85% of Activity milestones achieved in 2014.

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<td>Enabling Sub-Units</td>
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<td>Activities</td>
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<td>Total</td>
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<td>Total</td>
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Acknowledgments

Governance Authority

Professor Susan Kurrle, Curran Chair in Health Care of Older People in the Faculty of Medicine at the University of Sydney
Ms Carol Bennett, CEO, Alzheimer’s Australia, ACT
Dr Penny Flett, CEO, Brightwater Care Group, WA
Mr Ian Hardy, CEO, Helping Hand Aged Care, South Australia
Dr Stephen Judd, CEO, HammondCare, WA
Ms Louise O’Neill, Department of Social Services, ACT
Mr Alan Singh, National Health and Medical Research Council, ACT

Executive Committee

Professor Susan Kurrle
Professor Simon Biggs
Professor Maria Crotty
Professor Anneke Fitzgerald
Ms Joan Jackman
Assoc Professor Susan Koch

Enabling Sub-Unit Leads

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

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  
Dr Karla Seaman  
HammondCare  
Assoc Professor Colm Cunningham  
Ms Meredith Gresham  
Ms Rebecca Forbes  
Dr Catriona Lorang  
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Participating Institutions

Agency for Clinical Innovation
Alzheimer’s Australia
Brightwater Care Group
Flinders University
Griffith University
HammondCare
Helping Hand Aged Care
Monash University
National Health and Medical Research Council
Royal District Nursing Service
Southern New South Wales Local Health District
University of Melbourne
University of Newcastle
University of Queensland
University of Sydney
University of Western Sydney

Funding Partners

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http://sydney.edu.au/medicine/cdpc/

Australian Government
National Health and Medical Research Council

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EDUCATE AUSTRALIA

BRIGHTWATER
An independent Christian charity

HELPING HAND
new aged care

Cognitive Decline Partnership Centre

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