

2017 ANNUAL REPORT

NHMRC Partnership Centre: Dealing with Cognitive and Related
Functional Decline in Older People, at The University of Sydney



COGNITIVE
DECLINE
PARTNERSHIP
CENTRE



THE UNIVERSITY OF
SYDNEY

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Ms. Jennifer Lawrence, Brightwater Care Group

Prof. Chris Poulos, HammondCare

Mr Ian Hardy, Helping Hand Aged Care

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CDPC Directorate / Operations Team 2017

Mrs Jennifer Thompson, Operations Manager

Mrs Sally Grosvenor, Communications Manager

Ms Honor Morton, Communications & Engagement Officer

Mrs Rebecca Tam, Finance Officer

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This report covers the period 1 January 2017 – 31 December 2017

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NHMRC Cognitive Decline Partnership Centre 2017 Director Overview

Thank you for making time to read our Annual Report for 2017.

It was a very satisfying year for myself and my team here at the University of Sydney, with one of the highlights being our presence at the October NHMRC National Institute for Dementia Research Forum in Melbourne. That event was an excellent opportunity for us to showcase the wide range of work being done by the Cognitive Decline Partnership Centre (CDPC), with the involvement of our consumer representatives front and centre. It also



showed how our day-to-day focus is shifting from solely management of research projects, to dissemination and implementation of research outcomes and resources. Stories of our real impact across our four NHMRC Objectives and nine planned impacts are included in this report (page 6) and throughout this report.

The NHMRC have recently approved our requested CDPC end-date variation to 31 December 2019, which means we will have extra time to concentrate on our dissemination efforts and facilitate increased implementation into practice.

Planning of our work for 2019 by the CDPC Directorate team, Executive Committee, Governance Authority, Consumer Network members, and other key stakeholders will be part of a sub-meeting during our final Annual Meeting in Canberra in October 2018. We hope to see many of our CDPC members and stakeholders there.

A handwritten signature in blue ink that reads "Susan Kurrle".

Professor Susan Kurrle

Director of the Cognitive Decline Partnership Centre at the University of Sydney
Curran Professor in Health Care of Older People at the University of Sydney
Clinical Director of the Aged Care and Rehabilitation Network at the Northern Sydney Local Health District

2017 Story of Impact from one CDPC Implementation of Research-Informed Change Activity

IMPACT

Implementation of care and service models in health/aged care contexts, improving care outcomes for older people with cognitive decline

CDPC ACTIVITY 1320 – TELEHEALTH ENABLED PRESCRIBING FOR PEOPLE WITH DEMENTIA

After receiving a copy of the CDPC Mid-Term Report the Hon. Ken Wyatt, Minister for Aged Care and Indigenous Health responded that he read the report...

“with interest about the research the Centre is undertaking to improve best practice dementia care in Australia. The telehealth project to improve medicines use amongst persons with dementia is particularly interesting in the context of improving consistency and continuity of dementia care to all Australians, regardless of geographical location.”

2017 Story of Impact from one CDPC Synthesis and Dissemination of Existing Research Activity

IMPACT

Access to meaningful clinical guidelines reflecting current evidence on dementia care, enabling them to identify and respond to the condition more effectively

CDPC ACTIVITY 1313 – CLINICAL PRACTICE GUIDELINES AND PRINCIPLES OF CARE FOR PEOPLE WITH DEMENTIA

The Guidelines were included in the NSW Health Dementia Care Competency Framework online training resource, and the Community Cognition and Dementia Service at Cabrini Health embedded the Guidelines into the Cabrini Aged Care Integrity Guidelines for Care.

We provided a supply of the Consumer Companion Guide to Cabrini and many other entities to distribute to consumers and consumer groups to increase awareness of what the guidelines recommend.

2017 Story of Impact from one CDPC Collaborative New Research Activity

IMPACT

Tools and resources for changing attitudes to dementia and cognitive decline, increasing general awareness and promoting greater acceptance

CDPC ACTIVITY 1306 – FINANCIAL INSTITUTION POLICIES AND PRACTICES

The NSW Council of The Ageing (COTA) became interested in the outcomes and resources developed during this CDPC Activity and partnered with the Lead Investigator and the CDPC Policy & Legislation Enabling Sub-Unit to host 10 information sessions on Powers of Attorney for community members across centres in NSW.

The Australian Banking Association distributed the Activity report and training package to its members and the Commonwealth Bank of Australia are working towards introducing the training package for their front-line staff.

2017 Story of Impact from one CDPC Capacity Building Activity

IMPACT

Evidence-based tools and strategies to build/develop workforces to meet the growing demand for care and services for people with cognitive decline

CDPC ACTIVITY 1309/1328 – IMPLEMENTING AND EMBEDDING INTERPROFESSIONAL EDUCATION AND PRACTICE (IPEAC) ACROSS THE AGED CARE SECTOR

In 2017 staff from sites that piloted the IPEAC Toolkit resource indicated they would continue to direct students to the resources to support the student experience within their aged care facilities.

CDPC Directorate Summary

The NHMRC Partnership Centre: Dealing with Cognitive and Related Functional Decline in Older People (CDPC) five-year work plan continues to include a diverse range of activities across four NHMRC/CDPC objectives, eight CDPC themes, and nine originally planned impact areas. At the time of writing this report, the CDPC's website listed 58 academic publications released by 31 December 2017 (<http://sydney.edu.au/medicine/cdpc/>).

During 2017 the CDPC continued to grow from the original team of 17 Lead Investigators with 14 Activities. Since inception we have had over 300 members involved across 25 Completed Activities and Capacity Building and Synthesis and Dissemination Workshop



initiatives, 14 In Conduct Activities, and 2 Approved 2018 planned Capacity Building Workshop initiatives with a total of 41 CDPC funded research Activities and initiatives.

To meet the demands of dissemination and internal evaluation our Directorate team headed by the Operations Manager (Jennifer Thompson) composition changed with the move of our Project Administrator (Alexandra Kitching) to the position of Research Officer; our Communications Officer (Sally Grosvenor) promotion to Communications Manager; our Finance Officer (Rebecca Tam) increasing her hours; and on-boarding of a Communications and Engagement Officer (Honor Morton). This brought our Directorate team to a total of six staff including our Research Fellow (Dr Shannon McDermott), who along with the Director, Prof Susan Kurrle, support the CDPC research, finance, and administrative functions of the Centre.

In May 2017 a Priority Setting Initiative was completed with the majority of the available CDPC grant funds now allocated to research Activities. At the end of that allocation process and additional \$409,829.00 was granted across 9 research Activities and the Directorate team, for implementation initiatives including expanded marketing and dissemination of overall CDPC research outcomes. All of the above with the aim of facilitating our research to positively impact the lives of people with dementia and their families and carers.

In 2017 the CDPC's relationship with the NHMRC National Institute for Dementia Research (NNIDR) was further strengthened with the Director of the NNIDR stepping into the position of Chairperson for the CDPC Governance Authority. The CDPC earned a high profile and symposium session during the NNIDR Annual National Dementia Forum in October 2017.

The CDPC also participated fully in a 2017 NHMRC evaluation of Partnership Centres which mapped our progress against NHMRC's objectives. Unfortunately, despite the resultant report being complimentary of the CDPC's performance, the NHMRC made the decision to not extend the existence of this Partnership Centre beyond its current funding term. The CDPC is therefore now in the wind-down period of existence with plans being made to maximise impact, ensure outputs and developed resources are hosted elsewhere post 2019, and then finally, to offboard staff.

The CDPC now has just a year to complete the CDPC Work Plan. The current end-date in the NHMRC RGMS system was 11 April 2019. An end-date variation, with no additional funding requested, was submitted to the NHMRC on 29 November 2017. Now approved, this will take the CDPC to a final end-date of 31 December 2019. A comprehensive case for extension was submitted, and the extension was fully supported by the CDPC Executive Committee and CDPC Governance Authority. With a number of CDPC Activities not completing until the end of 2018 there was concern the current end-date will not allow time for full dissemination and facilitation of take-up and implementation of CDPC research Activity outcomes, outputs, and developed resources. With approval, the additional 8.5 months of existence will now enable the core CDPC Directorate team, with assistance from CDPC Executive Committee, Dementia Australia Consumer Network volunteer members, and CDPC Governance Authority, to fully manage finalised research outcomes, outputs and developed resources to enable achievement of maximum impact.

Alignment of CDPC Activities against both NHMRC Objectives and NNIDR Priorities continues to be one of the foci of our regular reporting and the Directorate team continue to collect stories of impact. Some examples of how we have performed against a selection of our nine (9) planned impacts in 2017 are provided on the following page.

Successes / Areas of Performance Strength and Strategic Position

The CDPC is no longer unique, as it was in 2014, but rather is one of three NHMRC Partnership Centres (<https://www.nhmrc.gov.au/grants-funding/apply-funding/partnerships-better-health/partnerships-centres>) facilitating collaboration between government, industry partners, consumers and research institutions.

CDPC researchers, partners including consumers, and Directorate team continue to develop and disseminate research-backed data and resources. During 2017 regular conversation and interactions occurred with key players in the decision making and policy process in Australia. An ongoing relationship between the CDPC and the NHMRC National Institute for Dementia Research (NNIDR) and the federal Department of Health, Dementia Section enabled the CDPC to present as a leading group in Australia for development of evidence-based research outcomes impacting care for people with dementia in Australia.

The portfolio of funded research that the CDPC has been able to bring together has the potential to greatly impact care for people with dementia in Australia. The CDPC Directorate regularly received invitations to represent care research process and outcomes into policy-maker forums. Evidence from CDPC research is increasingly being utilised or at least considered by policy-makers in the context of policy change. Collected stories of uptake and implementation give us strong indication that CDPC outputs and resources can, and will, positively impact the lives of people with dementia in Australia.

Communication, including Management Reporting

With many CDPC projects well into their funding term, 2017 was a year of increased dissemination of outputs and focus on where our research is having direct impact. While there was a continued emphasis on both internal and external communications, there was also concerted effort made for external engagement, enhancing existing strategic linkages, and creating increased opportunities for translating knowledge into practice.

A collaborative workshop between the CDPC and The Australian Prevention Partnership Centre (TAPPC) titled “Practical strategies to facilitate the use of evidence in complex systems” brought knowledge mobilisation experts Professor Diane Finegood and Professor Bev Holmes (Michael Smith Foundation for Health Research, Canada) to present, and work with our researchers on understanding strategies and barriers to implementation.



Discussions with Partner Institution representatives in 2017 strengthened the alignment of communication strategies and supported overall goals of both the CDPC and Partner Institutions: Brightwater Care Group (WA), Dementia Australia, Hammondcare (NSW), and Helping Hand Aged Care (SA).

In 2017 the CDPC was invited to link its Annual Meeting as part of the NHMRC National Institute for Dementia Research (NNIDR), Australia Dementia Forum. At this event the CDPC highlighted research outcomes through a dedicated oral presentation session and numerous poster presentations, during which we showcased the significant outcomes of the CDPC, and its strength as a model of true collaborative research with consumer involvement at the centre of that collaboration. Also emphasised was the commitment of all CDPC members to improve the lives of people with dementia and their carers.



Internationally, the CDPC enhanced its profile as one of Australia’s leading dementia research institutes. At the International Association of Gerontology and Geriatrics (IAGG) Conference in San Francisco, the largest academic conference on ageing in the world (<https://www.geron.org/meetings-events/iagg-2017-world-congress-of-gerontology-and-geriatrics>), more than a dozen CDPC members represented our research through symposium, oral and poster presentations, and panel discussions. During this year we also learned that RBK Stuttgart and Mannheim (Germany) translated the CDPC evaluated Care of Confused Hospitalised Older Persons (CHOPs) program resources (<http://sydney.edu.au/medicine/cdpc/resources/dem-care.php>) into German for implementation into their models of care.

Nationally, the National Dementia Conference ‘be the change’ held by Dementia Australia in October in Melbourne provided another opportunity for numerous members of the CDPC to disseminate their research outcomes. An exhibition booth dedicated to dissemination of CDPC outputs provided an outlet for enhanced networking and stakeholder engagement and was well attended (<https://dementia2017.org/>).

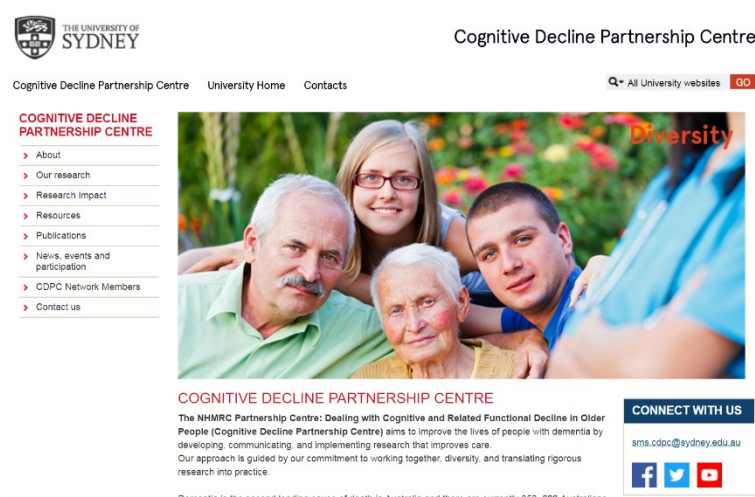
Management-reporting deadlines, including finance reporting deadlines, continued to be met throughout 2017. With an increased number of funded Activities producing valuable research outcomes, the requirement for increased dissemination outlets and opportunities resulted in expansion of the CDPC core Communications team, with the Centre now having a Communications Manager and CDPC Communications and Engagement Officer to carry us through to the end of 2019. Those receiving regular scheduled reports from the CDPC Directorate team are the Kolling Institute at The University of Sydney, CDPC Executive Committee, CDPC Governance Authority, NHMRC Partnership Centres Office, and the Department of Health – Dementia Section of the Australian Government.

Outputs

The intent of CDPC outputs is to maximise impact and implementation to positively impact the lives all people in Australia with cognitive decline and related functional decline, and their carers.

Throughout 2017, the CDPC Directorate Office and individual Activity teams, under the oversight of the Communications Manager (Sally Grosvenor), continued to disseminate and participate in an increasing number of Traditional (academic publication) and Non-Traditional (knowledge creation and knowledge impact) outputs/syntheses. With a number of Activities coming to completion in 2016/2017, presentation of evidence-based outputs in peer-reviewed/traditional outlets increased compared to the previous years (2015 = 83, 2016 = 96, 2017=121). Knowledge creation and knowledge impact (2015 = 105, 2016 = 224, 2017 = 217) remained a significant avenue for dissemination of Activity Outputs.

Website and Social Media



The screenshot shows the website for the Cognitive Decline Partnership Centre at The University of Sydney. The page features a navigation menu with links to 'About', 'Our research', 'Research Impact', 'Resources', 'Publications', 'News, events and participation', 'CDPC Network Members', and 'Contact us'. A central image shows a diverse group of people, including an elderly woman, a young man, and a woman, with the word 'Diversity' overlaid. Below the image, there is a 'CONNECT WITH US' section with social media icons for Facebook, Twitter, and YouTube, and the email address 'sms.cdpc@sydney.edu.au'. A small text box at the bottom states: 'Dementia is the second leading cause of death in Australia and there are currently 353,800 Australians'.

The CDPC website continued to evolve in 2017 and now includes social media links, a Research Impact Page, and real-time updates of peer-review publications and resources. This provides a primary portal for external engagement of the CDPC. <http://sydney.edu.au/medicine/cdpc/>

The CDPC Twitter feed https://twitter.com/nhmrc_cdpc continues to be a successful avenue for dissemination of CDPC outcomes, outputs and news, whilst offering an opportunity for the CDPC to

support internal and external collaborators and influencers through interaction. In 2017 the number of Twitter followers increased by 150 to 477. A 15% increase in followers occurred in July 2017 during IAGG Conference (San Francisco) and there was a 20% increase in followers in October 2017 during NNIDR and Dementia Australia Conferences (Melbourne).

CDPC Newsletter

The CDPC Newsletter was redesigned in 2017 to capture audience interest and drive to news stories on the CDPC webpage. We produced three newsletters during 2017 with an average open rate of 39%, and newsletter subscriptions increased from 240 to 350 recipients.

CDPC Newsletter – May 2017	https://us8.campaign-archive.com/?u=a2c793e133feca820741680d0&id=28cf882983
CDPC Newsletter – November 2017	https://us8.campaign-archive.com/?u=a2c793e133feca820741680d0&id=df8a01ec1c
CDPC Newsletter – December 2017	https://mailchi.mp/19daee7d0f79/caring-for-older-people-in-the-home-reablement-medication-simplification-2589537

Ensuring Maximum Impact of CDPC Developed Evidence, Outputs, Resources 2017-2019

Challenge: By mid-2017 the CDPC still had unallocated funds, and it was recognised that with at least thirteen (13) of our CDPC approved research Activities not completing until December 2018, the available timeframe (January 2019 to April 2019) for pushing CDPC research evidence, outputs, and developed resources to appropriate stakeholders and policymakers would be challenging given the end-date of 11 April 2019.

Remedial Action: By November 2017 the Directorate, Executive Committee, and Governance Authority had agreed there was a need to submit an End-Date Variation (with no additional required funds) to the NHMRC to take the end-date of the CDPC to 31 December 2019. This would allow an 8.5 month extended period of sustained dissemination and promotion of CDPC evidence, outputs, and resources to stakeholders and policymakers. That variation application was approved by the NHMRC in March 2018.

Benefit: With the End-Date Variation approved the core CDPC Directorate team will continue to 31 December 2019, enabling emphasis between January 2019 and December 2019 on not only the final reporting requirements for the Partnership Centre, but also on a push of CDPC evidence, outputs, and developed resources into policy and practice. The final CDPC financial resources are being allocated to cover increased impact initiatives, allowing the CDPC to complete impact initiatives to improve the care and lives of people with dementia, their carers, and their families.

Risk: Very little to no recognisable risk to funding partners, including the NHMRC, was identified in having the CDPC Directorate core team continuing to work on increasing impact of CDPC developed evidence, outputs, and resources in 2019.

Awareness of CDPC Evidence, Outputs, Resources within the National Landscape of Dementia Care

Challenge: The evidence, outputs, and resources of the CDPC have potential to create impact. However, there is currently no clear pathway established for one or more entities to hold/host the CDPC evidence, outputs, and resources once the CDPC has ceased to exist. The NNIDR (<https://www.nnidr.gov.au/>) is now empowered as the main driver of research and research communication overarching all dementia research in Australia. In 2017 the NNIDR was strengthened by the incorporation of what were the Dementia Collaborative Research Centres into the NNIDR, however by the end of 2017 there was no guarantee of tenure past 2019 for the NNIDR. This creates uncertainty around where researchers and others will be able to find comprehensive information and resources in care research post 2019.

Remedial Action: Through 2018 and 2019, until the end of the CDPC, the CDPC Directorate team will be looking to continue linkage with the NNIDR and other appropriate stakeholders eg. Dementia Training Australia, to establish agreement and linkages with them and additional entities, including residential aged-care peak bodies, that may be able to continue to hold/host legacy CDPC information. Linkages with the NNIDR in 2017 are listed here:

- NNIDR Board: Dr Jane Thompson (affiliated with CDPC through Alzheimer's Australia)
- NNIDR Expert Advisory Panel: Janice Besch (Chair, CDPC Governance Authority), Prof. Susan Kurrle (Director, CDPC); Prof. Dimity Pond (CDPC Lead Investigator), Louise Heuzenroeder until November 2017 (CDPC Consumer Network volunteer), Danijela Hlis invited December 2017 (CDPC Consumer Network volunteer)
- NNIDR Director Janice Besch chairs the CDPC Governance Authority
- Linkage of the CDPC Annual Meeting with the NNIDR Annual Symposium in Melbourne in October 2017.

Benefit: Continued development of strategic linkages and collaboration between the NNIDR and others, including Dementia Training Australia, will strengthen the CDPC's ability to guarantee its evidence, outputs, and resources continue to be available post CDPC shut-down in December 2019.

Risk: If the CDPC Directorate are unable to identify and organise other entities to host CDPC evidence, outputs, and resources post CDPC shut-down in December 2019 the impact of those resources will be lessened as much evidence into improving care may become unavailable.

CDPC Partner Organisation Statement from Brightwater Care Group, Hammondcare, and Helping Hand Aged Care

Brightwater, HammondCare and Helping Hand are very involved in the activities of the CDPC, both in the research sphere and as advocates for the principles involved in collaborative research and knowledge translation. People living with dementia and their support partners receiving community, acute or residential care services from our organisations and our workforce providing those services have been crucial to our involvement to date and will continue to be so.

Transforming standard research practices to integrate a collaborative approach that engages people with dementia, their support partners, service providers and their staff requires a significant commitment of time and energy. The Designated System Based Investigators (DSBIs) from each organisation continue to play an integral role as agents in this process of change. Our strong relationships with relevant industry and government stakeholders and the broader community across three states have also been critical and will continue to influence the success of outcomes.

The partner organisations look forward to our ongoing collaborative relationship with the CDPC community. We are confident the knowledge and experience gained by the CDPC and researchers through this partnership will continue to inform current and future research and knowledge translation activities.



Dementia Australia Consumer Network Statement

Provided by Joan Jackman (Dementia Australia CDPC Lead; Consumer Enabling Sub-Unit / Consumer Investigator)

The **Vision** of the CDPC which has continued to guide and focus our collaborative efforts is to improve the lives of people with dementia. The stated CDPC **Mission** within this is to develop and communicate research to improve the care of people with dementia.

Dementia Australia Consumer Network members have continued their collaborative involvement with the CDPC throughout 2017, working towards achievement of this mutual goal - and this is in keeping with the Funding Partner relationship of Dementia Australia (DA) with the CDPC. This partnership includes funding by Dementia Australia of a part-time Consumer Investigator position / Lead, Consumer Enabling Sub-Unit, together with their support for voluntary consumer involvement in the work of the CDPC.



Consumer involvement in the CDPC is considered to be part of the Centre's *uniqueness and strength*, in working together towards the achievement of the Partnership Centre's Vision. The *three tiers* of consumer involvement has continued to ensure a sustained commitment to the continuing work of the CDPC. This is achieved through the funded Consumer Investigator (CI) position (**Joan Jackman**); the Consumer Network group of *volunteer* DA Consumers (**Jenny Henderson, Louise Heuzenroeder, Tara Quirke, Ron Sinclair, Kate Swaffer, Jane Thompson, Kathy Williams**) who work with and support the work of the CI; and the *volunteer* DA Consumer Network members who are also aligned to, or selectively involved in specific Activity Teams (**Graeme Brough, Gary Collins, Mae Collins, Theresa Flavin, Imelda Gilmore, Ian Gladstone, Nadine Hedger, Danijela Hlis, Val Jenne, Les Leckie, Glenys Petrie, John Quinn, Maxine Thompson, Elaine Todd**). Newer Consumer Network members have also offered their time and experiences as opportunities may present (**Keren Glennen, Kerin Glennen, Astrid Heckler**).

CONSUMER INVOLVEMENT IN CDPC OPERATIONS

Executive Committee: The Dementia Australia (DA) Consumer Investigator (**Joan Jackman**) has continued membership in the monthly Executive Committee meetings, bringing relevant consumer perspectives and representation of the Consumer Network members involved in the CDPC, to the operational decision-making processes of the CDPC.

Scientific Sub-Committee: Consumers (**Ron Sinclair, Elaine Todd**) have continued their membership of this Committee, which concludes in April 2019. Their role primarily involves bringing a consumer perspective to the evaluation of Proposals for research Activities, with regard to the Review Protocol criteria. The volume of

Proposal reviews has been less for 2017, with final funding applications now submitted. The broad range of personal and professional skills, and experiences from which Consumer Network members may draw from for this Committee review process, has contributed to a robust and collaborative review of Proposals.

Steering Committee Meeting / Budget Priorities 2017-2019: This Steering Committee/Working Group was convened by the CDPC in May 2017, to prioritise the remaining budget expenditure to the current end date in April 2019. Funding Partners were represented by their Designated System Based Investigators (DSBIs); the Governance Authority (GA) by Annette Moxey (Dementia Australia); and the Consumer Network members by **Joan Jackman**. The CDPC Directorate team facilitated the process that also included representation from the Executive Committee and the NHMRC National Institute of Dementia Research (NNIDR). The recommendation for quarantining some funds to support relevant travel/accommodation requirements for *consumer involvement* in the CDPC to April 2019, was unanimously supported as one of the outcomes of this process. Recommended additional funding support for the CDPC Directorate Communications team for prioritised CDPC *dissemination* work to April 2019 was also supported, as was additional fund allocations for selected Activities to support dissemination initiatives.

Consumer Enabling Sub-Unit: Consumer involvement in CDPC Activities (1-37) has continued to be 100%. By September 2017 twenty-one of the Activities had achieved a status of *Completed*. Consumers continue in those Activities which are still *In Conduct*, with end-dates for most being December 2018. As partners in their research teams, Consumer Network members have been invited to contribute to the dissemination priorities of some Activities as they progress to their dates of completion. Disseminating, promoting, publicising and presenting has become an increasing priority for all team members with a commitment to *getting the word out there* about how the CDPC is making a difference to the lives of people with Dementia and the people who share their lives. One of the commended examples of this collaborative promotion was for the Activity 13: *Consumer Companion Guide to the Clinical Practice Guidelines and Principles of Care for People with Dementia*, for which proactive promotion was undertaken, involving several Consumer Network members included in the production of a promotional video for consumers. This involved **Louise Heuzenroeder, Ian Gladstone, and Ron Sinclair**.



Consumer Members: As members of the CDPC Activity teams, the Consumer Network members bring a wide variety of personal and professional skills, and experiences to the work of the CDPC. The Enabling Sub-Unit serves to *align* consumer interests, skills and experiences to Activity subject and team members, for the most effective collaboration and partnership. The Consumer Network members come from all States of Australia, with a continuing endeavour to be as 'representative' as their own experiences and that of each of their local Networks, will support.

Consumer Role: The integral inclusion of Consumer Network members in the research of the CDPC continues to be regarded as a unique feature of the Centre. Part of this uniqueness includes the support for Consumer Network members to contribute through a variety of consumer roles, including *investigative, advisory and participatory*. The emphasis on increasingly inviting consumers to contribute in an *investigative* or *advisory* role, as the Centre has evolved, has enabled the fuller potential of consumers to be realised in the development, implementation and dissemination of those Activity teams which have found this an enhancement to the team and its research. The full impact of this involvement, will hopefully be further reflected in the CDPC *Internal Evaluation* (2018) report when that project is finalised.



EVENTS INVOLVING CONSUMER NETWORK MEMBERS

CDPC Annual Meeting, 2017: Approximately eight Consumer Network members were supported by the CDPC to attend their Annual Meeting in October 2017. A Presentation was invited by **Louise Heuzenroeder** on the effectiveness of consumer involvement in Activity 13: Clinical Practice Guidelines and Principles of Care for People with Dementia, with the success of the team working with Consumer Network members and other consumers on the Project, ranked against the NHMRC recommendations for consumer involvement in research. **Ron Sinclair** was invited to share his personal experience about the impact of Dementia on his family, preceding the Outcomes and Outputs Session of the Annual Meeting.

NNIDR Forum, 2017: Keynote Consumer Presentation invited by **John Quinn**, supported by **Glenys Petrie**. **Jane Thompson** was invited to present a Poster on Inviting Public Involvement in NNIDR Research. **Joan Jackman** was the consumer representative with the Forum Planning Committee.

NNIDR Forum 2017 / Dementia Care Forum: This Forum was convened by the NNIDR to workshop and progress consumer involvement in research. A Communique' was developed with External Consultant facilitation, with recommendations for further consideration by the NNIDR, consistent with responsibilities to the Minister for Health. Consumer participants (DA/CDPC) included **Danijela Hlis, Joan Jackman, Glenys Petrie, John Quinn, Tara Quirke, Ron Sinclair, Kate Swaffer, Jane Thompson**.

Alzheimer's Australia (Dementia Australia) Bi-Annual Conference, 2017: Presentations and Posters were invited from **Graeme Brough, John Quinn and Glenys Petrie, Kate Swaffer**.

SPHERE Symposium, 2017: **Jane Thompson** was invited through the CDPC, to bring a consumer perspective to a Panel Session titled "What are we doing?"

Alzheimer's disease International (ADI) Conference, 2017: **Jane Thompson** was invited and supported to present on behalf of the CDPC at this international conference that took place in Japan.

CONSUMER NETWORK DIVERSITY / RESEARCH ENHANCEMENT

Personal and Professional Experience: Consumer Network members involved with the CDPC come with a diverse range of skills and experiences, which continues to provide a potentially rich resource for the inclusion of consumer perspectives in CDPC Research Activities. Some of these experiences in 2017 included:

Danijela Hlis – produced a bi-lingual publication of a collection of poems and stories which introduce the reader to the world of Dementia, titled *Forget-Me-Nots (2017)*

Louise Heuzenroeder - Awarded an Alzheimer’s Australia PhD Scholarship for research into *The 10 Principles in Dignity in Care*. Publication in the *Medic SA*, the SA Journal of the AMA (November 2017, *Using the Consumer Companion Guide to talk about dementia*). 2017 NNIDR Expert Advisory Panel member

Joan Jackman, Ron Sinclair, Jane Thompson - Dementia Australia Research Foundation Grant Application Consumer reviewers

Jane Thompson - NNIDR Advisory Board Member (Consumer), 2017

Four Consumers - Boosting Dementia Round 1 / Grant Applications Consumer Reviewers, 2017

CONSUMER NETWORK INVOLVEMENT IN CDPC EVALUATION

NHMRC External Evaluation by the NHMRC - Together with all members of the CDPC, Consumer Network members *voluntarily* contributed their time and experience to this independent evaluation at the commencement of 2017. It included a review of consumer involvement in the CDPC. The Report from this evaluation was available for limited distribution only.

CDPC Internal Interim Evaluation, 2017 - This Evaluation Project includes a review of Sustaining Partnerships, with it considered that *“consumers are an integral part to achieving the CDPC’s intended impact and, the involvement of consumers is considered to be a particularly invaluable part of the CDPC’s structure.”* Operationally it was considered *“for most of the people who participated in the qualitative interviews, involving consumers in research in particular was one of the biggest achievements of the CDPC to date”*. And Enabling Sub-Units were reported to have the opinion *“there were generally high levels of satisfaction regarding the consumers and industry enabling sub-units”*. With a 55.1% Very Satisfied (3rd highest to Chief Inv. and Team Members) rating for the Consumer Enabling Sub-Unit (23.02% increase on 2015 rating).

CONSUMER NETWORK ACKNOWLEDGEMENTS

The continuing support for Consumer Network member involvement in the CDPC by Dementia Australia (formerly Alzheimer’s Australia) through its Funding Partner arrangement with the NHMRC, since 2012 is appreciated. We continue to be indebted to the vision of Glenn Rees, Ellen Skladzien, and Chris Hatherly in embarking on this Partnership arrangement and their proactive support for consumer involvement from the beginning in 2012.

Appreciation is expressed for the Chief Investigator Professor Susan Kurrel for welcoming the involvement of Dementia Australia Consumer Network members and other consumers and continuing to actively support their involvement through each year of the CDPC’s growth and development.

The contribution of time, effort, skills and experience from all the consumers who choose to continue their voluntary involvement in the work of the CDPC is generous and unique in the sustainability and commitment the consumers have demonstrated with their involvement. Special mention is deserved for **Val Jenner**, who was caught up in the 2017 NZ floods and along with many others had to be rehomed. But through this, Val still made time as she was able, to continue her contribution to the work of the CDPC. A reflection perhaps of the commitment the Consumer Network members consistently demonstrate in wanting to

make a difference to the lives of people with Dementia and the people who share their lives.

Researchers, Industry Partners and Consumer Network members continue to learn a great deal from each other through the experiences we share in working with this *first* NHMRC Partnership Centre. We look forward to seeing the *impact* of what we have learned about effective collaboration in research in the next and final year of our work together in 2018, 2019, and as reflected in the impact we will have hopefully made in

improving the lives of people with Dementia.

Our appreciation to Dementia Australia and the CDPC for continuing to support consumers in ensuring that in researching about Dementia, there is

Nothing About Us – Without Us!

NNIDR PRIORITIES - CDPC ALIGNMENT
Living with Dementia (8 CDPC Activities)
Prevention (0 CDPC Activities)
Assessment Diagnosis (6 CDPC Activities)
Intervention Treatment (7 CDPC Activities)
Care (20 CDPC Activities)

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NHMRC/CDPC OBJECTIVE: COLLABORATIVE NEW RESEARCH		
CDPC 1301	Long Term Care Configurations	In Conduct
CDPC 1307	Regulation of Aged Care Services - Effects	Completed
CDPC 1306	Financial Institution Policies / Practices	Completed
CDPC 1311	Quality Use of Medicines	In Conduct
CDPC 1316	Healthy Ageing in Australian Physicians	Completed
CDPC 1317	Psychosocial Impact of Having a Parent with Dementia	Completed
CDPC 1318	Dementia in the Public Domain	In Conduct
CDPC 1319	Understanding risk and preventing falls and functional decline in older people	In Conduct
CDPC 1325	Consumer Journey Modeling – Ideal State Project	Completed
CDPC 1333	Validating and evaluating a quality of life instrument for people with dementia.	In Conduct

NHMRC/CDPC OBJECTIVE: SYNTHESIS AND DISSEMINATION		
CDPC 1310	Supporting and Caring for Residential Care Staff	Completed
CDPC 1313	National Australian Dementia Guidelines	Completed
CDPC 1305	National Advance Care Planning	Completed
CDPC 1303	Key Worker Role	Completed
CDPC 1308	Living with Dementia in the Community	Completed
CDPC 1314	Primary Care Consensus Guide	Completed
CDPC 1410	Policy & Legislation Knowledge Mobilisation NHMRC Partnership Centres Workshop 2017	Completed

NHMRC/CDPC OBJECTIVE: CAPACITY BUILDING		
CDPC 1309	Evaluation of Inter-Professional Education (IPE) in Residential Aged Care	Completed
CDPC 1315	Modelling for Estimation of Cost Effectiveness of Aged Care	Completed
CDPC 1401	Change Management Workshop 2014	Completed
CDPC 1402	Health Economics Workshop 2014	Completed
CDPC 1408	Policy Engagement Workshop 2015	Completed
CDPC 1409	Technology and Telehealth Workshop 2016	Completed
CDPC 1411	Health Economic Evaluation Workshop 2017	Completed
CDPC 1412	NHMRC Partnership Centres, Measuring the Impact of Research Guest Lecture - Trisha Greenhalgh, Anne Kelso - March 2018	Approved
CDPC 1413	Management of Change and Workforce Enabling Sub-Unit, Implementation and Sustainability Workshop - February 2018	Approved
CDPC 1306 affiliated	Financial Institution Policies / Practices - COTA Seminar Series 2017/2018. Supported by CDPC Policy & Legislation Enabling Sub-Unit	In Conduct

NHMRC/CDPC OBJECTIVE: IMPLEMENTATION		
CDPC 1322	Improving residential dementia care through staff	In Conduct
CDPC 1327	National Australia Dementia Guidelines Implementation - the use of 'audit and feedback' to improve care	In Conduct
CDPC 1324	Supported Decision Making in Dementia Care	In Conduct
CDPC 1302	Confused Hospitalised Older Persons Study (CHOPS)	Completed
CDPC 1304	Alternative Respite Models	Completed
CDPC 1312	Implementation of Vit-D Supplements in Residential Aged Care Facilities	Completed
CDPC 1320	Telehealth Enabled Prescribing in Dementia	In Conduct
CDPC 1321	Implementing Care of Older Persons with Dementia (COPE) in Australia	In Conduct
CDPC 1326	Dementia Delirium Care with Volunteers	Completed
CDPC 1328	Implementing and embedding interprofessional learning, education and practice across the aged care sector	Completed
CDPC 1329	Implementation Evaluation - Exercise Prescription (EP) in Aged Care Project	In Conduct
CDPC 1330	Innovation Research - understanding human-robot interaction	Completed
CDPC 1337	Development of Dementia Reablement Guidelines and Programs	In Conduct
CDPC 1338	Intervene Stage 2 – Pain management - best practice in residential aged care	In Conduct

CDPC Activity Listing 1 January 2017 - 31 December 2017

Completed CDPC Activity n=25	Name	Start Date	End Date	Status	Funded Institution and Investigators	Funded State	Primary Objective
CDPC 1302	Confused Hospitalised Older Persons Study (CHOPS)	01-Jul-13	31-Dec-15	Completed	Agency for Clinical Innovation Prof. Susan Kurrle	NSW	Implementation of Research Informed Change
CDPC 1303	Key Worker Role	13-Jan-14	31-Dec-16	Completed	Royal District Nursing Service Dr. Susan Koch	VIC	Synthesis and Dissemination
CDPC 1304	Alternative Respite Models	13-Jan-14	12-Apr-16	Completed	Royal District Nursing Service Dr. Susan Koch; Ms. Megan Corlis; Ms. Carolyn Curtis	SA	Implementation of Research Informed Change
CDPC 1305	National Advance Care Plan	13-Jan-14	31-Mar-17	Completed	HammondCare Prof. Meera Agar	NSW	Synthesis and Dissemination
CDPC 1306	Financial Institution Policies / Practices	13-Jan-14	12-Jan-15	Completed	Western Sydney University Ms. Sue Field	NSW	Collaborative New Research
CDPC 1307	Regulation of Aged Care Services – Effects	13-Jan-14	31-Dec-17	Completed	University of Melbourne Prof. Simon Biggs	VIC	Collaborative New Research
CDPC 1308	Living with Dementia in the Community	13-Jan-14	30-Jun-16	Completed	University of Newcastle Prof. Dimity Pond	SA	Synthesis and Dissemination
CDPC 1309	Evaluation of IPE in Residential Aged Care	01-Feb-13	31-Jan-16	Completed	Brightwater Care Group Ms. Karla Seaman; Dr. Mike Bird	WA	Capacity Building
CDPC 1310	Supporting and Caring for Residential Care Staff	01-Jul-13	30-Jun-15	Completed	Southern NSW Local Health District Dr. Katrina Anderson	NSW	Synthesis and Dissemination
CDPC 1312	Implementation of Vit-D Supplements in Residential Aged Care Facilities	13-Jan-14	30-Sep-17	Completed	University of Sydney Prof. Ian Cameron	NSW	Implementation of Research Informed Change
CDPC 1313	National Australian Dementia Guidelines	13-Jan-14	30-Sep-17	Completed	Flinders University Prof. Maria Crotty; A/Prof Craig Whitehead	SA	Synthesis and Dissemination
CDPC 1314	Primary Care Consensus Guide	13-Jan-14	30-Jun-17	Completed	University of Newcastle Prof. Dimity Pond	NSW	Synthesis and Dissemination

Completed CDPC Activity n=25	Name	Start Date	End Date	Status	Funded Institution and Investigators	Funded State	Primary Objective
CDPC 1315	Modelling for Estimation of Cost Effectiveness of Aged Care	13-Jan-14	12-Jun-16	Completed	Griffith University Dr. Tracy Comans; Mr. Lachlan Standfield	QLD	Capacity Building
CDPC 1316	Healthy Ageing in Australian Physicians	13-Jan-14	12-Jan-15	Completed	University of Sydney Prof. Susan Kurrle; Dr. Narelle Shadbolt	NSW	Collaborative New Research
CDPC 1317	Psychosocial Impact of Having a Parent with Dementia	13-Jan-14	13-Apr-15 (Extension approved to commence 2018)	Completed	University of Sydney Prof. Susan Kurrle; A/Prof Christopher Roberts; Ms. Karen Hutchinson	NSW	Collaborative New Research
CDPC 1325	Consumer Journey Modelling - Ideal State Project	1-Jul-16	30-Apr-17	Completed	Griffith University Prof. Anneke Fitzgerald	QLD	Collaborative New Research
CDPC 1326	Dementia Delirium Care with Volunteers	01-Mar-15	30-Nov-17	Completed	Southern NSW Local Health District Dr. Katrina Anderson; Ms. Cath Bateman; Ms. Annaliese Blair	NSW	Implementation of Research Informed Change
CDPC 1328	Implementing and Embedding Interprofessional Learning, Education and Practice (IPE) Across the Aged Care Sector	12-Apr-16	17-Jul-17	Completed	Brightwater Care Group Dr Angelita Martini	WA	Implementation of Research Informed Change
CDPC 1330	Do socialisation robots facilitate increase social engagement in aged care?	1-Aug-16	17-Jul-17	Completed	Brightwater Care Group Dr Angelita Martini	WA	Implementation of Research Informed Change
CDPC 1401	Change Management Workshop	07-Feb-14	19-Aug-14	Completed	Prof. Anneke Fitzgerald Management of Change & Workforce Enabling Sub-Unit	QLD	Capacity Building
CDPC 1402	Health Economics Workshop	12-Apr-14	13-Apr-14	Completed	Dr. Tracy Comans Health Economics Enabling Sub-Unit	QLD	Capacity Building
CDPC 1408	Policy Engagement Workshop	n/a	23-Feb-15	Completed	Ms. Anne Cumming Policy & Legislation Enabling Sub-Unit	NSW	Capacity Building

Completed CDPC Activity n=25	Name	Start Date	End Date	Status	Funded Institution and Investigators	Funded State	Primary Objective
CDPC 1409	Technology & Telehealth Workshop	n/a	09-May-16	Completed	Prof. Len Gray Technology & Telehealth Enabling Sub-Unit	QLD	Capacity Building
CDPC 1410	Policy & Legislation Knowledge Mobilisation Workshop	n/a	30-Mar-17	Completed	Ms. Anne Cumming Policy & Legislation Enabling Sub-Unit	NSW	Synthesis & Dissemination
CDPC 1411	Health Economic Evaluation Workshop	n/a	15-Jun-17	Completed	Dr. Tracy Comans Health Economics Enabling Sub-Unit	QLD	Capacity Building
In Conduct CDPC Activity n=13	Name	Start Date	End Date	Status	Funded Institution and Investigators	Funded State	Primary Objective
CDPC 1301	Long Term Care Configurations	13-Jan-14	31-Dec-18	In Conduct	Flinders University Prof. Maria Crotty	SA	Collaborative New Research
CDPC 1306 affiliated	Financial Institution Policies and Practices – COTA Seminar Series 2017/1028. Supported by CDPC Policy & Legislation Enabling Sub- Unit	23-Nov-17	07-May-18	In Conduct	N/A – contracted provider	N/A	Capacity Building
CDPC 1311	Quality Use of Medicines	13-Jan-14	12-Jan-19	In Conduct	University of Sydney / Monash University Prof. Sarah Hilmer; A/Prof Simon Bell	NSW / VIC	Collaborative New Research
CDPC 1318	Dementia in the Public Domain	1-Jan-16	31-Dec-18	In Conduct	University of Melbourne Prof. Simon Biggs	VIC	Collaborative New Research
CDPC 1319	Understanding risk and preventing falls and functional decline in older people	01-Jul-15	31-Dec-18	In Conduct	University of Sydney Prof. Jacqui Close; Dr. Morag Taylor; Prof. Susan Kurrle	NSW	Collaborative New Research
CDPC 1320	Telehealth Enabled Prescribing in Dementia	1-Jan-16	31-Dec-18	In Conduct	University of Queensland Prof. Len Gray	QLD	Implementation of Research Informed Change
CDPC 1321	Implementing Care of Older Persons with Dementia (COPE) in Australia	31-Mar-16	31-Dec-18	In Conduct	University of Sydney / Flinders University Prof. Lindy Clemson	NSW	Implementation of Research Informed Change
CDPC 1322	Supporting and Caring for Residential Care Staff (extension)	1-Oct-16	31-Dec-18	In Conduct	Southern NSW Local Health District Dr. Katrina Anderson	NSW	Implementation of Research Informed Change

Completed CDPC Activity n=25	Name	Start Date	End Date	Status	Funded Institution and Investigators	Funded State	Primary Objective
CDPC 1324	Supported Decision Making in Dementia Care	1-Jan-16	31-Dec-18	In Conduct	The University of Western Australia Dr. Craig Sinclair	WA	Implementation of Research Informed Change
CDPC 1327	National Quality Collaborative (Activity 13 extension – Guidelines Implementation – use of audit and feedback to improve care)	01-Sep-17	31-Dec-18	In Conduct	Flinders University Dr. Kate Laver	SA	Implementation of Research Informed Change
CDPC 1329	Implementation Evaluation - Exercise Prescription (EP) in Aged Care Project	1-Apr-16	31-Dec-18	In Conduct	Helping Hand Aged Care Ms. Megan Corlis	SA	Implementation of Research Informed Change
CDPC 1333	Validating and evaluating a quality of life (QOL) instrument for people with dementia	15-Sep-16	15-Nov-18	In Conduct	Griffith University (to 31-Oct-17) now University of Queensland (from 01-Nov-17) Dr. Tracy Comans	QLD	Collaborative New Research
CDPC 1337	Development of evidence-based Dementia Reablement Guidelines and Programs deliverable to people with early – moderate dementia.	16-Jan-17	31-May-18	In Conduct	Hammondcare Prof. Christopher Poulos	NSW	Implementation of Research Informed Change
CDPC 1338	Intervene Stage 2 - Pain management - best practice in residential aged care	1-Nov-16	31-Oct-18	In Conduct	Hammondcare Prof. Colm Cunningham	NSW	Implementation of Research Informed Change
Proposal and Budget Fully Approved CDPC Activity n=2	Name	Start Date	End Date	Status	Funded Institution and Investigators	Funded State	Primary Objective
CDPC 1412	NHMRC Partnership Centres, Measuring the Impact of Research Guest Lecture – Trisha Greenhalgh, Anne Kelso	19-Mar-18	19-Mar-18	Approved	Ms Anne Cumming Policy & Legislation Enabling Sub-Unit	NSW	Capacity Building
CDPC 1413	Implementation and Sustainability Workshop	22-Feb-18	23-Feb-18	Approved	Prof. Anneke Fitzgerald Management of Change & Workforce Enabling Sub-Unit	QLD	Capacity Building

CDPC PEER-REVIEWED PUBLICATIONS TO 31 DECEMBER 2017 (n=58)

1. **Stasinopoulos, J., Bell, J. S., Ryan-Atwood, T. E., Tan, E. C., Ilomäki, J., Cooper, T., ... & Sluggett, J. K.** (2017). Frequency of and factors related to pro re nata (PRN) medication use in aged care services. *Research in Social and Administrative Pharmacy*, doi.org/10.1016/j.sapharm.2017.11.004 [\[More Information\]](#)
2. **Nguyen, K. H., Sellars, M., Agar, M., Kurrle, S., Kelly, A., & Comans, T.** (2017). An economic model of advance care planning in Australia: a cost-effective way to respect patient choice. *BMC health services research*, 17(1), 797. [\[More Information\]](#)
3. **Hutchinson, K., Roberts, C., & Daly, M.** (2017). Identity, impairment and disablement: exploring the social processes impacting identity change in adults living with acquired neurological impairments. *Disability & Society*, 1-22. [\[More Information\]](#)
4. **Milte, R., Ratcliffe, J., Chen, G., & Crotty, M.** (2017). What Characteristics of Nursing Homes Are Most Valued by Consumers? A Discrete Choice Experiment with Residents and Family Members. *Value in Health*. [\[More Information\]](#)
5. **Dyer, S. M., Harrison, S. L., Laver, K., Whitehead, C., & Crotty, M.** (2017). An overview of systematic reviews of pharmacological and non-pharmacological interventions for the treatment of behavioral and psychological symptoms of dementia. *International psychogeriatrics*, 1-15. [\[More Information\]](#)
6. **Ratcliffe, J., Flint, T., Easton, T., Killington, M., Cameron, I., Davies, O., ... & Crotty, M.** (2017). An empirical comparison of the EQ-5D-5L, DEMQOL-U and DEMQOL-Proxy-U in a post-hospitalisation population of frail older people living in residential aged care. *Applied health economics and health policy*, 15(3), 399-412. [\[More Information\]](#)
7. **Liu, E., Dyer, S. M., O'Donnell, L. K., Milte, R., Bradley, C., Harrison, S. L., ... & Crotty, M.** (2017). Association of cardiovascular system medications with cognitive function and dementia in older adults living in nursing homes in Australia. *Journal of geriatric cardiology: JGC*, 14(6), 407. [\[More Information\]](#)
8. **Taylor, M. E., Lasschuit, D. A., Lord, S. R., Delbaere, K., Kurrle, S. E., Mikolaizak, A. S., ... & Close, J. C.** (2017). Slow gait speed is associated with executive function decline in older people with mild to moderate dementia: A one year longitudinal study. *Archives of gerontology and geriatrics*, 73, 148-153. [\[More Information\]](#)
9. **Milte, R., Ratcliffe, J., Bradley, C., Shulver, W., & Crotty, M.** (2017). Evaluating the quality of care received in long-term care facilities from a consumer perspective: development and construct validity of the Consumer Choice Index–Six Dimension instrument. *Ageing & Society*, 1-23. [\[More Information\]](#)
10. **Walker, P., Miller Amberber, A., Kurrle, S., Kifley, A., Cameron, I.** (2017). Prevalence of vitamin D supplement use in Australian residential aged care facilities in November 2014. *BMC Research Notes*. [\[More Information\]](#)
11. **Standfield, L. B., Comans, T., & Scuffham, P.** (2017). A simulation of dementia epidemiology and resource use in Australia. *Australian and New Zealand Journal of Public Health*. [\[More Information\]](#)
12. **Milte, R., Shulver, W., Killington, M., Bradley, C., Miller, M., & Crotty, M.** (2017). Struggling to maintain individuality—describing the experience of food in nursing homes for people with dementia. *Archives of Gerontology and Geriatrics*. 72, 52-58 [\[More Information\]](#)
13. **Freeman, C. R., Peel, N. M., Watts, J. N., Gaeae-Atefi, T. A., Caffery, L. J., Hubbard, R. E., ... & Gray, L. C.** (2017). Development of a protocol for telehealth Residential Medication Management Reviews to enable collaboration of pharmacists and geriatricians. *Journal of Pharmacy Practice and Research*, 47(2), 153-157. [\[More Information\]](#)
14. **Sluggett, J. K., Hendrix, I., & Bell, J. S.** (2017). Evidence-based deprescribing of protein pump inhibitors in long-term care. [\[More Information\]](#)

15. **Reeve, E., Trenaman, S. C., Rockwood, K., & Hilmer, S. N.** (2017). Pharmacokinetic and pharmacodynamic alterations in older people with dementia. *Expert opinion on drug metabolism & toxicology*, 13(6), 651-668. [\[More Information\]](#)
16. **Reeve, E., Ong, M., Wu, A., Jansen, J., Petrovic, M., & Gnjjidic, D.** (2017). A systematic review of interventions to deprescribe benzodiazepines and other hypnotics among older people. *European journal of clinical pharmacology*, 73(8), 927-935. [\[More Information\]](#)
17. **Easton, T., Milte, R., Crotty, M., & Ratcliffe, J.** (2017). Where's the evidence? a systematic review of economic analyses of residential aged care infrastructure. *BMC Health Services Research*, 17(1), 226. [\[More Information\]](#)
18. **Sluggett, J. K., Ilomäki, J., Seaman, K. L., Corlis, M., & Bell, J. S.** (2017). Medication management policy, practice and research in Australian residential aged care: Current and future directions. *Pharmacological Research*, 116, 20-28. [\[More Information\]](#)
19. **Taylor, M. E., Lord, S. R., Delbaere, K., Kurrle, S. E., Mikolaizak, A. S., & Close, J. C.** (2017). Reaction time and postural sway modify the effect of executive function on risk of falls in older people with mild to moderate cognitive impairment. *The American Journal of Geriatric Psychiatry*, 25(4), 397-406. [\[More Information\]](#)
20. **Farrer, O., Yaxley, A., Walton, K., Milte, R., & Miller, M.** (2017). The 'diabetic diet': a web based survey for determining the incidence, rationale, composition and implications in residential aged care facilities. *Journal of Nursing Home Research*, 3, 50-53. [\[More Information\]](#)
21. **Nguyen, K. H., Mulhern, B., Kularatna, S., Byrnes, J., Moyle, W., & Comans, T.** (2017). Developing a dementia-specific health state classification system for a new preference-based instrument AD-5D. *Health and Quality of Life Outcomes*, 15(1), 21. [\[More Information\]](#)
22. **Reeve, E., Thompson, W., & Farrell, B.** (2017). Deprescribing: A narrative review of the evidence and practical recommendations for recognizing opportunities and taking action. *European journal of internal medicine*, 38, 3-11. [\[More Information\]](#)
23. **Chan, B., Reeve, E., Matthews, S., Carroll, P. R., Long, J. C., Held, F., ... & Hilmer, S. N.** (2017). Medicine information exchange networks among healthcare professionals and prescribing in geriatric medicine wards. *British journal of clinical pharmacology*, 83(6), 1185-1196. [\[More Information\]](#)
24. **Seaman, K., Saunders, R., Williams, E., Harrup-Gregory, J., Loffler, H., & Lake, F.** (2017). An examination of students' perceptions of their interprofessional placements in residential aged care. *Journal of Interprofessional Care*, 31(2), 147-153. [\[More Information\]](#)
25. **Taylor, M. E., Lord, S. R., Brodaty, H., Kurrle, S. E., Hamilton, S., Ramsay, E., ... & Close, J. C.** (2017). A home-based, carer-enhanced exercise program improves balance and falls efficacy in community-dwelling older people with dementia. *International Psychogeriatrics*, 29(1), 81-91. [\[More Information\]](#)
26. **Kouladjian O'Donnell, L., Gnjjidic, D., Nahas, R., Bell, J. S., & Hilmer, S. N.** (2016). Anticholinergic burden: considerations for older adults. *Journal of Pharmacy Practice and Research*. [\[More Information\]](#)
27. **Lalic, S., Sluggett, J. K., Ilomäki, J., Wimmer, B. C., Tan, E. C., Robson, L., ... & Bell, J. S.** (2016). Polypharmacy and Medication Regimen Complexity as Risk Factors for Hospitalization Among Residents of Long-Term Care Facilities: A Prospective Cohort Study. *Journal of the American Medical Directors Association*, 17(11), 1067-e1. [\[More Information\]](#)
28. **Jamsen, K. M., Gnjjidic, D., Hilmer, S. N., Ilomäki, J., Le Couteur, D. G., Blyth, F. M., ... & Bell, J. S.** (2016). Drug Burden Index and change in cognition over time in community-dwelling older men: the CHAMP study. *Annals of Medicine*, 1-8. [\[More Information\]](#)
29. **Dyer, S. M., Laver, K., Pond, C. D., Cumming, R. G., Whitehead, C., & Crotty, M.** (2016). Clinical practice guidelines and principles of care for people with dementia in Australia. *Australian family physician*, 45(12), 884. [\[More Information\]](#)
30. **Taylor, M. E., Lord, S. R., Delbaere, K., Kurrle, S. E., Mikolaizak, A. S., & Close, J. C.** (2016). Reaction Time and Postural Sway Modify the Effect of Executive Function on Risk of Falls in Older People with Mild to Moderate Cognitive Impairment. *The American Journal of Geriatric Psychiatry*, [\[More Information\]](#)

31. **Perimal-Lewis, L., Bradley, C., Hakendorf, P. H., Whitehead, C., Heuzenroeder, L., & Crotty, M.** (2016). The relationship between in-hospital location and outcomes of care in patients diagnosed with dementia and/or delirium diagnoses: analysis of patient journey. *BMC Geriatrics*, 16(1), 190. [\[More Information\]](#)
32. **Easton, T., Milte, R., Crotty, M., & Ratcliffe, J.** (2016). Advancing aged care: a systematic review of economic evaluations of workforce structures and care processes in a residential care setting. *Cost Effectiveness and Resource Allocation*, 14(1), 12. [\[More Information\]](#)
33. **Goeman, D., Comans, T., Enticott, J. C., Renehan, E., Beattie, E., Kurrle, S., & Koch, S.** (2016). Evaluating the Efficacy of the “Support for Life” Program for People with Dementia and Their Families and Carers’ to Enable Them to Live Well: A Protocol for a Cluster Stepped Wedge Randomized Controlled Trial. *Frontiers in Public Health*, 4. [\[More Information\]](#)
34. **Laver, K., Cumming, R., Dyer, S., Agar, M., Anstey, K. J., Beattie, E., ... & Dietz, M.** (2016). Evidence-based occupational therapy for people with dementia and their families: What clinical practice guidelines tell us and implications for practice. *Australian Occupational Therapy Journal*. [\[More Information\]](#)
35. **Dyer, S. M., Flicker, L., Laver, K., Whitehead, C., & Cumming, R.** (2016). The clinical value of fluid biomarkers for dementia diagnosis. *The Lancet. Neurology*, 15(12), 1204. [\[More Information\]](#)
36. **Dyer, S. M., Crotty, M., Fairhall, N., Magaziner, J., Beaupre, L. A., Cameron, I. D., & Sherrington, C.** (2016). A critical review of the long-term disability outcomes following hip fracture. *BMC Geriatrics*, 16(1), 158. [\[More Information\]](#)
37. **Killington, M., Walker, R., & Crotty, M.** (2016). The chaotic journey: Recovering from hip fracture in a nursing home. *Archives of Gerontology and Geriatrics*, 67, 106-112. [\[More Information\]](#)
38. **Laver, K., Milte, R., Dyer, S., & Crotty, M.** (2016). A Systematic Review and Meta-Analysis Comparing Carer Focused and Dyadic Multicomponent Interventions for Carers of People With Dementia. *Journal of Aging and Health*. [\[More Information\]](#)
39. **Goeman, D., Renehan, E., & Koch, S.** (2016). What is the effectiveness of the support worker role for people with dementia and their carers? A systematic review. *BMC Health Services Research*, 16(1), 285. [\[More Information\]](#)
40. **Bird, M., Anderson, K., MacPherson, S., & Blair, A.** (2016). Do interventions with staff in long-term residential facilities improve quality of care or quality of life people with dementia? A systematic review of the evidence. *International Psychogeriatrics*, 28 (12) 1937-1963. [\[More Information\]](#)
41. **Hilmer, S. N.** (2016). Strategies to reduce medication errors. [More Information](#)
42. **Reeve, E., Low, L. F., & Hilmer, S. N.** (2016). Beliefs and attitudes of older adults and carers about deprescribing of medications: a qualitative focus group study. *Br J Gen Pract*, 66 (649) e561-e567. [\[More Information\]](#)
43. **Laver, K., Dyer, S., Whitehead, C., Clemson, L., & Crotty, M.** (2016). Interventions to delay functional decline in people with dementia: a systematic review of systematic reviews. *BMJ open*, 6(4), e010767. [\[More Information\]](#)
44. **Laver, K.** (2016). Clinical Practice Guidelines for Dementia in Australia: A step towards improving uptake of research findings in health and aged care settings. *Australasian journal on ageing*. [\[More Information\]](#)
45. **Lalic, S., Jansen, K. M., Wimmer, B. C., Tan, E. C., Hilmer, S. N., Robson, L., ... & Bell, J. S.** (2016). Polypharmacy and medication regimen complexity as factors associated with staff informant rated quality of life in residents of aged care facilities: a cross-sectional study. *European journal of clinical pharmacology*, 72(9), 1117-1124. [\[More Information\]](#)
46. **Hutchinson, K., Roberts, C., Daly, M., Bulsara, C., & Kurrle, S.** (2016). Empowerment of young people who have a parent living with dementia: a social model perspective. *International Psychogeriatrics*, 28(04), 657-668. [\[More Information\]](#)
47. **Anderson, K., Bird, M., MacPherson, S., & Blair, A.** (2016). How do staff influence the quality of long-term dementia care and the lives of residents? A systematic review of the evidence. *International Psychogeriatrics*, 28(8) 1263-1281. [\[More Information\]](#)

48. **Laver, K., Cumming, R. G., Dyer, S. M., Agar, M. R., Anstey, K. J., Beattie, E., ... & Dietz, M.** (2016). Clinical practice guidelines for dementia in Australia. *Med J Aust*, 204(5), 191-193. [\[More Information\]](#)
49. **Jansen, K. M., Bell, J. S., Hilmer, S. N., Kirkpatrick, C. M., Ilomäki, J., Le Couteur, D., ... & Cumming, R. G.** (2016). Effects of Changes in Number of Medications and Drug Burden Index Exposure on Transitions Between Frailty States and Death: The Concord Health and Ageing in Men Project Cohort Study. *Journal of the American Geriatrics Society*, 64(1), 89-95. [\[More Information\]](#)
50. **Jansen, K. M., Ilomäki, J., Hilmer, S. N., Jokanovic, N., Tan, E. C., & Bell, J. S.** (2016). A systematic review of the statistical methods in prospective cohort studies investigating the effect of medications on cognition in older people. *Research in Social and Administrative Pharmacy*, 12(1), 20-28. [\[More Information\]](#)
51. **Milte, R., Shulver, W., Killington, M., Bradley, C., Ratcliffe, J., & Crotty, M.** (2016). Quality in residential care from the perspective of people living with dementia: The importance of personhood. *Archives of Gerontology and Geriatrics*, 63, 9-17. [\[More Information\]](#)
52. **Reeve, E., Simon Bell, J., & N Hilmer, S.** (2015). Barriers to optimising prescribing and deprescribing in older adults with dementia: A narrative review. *Current Clinical Pharmacology*, 10(3), 168-177. [\[More Information\]](#)
53. **Bell, S., J., Kurrle, S., & N Hilmer, S.** (2015). Editorial (Thematic Issue: Medication Management for People with Dementia or Cognitive Impairment). *Current Clinical Pharmacology*, 10(3), 166-167. [\[More Information\]](#)
54. **Reeve, E., Gnjdic, D., Long, J., & Hilmer, S.** (2015). A systematic review of the emerging definition of 'deprescribing' with network analysis: implications for future research and clinical practice. *British Journal of Clinical Pharmacology*, 80(6), 1254-1268. [\[More Information\]](#)
55. **Scott, I. A., Hilmer, S. N., Reeve, E., Potter, K., Le Couteur, D., Rigby, D., ... & Jansen, J.** (2015). Reducing inappropriate polypharmacy: the process of deprescribing. *JAMA Internal Medicine*, 175(5), 827-834. [\[More Information\]](#)
56. **Seaman, K. L., Bulsara, C. E., & Saunders, R. D.** (2015). Interprofessional learning in residential aged care: providing optimal care for residents. *Australian Journal of Primary Health*, 21(3), 360-364. [\[More Information\]](#)
57. **Tan, E. C., Visvanathan, R., Hilmer, S. N., Vitry, A. I., Quirke, T., Emery, T., ... & Reeve, E.** (2014). Analgesic use, pain and daytime sedation in people with and without dementia in aged care facilities: a cross-sectional, multisite, epidemiological study protocol. *BMJ open*, 4(6), e005757. [\[More Information\]](#)
58. **Hutchinson, K., Roberts, C., Kurrle, S., & Daly, M.** (2014). The emotional well-being of young people having a parent with younger onset dementia. *Dementia*, 1471301214532111. [\[More Information\]](#)

CDPC PLANNED IMPACTS

Original impacts identified during strategic meetings in 2014

1. Aged care providers and health decision makers throughout Australia will have a measure of the real cost of providing care to people with dementia, enabling them to plan services and shape policy more effectively and efficiently.
2. The Centre will evaluate and develop plans to inform the implementation of new guidance and respite models in multiple locations throughout Australia that will assist informal and family carers to identify appropriate care options and pathways.
3. Participating financial, legal and health institutions in a range of locations will adopt uniform policies & practices, enabling & empowering staff to respect & uphold the wishes of older people with cognitive decline who have used substitute decision-making instruments.
4. Government and senior decision makers will have tools and resources for changing attitudes to dementia and cognitive decline, increasing general awareness and promoting greater acceptance.
5. Aged care providers and healthcare organisations will have evidence-based tools and strategies to build and develop their workforces to meet the growing demand for care and services for people with cognitive decline.
6. Aged care providers and health decision makers will have evidence on the factors that make regulations for the management of cognitive decline, either effective or ineffective.
7. Aged care and health organisations around Australia will have tools and implementation strategies for improving medication management practices for older people with cognitive decline.
8. Health professionals and carers in primary care, aged care and hospital settings will have access to meaningful clinical guidelines reflecting current evidence on dementia care, enabling them to identify and respond to the condition more effectively.
9. The Centre will manage and evaluate the implementation of proven care and service models in health and aged care contexts, improving care outcomes for older people with cognitive decline.

Additional impacts identified during the lifespan of the CDPC

Government, senior decision makers, and other players in the policy space in Australia and internationally will have evidence based recommendations to inform policy.

People with dementia, and their carers, are given opportunities to share the “lived experience” and are embedded into all stages of the research process to ensure research has validity and authenticity.