

# 2018 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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**This report covers the period 1 January 2018 – 31 December 2018**

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## DIRECTOR OVERVIEW



Thank you for making time to read our Annual Report for 2018.

In this 5<sup>th</sup> year of existence the Centre continued to consolidate its position as a funder of dementia care research that has the potential to impact the care of people with dementia in Australia very positively.

Our team's work on disseminating research evidence, outcomes and resources has increased and continues as the primary focus, of our Directorate team.

It has been pleasing to see a number of our research projects moving from development of evidence through into implementation of evidence-based change in systems and processes. We are, for the second year, providing examples from the stories we have received that give evidence to our real impact across our four NHMRC Objectives and nine planned impacts.

Our Directorate team is now working towards the finalisation of the Centre at 31 December 2019 in continued partnership with our funding and research partners, and we believe that we will complete the work of the Centre having left a positive mark on dementia care and dementia care research in Australia.



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

### **2018 Story of Impact: Implementation of Research-Informed Change**

#### **IMPACT**

There has been implementation of care and service models in health/aged care contexts, improving care outcomes for older people with cognitive decline

#### **CDPC ACTIVITY 1304 – EVALUATION OF ALTERNATIVE RESPITE MODELS (WEAVERS)**

The WEAVERS model has now been implemented in communities in Queensland, New South Wales, Victoria, Western Australia, Tasmania and New Zealand.

#### **CDPC ACTIVITY 1321 - IMPLEMENTING COPE IN AUSTRALIA**

Montefiore have implemented COPE across two sites under their Help@Home program, with confirmation that they plan to continue to feature COPE as part of the suite of programs available.

### **2018 Story of Impact: Synthesis and Dissemination of Existing Research**

#### **IMPACT**

Health professionals and carers in primary care, aged care and hospital settings have 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 GUIDELINES FOR CARE OF PEOPLE WITH DEMENTIA**

DBMAS Hunter New England and Canberra staff have copies of the Guidelines and Consumer Booklet on their desks as a reference.

The Australian Aged Care Quality Agency implemented the Clinical Guidelines as a reference / resource under Aged Care Quality Standard 3 and as a Guidance Resource. (August 2018)

The New England North West LHD/PHN resource "Dementia Care Information" booklet includes the Guidelines as a recommended resource.

### **2018 Story of Impact: Collaborative New Research**

#### **IMPACT**

The Centre has managed and evaluated the implementation of proven care and service models in health and aged care contexts, improving care outcomes for older people with cognitive decline.

#### **CDPC ACTIVITY 1301 – MODELS OF CARE**

Dementia Training Australia have embedded the Consumer Choice Index - 6 Dimensions (CCI-6D) as a national resource for estimating impact of tailored training packages for aged care providers.

South Australia Health have implemented the CCI-6D tool in a specialist psychogeriatric unit within a state-funded residential care facility.

### **2018 Story of Impact: Capacity Building**

#### **IMPACT**

There are 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 1324 – SUPPORTED DECISION-MAKING IN DEMENTIA CARE**

Churches of Christ in Queensland have implemented the Policy Development Guideline and resources into their in-house staff training programs and presentations.

Dementia Australia have embedded the Policy Development Guideline into Certificate IV in Dementia Practice.

#### **ACROSS ALL CDPC ACTIVITIES**

15,740 people were recorded as having attended capacity building training events in 2018.



## CDPC Directorate Summary

The NHMRC Partnership Centre: Dealing with Cognitive and Related Functional Decline in Older People (CDPC) six-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. By 31 December 2018 the CDPC's website listed 98 academic publications released, up from 58 at the end of 2017. In 2018 over 740 institutions were known to have implemented CDPC evidence into practice, and the CDPC's research evidence was represented in 141 training sessions, reaching 15,740 people.

Since the Centre's inception over 380 people have been involved across 32 research Activities and 11 synthesis and



dissemination workshops and initiatives, for a total of 43 CDPC funded research Activities and initiatives. During the Centre's six years of existence 74% (~16.5M) of the Centre's funds have directly supported research Activity teams; while 19% (~4.5M, ~750K/yr) has supported centralised administration and staffing of the Centre, which has included dissemination initiatives, the Dementia Australia Consumer Lead, and travel support for researchers and consumer advocates; and 7% (~1.6M, ~270K/yr) of CDPC funding has supported specialist Enabling Sub-Unit staff availability to liaise and consult with researchers and policy-makers to assist in strengthening the quality of research.

Building capacity in the workforce has remained an important part of CDPC funding, with 13 higher education (Masters and PhD) students identified as having been supported in some capacity by CDPC funds in 2018; up from just 3 students reported as supported in 2014.

In October 2018 a new Priority Setting Workshop was completed with additional \$136,040.00 of CDPC grant funds allocated to eight (8) of the CDPC research Activities to enable further dissemination and implementation initiatives and, with the aim of facilitating our research to positively impact the lives of people with dementia and their families and carers.

A 2019 Operations Strategic Plan was created in late 2018. This plan is being referenced throughout 2019 by the Directorate team and provides a good overview of developed resources, identified end-users for resources, and the evidence developed by all CDPC grant funded research Activities.

The CDPC's relationship with the NHMRC National Institute for Dementia Research (NNIDR) continued strongly, with the Director of the NNIDR remaining in the position of Chairperson for the CDPC Governance Authority as agreed by the CDPC Governance Authority members. The CDPC maintained its high profile during the NNIDR Annual National Dementia Forum in 2018 with a number of CDPC research teams presenting.

The CDPC during 2019 will be in the wind-down mode, after the NHMRC's decision to not refund the Centre for a further 5-year period. The Directorate team, in partnership with the Executive Committee, Governance Authority, researchers, partners, and consumers are working to maximise impact, and ensure outputs and resources are hosted elsewhere post 2019. Some examples of how we have performed against a selection of our nine (9) planned impacts in 2017 are provided on the previous page.

## Successes / Areas of Performance Strength and Strategic Position

The CDPC has continued to be a strong NHMRC Partnership Centre for Better Health, one of the three now in existence in Australia (<https://nhmrc.gov.au/research-policy/research-translation-and-impact/partnership-centres-better-health>) facilitating collaboration between government, industry partners, consumers and research institutions.

### QUALITY USE OF MEDICINES TO OPTIMISE AGEING IN OLDER AUSTRALIANS:

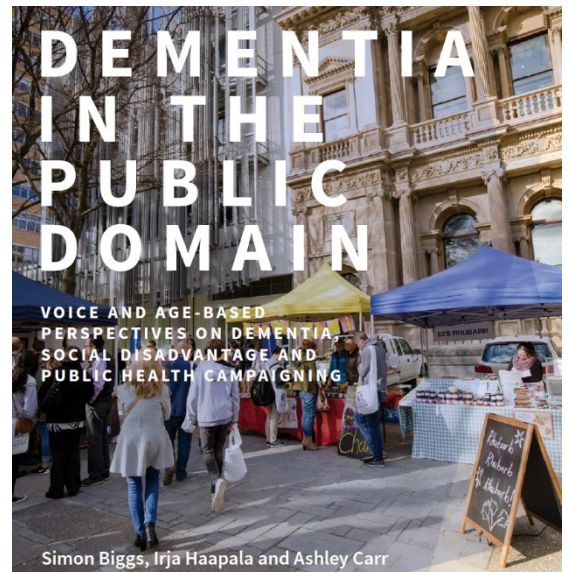
Recommendations for a National  
Strategic Action Plan to Reduce  
Inappropriate Polypharmacy



CDPC researchers, partners, including consumers, and Directorate team continue to develop and disseminate research-backed data and resources. During 2018, regular conversations 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 continue 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 continues to have the potential to greatly impact care for people with dementia in Australia. The CDPC Directorate have regularly received invitations to represent care research processes 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.





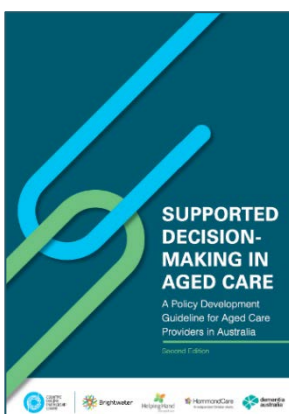
## COMMUNICATION

Creating and strengthening relationships with key stakeholders that provide an environment for sustainability of CDPC initiatives and interventions to improve the care of people living with dementia has been a major focus in 2018. As many of our projects completed their funding term, project teams have been busy producing targeted dissemination material. Detailed final reports, publications, workshops, brochures and policy briefs have been created to enhance engagement and increase the likelihood that research findings will influence service delivery and the current policy environment.



The CDPC understands the importance of demonstrating the impact or potential impact its program of work is having on clinical practice, service provision and health care policy. Throughout its funding term the CDPC has provided opportunities for CDPC members to understand the importance of demonstrating research impact and how to apply this in the research process. A collaborative special event with the Sax Institute, the Australian Prevention Partnership Centre, and the Centre for Health System Sustainability, brought the world-renowned public health expert and advocate for increasing the use of knowledge in healthcare policy and practice, Professor Trisha Greenhalgh OBE and NHMRC CEO Anne Kelso to present a public lecture on measuring research impact. This sold out event, at the University of Sydney, provided an opportunity to hear what it means to achieve research impact and how to measure it.

Co-production with our aged care industry partners and consumers has influenced the likelihood that many research findings will be implemented into practice. The release of the paper “Cluster models of residential aged care are associated with fewer hospitalisations and better quality of life: an Australian cross-sectional study” in the Medical Journal of Australia was the culmination of this 5-year project that examined smaller home-like models of care with standard residential aged care. This publication received substantial media attention with radio, TV interviews and numerous editorial pieces published within the aged care and broader public publications. The study is also informing into government policy on alternate care models in Australia.



The launch of a step-by-step guide “Supported Decision-Making in Aged Care: A Policy Development Guideline for Aged Care Providers in Australia” as a preliminary event to HammondCare’s Dementia Conference and subsequent education workshops across Australian aged care organisations highlights importance of supported decision-making for people with dementia. This is at the centre of the new Aged Care Quality Standards in Australia and is a cited resource by the Aged Care Quality and Safety Commission. Over 120 aged care staff have received the training in addition to two train the trainer workshops completed in NSW. The project team also produced a range of resources from consumer guides, videos and webinars to assist with embedding a culture of supported decision-making within our care system.

Collaboration with external organisations to facilitate implementation of CDPC findings was also a highlight in 2018. The CDPC and the Council on the Aged (COTA) linked to present a series of 12 seminars across regional

and rural NSW on the importance of understanding who you should appoint to make financial decisions for you if you are no longer able. Over 280 people attended the series many expressing they found the session extremely useful for future financial planning.

Several CDPC projects have delivered workshops to project team members, collaborators and invited interested parties. The workshops were an opportunity to present on research outcomes and provide interactive forums to assist in the formulation key recommendations and focus for final dissemination activities. Projects adopting this approach in 2018 included “Implementing and embedding IPE across the aged care sector”, “Validating and evaluating a quality of life instrument for people with dementia”, “Dementia in the Public domain” and “Implementing COPE in Australia.”



CDPC members continued to enhance the Centre’s profile as a leading research institute in dementia care with research presented at over 65 national and international conferences. In July - August 2018, several researchers, directorate staff, and consumers were supported by the CDPC to attend and present at the 33<sup>rd</sup> International Conference of Alzheimer’s Disease International (ADI) (Chicago), Alzheimer’s Association International Conference (Chicago), and the International Federation on Ageing (Toronto). The ADI conference included the premiere of the program “Every three seconds”, which highlighted innovation and action in the field of dementia. The program featured several of the CDPC research projects and available resources and was disseminated to an international audience.

Management-reporting deadlines, including finance reporting deadlines, continued to be met throughout 2018. Increased budget in 2018 for dissemination and implementation activities was expended on printing and distribution of CDPC resources. 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 in 2018**

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. By December 2018 the CDPC had disseminated 1393 total outputs, with 433 of those having been in 2018.

Throughout 2018, 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 several Activities coming to completion 2016/2017, presentation of evidence-based outputs in peer-reviewed/traditional outlets increased compared to the previous years (2015 = 83, 2016 = 96, 2017=121, 2018=164). Knowledge creation and knowledge impact (2015 = 105, 2016 = 224, 2017 = 217, 2018=256) remained a significant avenue for dissemination of Activity Outputs.

### **Website and Social Media**

The CDPC website continued to evolve in 2018. The inclusion of a links on the homepage to “connect with the CDPC”, social media links, and “subscribe to newsletter” has seen an increase in external engagement (see below). Real-time updates of peer-review publications and resources also continued throughout 2018. This provides a primary portal for engagement of the CDPC. <http://sydney.edu.au/medicine/cdpc/>

CDPC YouTube Channel was launched in November 2017. As of 31 December 2018, there were 42 videos uploaded with 1,997 video views. [https://www.youtube.com/channel/UCEw\\_RxNXXGb9HXyY8698Khg](https://www.youtube.com/channel/UCEw_RxNXXGb9HXyY8698Khg)

CDPC Facebook Page was launched in March 2018 with a total of 76 followers. Although the number of followers is quite low the Reach of the page averaged over 100/month in 2018. <https://www.facebook.com/CDPCresearch/>

The CDPC Twitter feed [https://twitter.com/nhmrc\\_cdpc](https://twitter.com/nhmrc_cdpc) continues to be a successful avenue for dissemination of CDPC outcomes, outputs and news, while offering an opportunity for the CDPC to support internal and external collaborators and influencers through interaction. In 2018 the number of Twitter followers increased by 291 to 768. The CDPC has tweeted a total of 1713 tweets about CDPC research and outcomes.



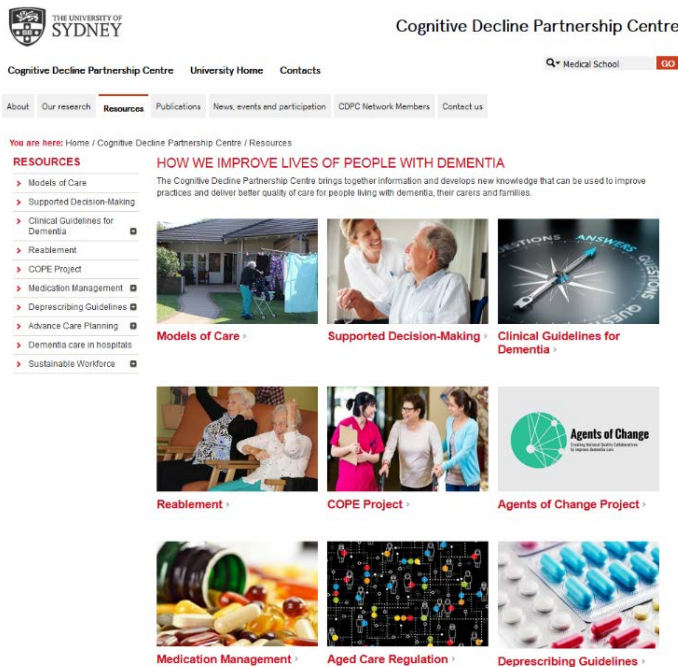
### **CDPC Newsletter**

Five (5) CDPC Newsletter were produced during 2018 with an average open rate of 40%, and newsletter subscriptions increased from 350 to 960 recipients.

- |                                  |   |
|----------------------------------|---|
| CDPC Newsletter – February 2018  | <a href="https://mailchi.mp/4c9d275fb23c/deprescribing-guideline-care-costs-top-ten-speech?e=19d49ebf44">https://mailchi.mp/4c9d275fb23c/deprescribing-guideline-care-costs-top-ten-speech?e=19d49ebf44</a> |
| CDPC Newsletter – April 2018     | <a href="https://mailchi.mp/1be1c2609ecd/vitamin-d-falls-report">https://mailchi.mp/1be1c2609ecd/vitamin-d-falls-report</a>   |
| CDPC Newsletter – July 2018      | <a href="https://mailchi.mp/ff4da38ff9cc/cdpc-newsletter-july-2018">https://mailchi.mp/ff4da38ff9cc/cdpc-newsletter-july-2018</a>   |
| CDPC Newsletter – September 2018 | <a href="https://mailchi.mp/9b8a227e6e8b/cdpc-newsletter-july-2797785">https://mailchi.mp/9b8a227e6e8b/cdpc-newsletter-july-2797785</a>   |
| CDPC Newsletter – December 2018  | <a href="https://mailchi.mp/bf511065ec59/cdpc-newsletter-dec-2018">https://mailchi.mp/bf511065ec59/cdpc-newsletter-dec-2018</a>   |

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

**Challenge:** By mid-2018 it had been identified that the CDPC had funds still available for allocation for further research and implementation initiatives.



**Remedial Action:** a priority setting workshop was held by the CDPC Directorate in October 2018. Key stakeholders were invited to take part in the workshop activity with the aim of creating a prioritised listing of proposed CDPC 2019 initiatives to inform the allocation of available funds. As a result of the workshop the CDPC Governance Authority approved allocations of funding to the value of \$136,040.00 in November 2018.

**Benefit:** By maximising distribution of CDPC funds for dissemination and implementation initiatives, impact of CDPC's research outcomes and outputs for improving care for people with dementia will also be maximised.

**Risk:** Very little to no recognisable risk to funding partners, including the NHMRC, was identified for

maximising distribution of CDPC funds for further initiatives to be completed in 2019, however there is a risk that due to limitation of time of the CDPC, the impact of these initiatives may not be reported.



### **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. The University of Sydney, the NNIDR, and 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 entities, agreed in 2018 and early 2019 are listed here:

- NNIDR Board: Dr Jane Thompson (affiliated with CDPC through Dementia Australia)
- NNIDR Expert Advisory Panel: Janice Besch (Chair, CDPC Governance Authority), Prof. Susan Kurrle (Director, CDPC); Prof. Dimity Pond (CDPC Lead Investigator), Danijela Hlis (CDPC Consumer Network volunteer)
- NNIDR Director Janice Besch chairs the CDPC Governance Authority
- The NNIDR have indicated they will allocate space on their 2019 trade stand at the AAG conference in October/November 2019 for CDPC resources and outputs.
- In 2019 the CDPC is to be involved in piloting a prototype form that will assist in identifying resources ready for DTA consideration for dissemination and implementation in workforce training.
- The University of Sydney has agreed to support the CDPC website, which houses CDPC Resources, for 5 years post 2019. Professor Kurrle has also agreed to support maintenance of this site during this period.

**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:** That despite the CDPC Directorate and partners dissemination efforts the impact of CDPC developed resources will be lessened post December 2019.

## CDPC PARTNER ORGANISATION STATEMENT

Led by Designated Systems Based Investigators (DSBIs), Brightwater Care Group, HammondCare and Helping Hand Aged Care are actively engaged in informing and supporting initiatives that embed positive CDPC research outcomes into policy and practice.



The three aged care industry partners have worked closely with CDPC members, researchers and consumers to provide experienced practical input into developing resources, and a broad range of dissemination and knowledge translation activities in the states in which they operate.

Initiatives included in-house staff training to implement the CDPC research activity outcomes and resources into practice; engaging with our contacts and networks across the aged care sector to disseminate resources; promoting and hosting workshops across a broad range of activities including Supported Decision Making, Exercise Physiology in Aged Care for People with Dementia, and Regulation in Aged Care.

This approach has had significant impact from a policy perspective through influencing agencies such as the Aged Rights Advocacy Service (ARAS) and Older Persons Advocacy Network (OPAN). The Consumer Guides for Supported Decision Making and the Dementia Clinical Practice Guidelines have been promoted widely to our clients and their families through our websites, at all our contact points with current and prospective clients and championed by our organisations' consumer representative groups.

As the CDPC draws to a close at the end of 2019 it is important to reflect on the unique collaboration that has been fostered between consumers, industry and researchers. Breaking down silos has not always been easy!

The CDPC commenced with a vision of the NHMRC and expert consultant Jonathon Lomas, for a collaboration that would commence with the research question and flow through to implementing outputs to achieve systemic and positive change that benefit people with dementia and those who provide support, in Australia.

Three groups of collaborators were developed: the consumer investigators, the designated systems-based investigators (industry - DSBIs) and academic researchers. Each activity has had differing ways of collaborating, ranging from active engagement in each facet of the research process, to a more 'business as usual' approach using consumers and industry as commentators on steering or advisory committees.

As DSBIs, we have felt that the involvement of industry was critical from the inception of research. The shaping of the research question has implications for the expression of results. And, in turn, publishing results in ways that are useful for industry (whether positive or negative results) is critical for the success of implementation.



The end of tenure of the CDPC should leave the research community in Australia with the message that ‘going it alone’ is no longer adequate. Involving the people that research is designed to affect, and effect change for, as well as those who have responsibility to implement research findings, are key to the research process in tangible and practical ways.

As well as broader research collaborations, another key outcome of our CDPC involvement has been the development of strong and continuing relationships between industry partners. The sharing of ideas, information and practical know-how has been advantageous to organisations, staff, and the people for whom we serve. Collaborations with consumers and researchers will continue in multiple ways: partnering on applications for new research funding opportunities and the ability to look more at internal evaluation processes and apply research vigour.

DSBI Authors: Wendy Hudson (Brightwater Care Group), Meredith Gresham (HammondCare), Megan Corlis (Helping Hand Aged Care)

## CONSUMER ADVOCATES IN DEMENTIA RESEARCH : RESEARCH FOR US – WITH US

Provided by Joan Jackman DipOT, GradDipEdStud, MHPEd, MA. (Dementia Australia/CDPC Consumer Investigator and Consumer Advocate (Dementia & Delirium))

In 2012 the NHMRC established the **Cognitive Decline Partnership Centre (CDPC)** as part of the Federal Government’s ‘Partnerships for Better Health Program’. This *first* NHMRC Partnership Centre was launched in April 2013 by the then Minister for Health and Ageing, Mark Butler. The \$25,000,000 Partnership Centre was co-funded by the NHMRC, Alzheimer’s Australia (now Dementia Australia) and three Age Care Service Providers

(Brightwater, HammondCare and Helping Hand), working in collaboration for the achievement of a shared **Vision** - *to improve the lives of people with dementia, and Mission* - *to develop and communicate research to improve the care of people with dementia.*



An identified unique strength of the CDPC, has been the *involvement* of **Consumers (people with dementia and/or their care partners)** in many aspects of the Partnership Centre’s Governance, Operations and Research Activities. This Consumer involvement has been a continuing and sustained feature of the CDPC since 2012, initially under the auspices of Alzheimer’s Australia and its newly created Consumer Dementia Research Network (CDRN). The subsequent ongoing involvement of Consumers from 2016 to 2018 has been part of the continuing Funding Partnership with Dementia Australia through its part-time Consumer Investigator position, together with a supportive position for Consumers to continue their involvement with the CDPC in a *voluntary* capacity, if they chose.

Importantly, the strength of the Consumer involvement in, and contribution to, the CDPC for this 2012-2018 period, has come *not* from *one* ‘Representative Consumer Position’, but rather from having 20-25 very different people from diverse personal and professional backgrounds and experiences. These Consumers are *not* researchers, academics or clinicians, but instead bring informed perspectives from their personal experiences of the impact of Dementia; either in having the condition, or in sharing in and supporting the life of a person with dementia. This informs what they each bring to CDPC research to further sharpen the *focus* and *relevance* to Consumers of the Projects undertaken, as collaborative members of the Project Teams.

### CONSUMER INVOLVEMENT - SUMMARY

Dementia is one of the most complex, variable conditions a person can experience. We know that if you have met a person with Dementia, you have done just that, met *one person* with Dementia; such is the huge variability in how this condition manifests and impacts people. As mentioned by the Consumers in the CDPC Annual Meeting in October 2018, this is a huge challenge for researchers in Dementia, particularly in endeavouring to bring about change in policy, systems and practice through research; an impact objective of the CDPC. What Consumers bring to the table is an *informed* perspective, with a sharpened focus on the relevance and application of Dementia Research *to issues which are important to Consumers.*

Research can lead to much needed change and the work of the CDPC, through its collaborative approach to research, has continued to make a significant contribution to achieving the Vision of the CDPC *To Improve the Lives of People with Dementia*. The range and diversity of the 14 Projects on which we commenced in 2012, has broadened. By December 2018 there had been an increasing focus on the *Social* context of living with Dementia (Activities 1307, 1318), as well as *‘living well’ and ‘maintaining enhancing health’* (Activity 1337), including whilst in RAC (Activity 1329). Living well in the *community and at home* has become more of a focus (Activities 1321), as well as more responsible, informed use and prescription of medications (Activity 11). The capacity of people with Dementia to be involved in decisions about themselves through the progression of their condition, was importantly addressed with Consumers and Professionals (Activity 1324). Education regarding the responsible role of Financial Institutions in their Policies and Practices (Activity 1306) has continued through urban and regional workshops for professionals and consumers.

We have also seen a greater emphasis in more recent Activities to producing outputs specifically for the public (consumers). This has been a welcome shift in priorities for Activities, which has been greatly appreciated by the Consumers. Further vigorous *dissemination* by the CDPC of these valuable resources is encouraged for 2019.

Consumers have contributed in part to the diversification of CDPC Projects and their intended outcomes and outputs. But this could only be achieved with the sort of *collaborative approach* to research which the CDPC fosters. As Consumers involved through the last 6.5 years of the CDPC to December 2018, we would like to acknowledge the supportive position of Dementia Australia for the involvement of Consumers in the CDPC, including the funding to December 2018 of the Consumer Investigator Position (part-time).

Appreciation is expressed to Professor Susan Kurrle for her continuing positive leadership and support for Consumer involvement in the CDPC. This appreciation is also extended to the CDPC Operations Team who continue to do a remarkable job for us all, with their small number of very talented people. We would also like to thank all the researchers and Activity teams with whom we continue to learn so much.

Importantly, appreciation is expressed to *each* of the Consumers who have chosen to continue their involvement with the CDPC through to December 2018. Their commitment of time, experience and expertise has continued to be generous and invaluable. Appreciation is especially extended to Tara Quirke for her continuing commitment to the CDPC in the face of adversity.

We look forward to continuing to work together with the CDPC into the extended period of 2019, with the important focus of *dissemination*. The Consumer Investigator will continue in a small number of casual hours, together with those Consumers who choose to continue their involvement, as invited.

THANK YOU EVERYONE!

#### CONSUMER INVOLVEMENT – CDPC OPERATIONS

**Consumer ‘Three Tier System’ of involvement in the CDPC:** Consumer involvement in the CDPC has been structured on a *Three Tier System* of involvement, as originally recommended by Alzheimer’s Australia to the CDRN. This *System* structure has continued through to December 2018, supporting the *sustained* involvement of the Consumers through the 6.5 years.

**The 1<sup>st</sup> Tier** consists of the one paid part-time Consumer Investigator (CI) position. The **2<sup>nd</sup> Tier** has consisted of voluntary Consumers (Jenny Henderson, Louise Heuzenroeder, Tara Quirke, Ron Sinclair, Kate Swaffer, Jane

Thompson, Kathy Williams), who support the CI in involvement of Consumers in the work of the CDPC. The **3<sup>rd</sup> Tier** also consists of voluntary Consumers, who in addition to Tier 1 and 2 Consumers, are selectively involved in Project Activity Teams (Graeme Brough, Gary Collins, Mae Collins, Theresa Flavin, Imelda Gilmore, Ian Gladstone, Nadine Hedger, Danijela Hlis, Val Jenner, Les Leckie, Glenys Petrie, John Quinn, Karine Shellshear, Elaine Todd). A smaller number of consumers have also expressed interest in opportunities if/when they should arise and in receiving CDPC Communications of interest (Val Fell, Keren Glennen, Kerin Glennen, Astrid Heckler).

An important feature of this structure comes from the origins of our involvement through the former CDRN, which included the capacity to *know the consumer*. Through the structure and support initially provided by Alzheimer's Australia to the CDRN, we were able to identify and harness *specific personal experiences*, expertise and strengths from the Network. This has *continued* to support the most *effective alignment* of individual Consumers to the specific needs and demands of CDPC initiatives, through to December 2018.

There has been continued involvement of the Consumer Investigator in the Executive Committee (*Joan Jackman*); 5 Consumers were invited to contribute to the CDPC Strategic Prioritising Workshop in October 2018 (*Joan Jackman, Glenys Petrie, John Quinn, Jane Thompson, Kathy Williams*). Convening of the Scientific Sub-Committee was not required in 2018 (*Ron Sinclair, Elaine Todd*). Operationally within the CDPC, the Consumers continued their involvement from the Consumer Enabling Sub-Unit (ESU) organisational structure, for which the Consumer Investigator was the Lead (*Joan Jackman*). Periodically, some Project Teams also sourced their Consumers from outside this ESU resource group.

#### CONSUMER INVOLVEMENT – ACTIVITIES

There continued to be an involvement of Consumers in *most* of the 32 CDPC Activities, as needed. Levels of involvement vary between *participatory, advisory and investigative* roles, depending on the Activity and team. An increasing involvement of Consumers in *all* stages of the Activities and in *advisory and/or investigative* roles has been experienced into 2018, as Consumers have become more confident with what they feel able to contribute, and comfortable with their co-Team members. Team members have also become increasingly familiar and comfortable in working equitably with Consumers.

#### CONSUMER INVOLVEMENT – DISSEMINATION

As emphasis of Activities has moved increasingly to *dissemination* of Activity resources and outputs, Consumers have been selectively invited to be part of *dissemination strategies*. This has included contributing to **Workshops** for Activity 1318 (*Danijela Hlis, Tara Quirke, Tony Ramshaw*); Activity 1321 (*Danijela Hlis, Joan Jackman, Glenys Petrie, John Quinn, Jane Thompson*); Activity 1333 (*Elaine Todd*). **Project Resource** development has included Activity 1338 videos and flipcharts for Consumers/Staff (*Danijela Hlis/CALD*); Activity 1301 video (*Elaine Todd, Kathy Williams*); Activity 1324 video (*Theresa Flavin*); Activity 1337 three handbooks (*Theresa Flavin, Joan Jackman, Glenys Petrie, John Quinn, Ron Sinclair*); Activity 1313 Consumer Companion Guide (*Louise Heuzenroeder, Joan Jackman, Jane Thompson*). Most Activities have invited Consumer review of draft Final Reports, with contributions and suggestions for potential enhancements, particularly in enhancing *Consumer/Public accessibility* to the Reports and the Activity outputs.

## CONSUMER INVOLVEMENT - EVENTS

**INTERNAL: CDPC Annual Meeting (October 2018)** where approximately 10 Consumers were supported by the CDPC to attend and contribute to this final meeting. Consumers were invited to contribute an **Opening Consumer Panel Presentation/Discussion** titled *Public (Consumer) Involvement in Research: Are we making a difference for people impacted by Dementia? The CDPC perspective* (Theresa Flavin, Jenny Henderson, Danijela Hlis, Joan Jackman, Les Leckie, Glenys Petrie, John Quinn, Jane Thompson, Kathy Williams).

### **EXTERNAL: Australian Dementia Forum (NNIDR)**

**(June 2018) Q & A Discussion** titled Supported Decision-making, the lived experience of consumer impact in dementia research (Theresa Flavin with Maree McCabe); **Consumer Involvement in Research Panel Presentation** (Ian Gladstone, Danijela Hlis, Ron Sinclair, Elaine Todd); **Activity 1324 Launch (June 2018)** (Theresa Flavin); **33rd International Conference of ADI (Chicago, July 2018)** paper presentation titled The NHMRC Partnership Centre for Dealing with Cognitive and Related Functional Decline in Older People: An Australian Model for Public Involvement in Dementia research (Jane Thompson); **ADI Promotional Video Every Three Minutes** (Elaine Todd); **International Federation on Ageing (IFA) 14<sup>th</sup> Global Conference (Toronto, August 2018)** co-paper presentation titled Active Consumer Involvement in Dementia Research is Achievable (Tara Quirke); **AAG Webinar (September 2018)** Successfully Engaging Consumers in Ageing Research (Jane Thompson).



## CONSUMER INVOLVEMENT - DIVERSITY IN INVOLVEMENT/CONTRIBUTIONS

Consumers have continued to enhance their skills and experiences through accepting opportunities to be involved and contribute to a broad range of activities related to Consumer involvement in research, which continue to inform and enhance what they also contribute to the CDPC. This includes but is not limited to: **NHMRC Boosting Dementia Grant Application Reviews (4 Consumers)**; **NNIDR Board (Jane Thompson)**; **NNIDR Consumer Involvement Program Reference Group (John Quinn)**; **Dementia Australia Research Foundation (DARF) Scientific Panel (Ian Gladstone; Jane Thompson)** and **DARF Grant Reviews (4 Consumers)**; **ACSQHC Advisory Committees (Louise Heuzenroeder; Joan Jackman)**; **PhD Candidates (Louise Heuzenroeder; Kate Swaffer)**.

## CONSUMER INVOLVEMENT - EVALUATION

**The CDPC Interim Evaluation Findings Report (2017)** reported that “While the partnerships between academics, industry partners and consumers are an integral part to achieving the CDPC’s intended impact, the involvement of consumers is considered a particularly invaluable part of the CDPC’s structure. Trust and respect are necessary to ensure that the contributions from the consumers are heard and integrated into research; this was viewed by many stakeholders as a strength of the CDPC.”. Additionally, it was reported that “Many consumers who were interviewed felt that they were respected and listened to. To continue to strengthen this collaborative partnership, the CDPC partners could benefit from a guide or booklet to outline



how to best involve consumers in research and the appropriate language to use. For most of the people who participated in the qualitative interviews involving consumers in research in particular was one of the biggest achievements to date.”

The **2018 Final Evaluation Report** is yet to be released, however preliminary feedback has indicated that “The majority of qualitative interviewees felt that involvement of Consumers in research from the beginning was one of the CDPC’s strongest assets.” and that “Consumers are one of the CDPC’s best assets, contributing to ensuring Projects reflect consumer needs ... and bringing the ‘real-world’ to Activities”. It was further noted that “Consumers are one of the most unique parts of the CDPC’s structure”, with “it would be even better with greater diversity of consumers in the future.”



**Schema 1: Alignment of CDPC Activities and Initiatives to CDPC Themes at 31 December 2018**

**CDPC / NHMRC OBJECTIVES**

	Collaborative New Research
	Synthesis and Dissemination
	Capacity Building
	Implementation of Research Informed Change

Service Model Options		
CDPC 1301	Long Term Care Configurations	Completed
CDPC 1302	Confused Hospitalised Older Persons Study (CHOPS)	Completed
CDPC 1315	Modelling for Estimation of Cost Effectiveness of Aged Care	Completed
CDPC 1326	Dementia Delirium Care with Volunteers	Completed
CDPC 1333	Validating and evaluating a quality of life instrument for people with dementia.	In Conduct
CDPC 1337	Development of Dementia Reablement Guidelines and Programs	Completed

Attitude and Culture		
CDPC 1307	Regulation of Aged Care Services - Effects	Completed
CDPC 1308	Living with Dementia in the Community	Completed
CDPC 1318	Dementia in the Public Domain	Completed

Planning for Later Life		
CDPC 1305	National Advance Care Planning	Completed
CDPC 1306	Financial Institution Policies / Practices	Completed
CDPC 1324	Supported Decision Making in Dementia Care	Completed

Medication Management		
CDPC 1311	Quality Use of Medicines	In Conduct
CDPC 1312	Implementation of Vit-D Supplements in Residential Aged Care Facilities	Completed
CDPC 1320	Telehealth Enabled Prescribing in Dementia	In Conduct

Workforce Development and Education		
CDPC 1309	Evaluation of Inter-Professional Education (IPE) in Residential Aged Care	Completed
CDPC 1310	Supporting and Caring for Residential Care Staff	Completed
CDPC 1316	Healthy Ageing in Australian Physicians	Completed
CDPC 1322	Improving residential dementia care through staff	In Conduct
CDPC 1328	Implementing and embedding interprofessional learning, education and practice across the aged care sector	Completed
CDPC 1338	Intervene Stage 2 – Pain management - best practice in residential aged care	In Conduct
CDPC Events	Workshops and Information Sessions: Change Management Implementation and Sustainability, Health Economics, Powers of Attorney, Technology & Telehealth, CDPC/COTA Powers of Attorney Seminar Series, and NHMRC Partnership Centres joint events: Policy Engagement, Measuring Impact	Completed

Clinical Guidelines		
CDPC 1313	National Australian Dementia Guidelines	Completed
CDPC 1314	Primary Care Consensus Guide	Completed
CDPC 1327	National Australia Dementia Guidelines Implementation: use of audit and feedback to improve care	In Conduct

Functional Decline		
CDPC 1319	Understanding risk and preventing falls and functional decline in older people	In Conduct
CDPC 1321	Implementing Care of Older Persons with Dementia (COPE) in Australia	In Conduct
CDPC 1329	Implementation Evaluation - Exercise Prescription (EP) in Aged Care Project	Completed
CDPC 1330	Innovation Research - understanding human-robot interaction	Completed

Pathways and Navigation		
CDPC 1303	Key Worker Role	Completed
CDPC 1304	Alternative Respite Models	Completed
CDPC 1317	Psychosocial Impact of Having a Parent with Dementia	Completed
CDPC 1325	Consumer Journey Modeling – Ideal State Project	Completed

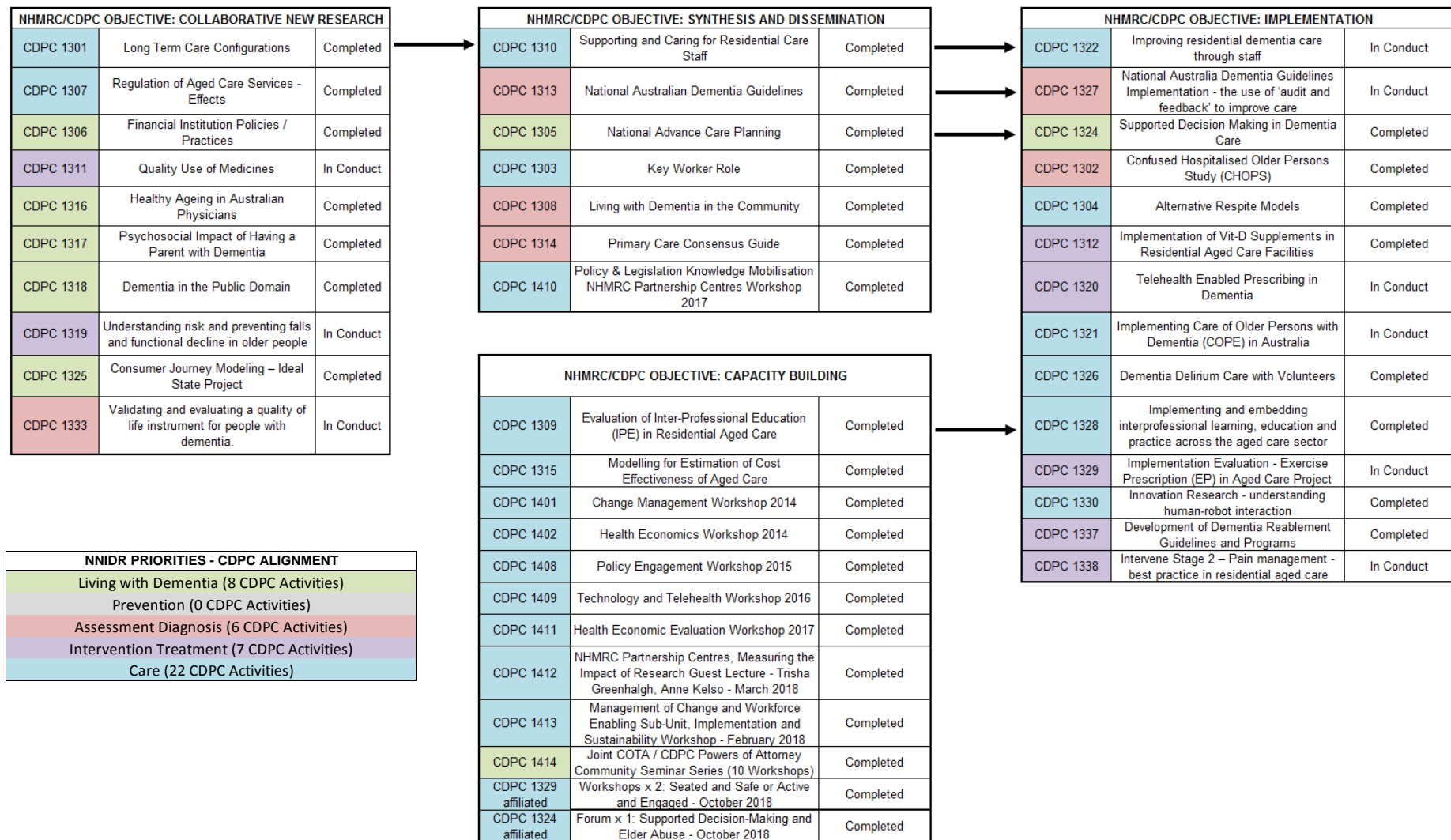
**Schema 2: Activity Alignment of NHMRC/CDPC Objectives and CDPC Themes: at 31 December 2018**

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NHMRC/CDPC OBJECTIVE: COLLABORATIVE NEW RESEARCH			NHMRC/CDPC OBJECTIVE: SYNTHESIS AND DISSEMINATION			NHMRC/CDPC OBJECTIVE: IMPLEMENTATION		
CDPC 1301	Long Term Care Configurations	Completed	CDPC 1310	Supporting and Caring for Residential Care Staff	Completed	CDPC 1322	Improving residential dementia care through staff	In Conduct
CDPC 1307	Regulation of Aged Care Services - Effects	Completed	CDPC 1313	National Australian Dementia Guidelines	Completed	CDPC 1327	National Australia Dementia Guidelines Implementation - the use of 'audit and feedback' to improve care	In Conduct
CDPC 1306	Financial Institution Policies / Practices	Completed	CDPC 1305	National Advance Care Planning	Completed	CDPC 1324	Supported Decision Making in Dementia Care	Completed
CDPC 1311	Quality Use of Medicines	In Conduct	CDPC 1303	Key Worker Role	Completed	CDPC 1302	Confused Hospitalised Older Persons Study (CHOPS)	Completed
CDPC 1316	Healthy Ageing in Australian Physicians	Completed	CDPC 1308	Living with Dementia in the Community	Completed	CDPC 1304	Alternative Respite Models	Completed
CDPC 1317	Psychosocial Impact of Having a Parent with Dementia	Completed	CDPC 1314	Primary Care Consensus Guide	Completed	CDPC 1312	Implementation of Vit-D Supplements in Residential Aged Care Facilities	Completed
CDPC 1318	Dementia in the Public Domain	Completed	CDPC 1410	Policy & Legislation Knowledge Mobilisation NHMRC Partnership Centres Workshop 2017	Completed	CDPC 1320	Telehealth Enabled Prescribing in Dementia	In Conduct
CDPC 1319	Understanding risk and preventing falls and functional decline in older people	Completed				CDPC 1321	Implementing Care of Older Persons with Dementia (COPE) in Australia	In Conduct
CDPC 1325	Consumer Journey Modeling – Ideal State Project	Completed	NHMRC/CDPC OBJECTIVE: CAPACITY BUILDING			CDPC 1326	Dementia Delirium Care with Volunteers	Completed
CDPC 1333	Validating and evaluating a quality of life instrument for people with dementia.	In Conduct	CDPC 1309	Evaluation of Inter-Professional Education (IPE) in Residential Aged Care	Completed	CDPC 1328	Implementing and embedding interprofessional learning, education and practice across the aged care sector	Completed
			CDPC 1315	Modelling for Estimation of Cost Effectiveness of Aged Care	Completed	CDPC 1329	Implementation Evaluation - Exercise Prescription (EP) in Aged Care Project	Completed
			CDPC 1401	Change Management Workshop 2014	Completed	CDPC 1330	Innovation Research - understanding human-robot interaction	Completed
			CDPC 1402	Health Economics Workshop 2014	Completed	CDPC 1337	Development of Dementia Reablement Guidelines and Programs	Completed
			CDPC 1408	Policy Engagement Workshop 2015	Completed	CDPC 1338	Intervene Stage 2 – Pain management - best practice in residential aged care	In Conduct
			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	Completed			
			CDPC 1413	Management of Change and Workforce Enabling Sub-Unit, Implementation and Sustainability Workshop x 2 - February 2018	Completed			
			CDPC 1414	Joint COTA / CDPC Powers of Attorney Community Seminar Series (10 Workshops)	Completed			
			CDPC 1329 affiliated	Workshops x 2: Seated and Safe or Active and Engaged - October 2018	Completed			
			CDPC 1324 affiliated	Forum x 1: Supported Decision-Making and Elder Abuse - October 2018	Completed			

**Schema 3: Activity Alignment of NHMRC/CDPC Objectives and NNIDR Priorities: at 31 December 2018**



**Table 1: NHMRC Cognitive Decline Partnership Centre (CDPC) – Activities Listing 1 January 2018 - 31 December 2018**

Completed CDPC Activity n=33	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	WA	Capacity Building

					Ms. Karla Seaman; Dr. Mike Bird		
CDPC 1310	Supporting and Caring for Residential Care Staff	01-Jul-13	30-Sep-15	Completed	Southern NSW Local Health District Dr. Katrina Anderson	316BNSW	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
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	12-Apr-15	Completed	University of Sydney Prof. Susan Kurrle; A/Prof Christopher Roberts; Ms. Karen Hutchinson	NSW	Collaborative New Research
CDPC 1318	Dementia in the Public Domain	1-Jan-16	31-Dec-18	Completed	University of Melbourne Prof. Simon Biggs	VIC	Collaborative New Research

CDPC 1324	Supported Decision Making in Dementia Care	1-Jan-16	31-Dec-18	Completed	The University of Western Australia Dr. Craig Sinclair	WA	Implementation of Research Informed Change
CDPC 1324 affiliated	Forum – Supported Decision-Making and Elder Abuse	15-Oct-18	15-Oct-18	Completed	The University of Western Australia Dr Craig Sinclair	WA	Capacity Building
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 1329 affiliated	Workshops x 2: Seated and Safe, or Active and Engaged	October 2018	October 2018	Completed	Helping Hand Aged Care Ms. Megan Corlis	SA	Capacity Building
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 1337	Development of evidence-based Dementia Reablement Guidelines and Programs deliverable to people with early – moderate dementia.	16-Jan-17	31-May-18	Completed	Hammondcare Prof. Christopher Poulos	NSW	Implementation of Research Informed Change



CDPC 1401 Initiative	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 Initiative	Health Economics Workshop	12-Apr-14	13-Apr-14	Completed	Dr. Tracy Comans Health Economics Enabling Sub-Unit	QLD	Capacity Building
CDPC 1408 Initiative	Policy Engagement Workshop	n/a	23-Feb-15	Completed	Ms. Anne Cumming Policy & Legislation Enabling Sub-Unit	NSW	Capacity Building
CDPC 1409 Initiative	Technology & Telehealth Workshop	n/a	09-May-16	Completed	Prof. Len Gray Technology & Telehealth Enabling Sub-Unit	QLD	Capacity Building
CDPC 1410 Initiative	Policy & Legislation Knowledge Mobilisation Workshop	n/a	30-Mar-17	Completed	Ms. Anne Cumming Policy & Legislation Enabling Sub-Unit	NSW	Synthesis & Dissemination
CDPC 1411 Initiative	Health Economic Evaluation Workshop	n/a	15-Jun-17	Completed	Dr. Tracy Comans Health Economics Enabling Sub-Unit	QLD	Capacity Building
CDPC 1412 Initiative	NHMRC Partnership Centres, Measuring the Impact of Research Guest Lecture – Trisha Greenhalgh, Anne Kelso	19-Mar-18	19-Mar-18	Completed	Ms Anne Cumming Policy & Legislation Enabling Sub-Unit	NSW	Capacity Building
CDPC 1413 Initiative	Implementation and Sustainability Workshop	22-Feb-18	23-Feb-18	Completed	Prof. Anneke Fitzgerald Management of Change & Workforce Enabling Sub-Unit	QLD	Capacity Building

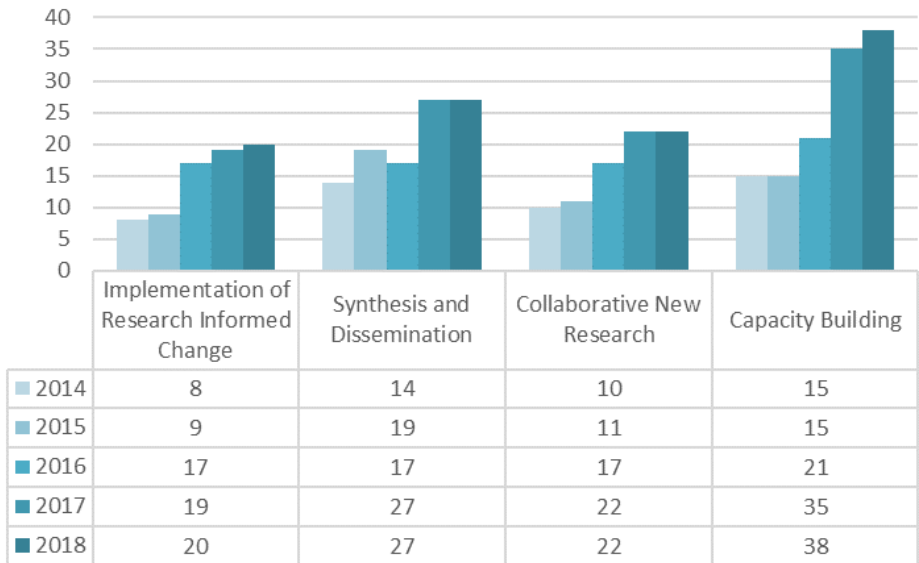
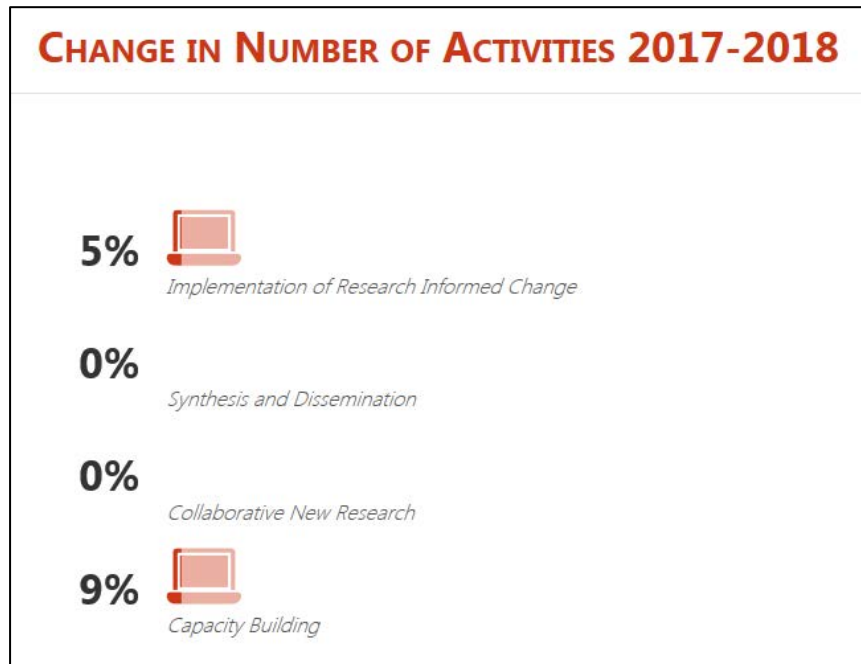
CDPC 1414 Initiative	Joint COTA / CDPC Powers of Attorney Community Seminar Series	06-Nov-17	03-May-18	Completed	Adjunct Assoc. Prof. Sue Field Policy & Legislation Enabling Sub-Unit	542BNSW	Capacity Building
Milestones Still to Complete at 1 January 2019 CDPC Activity n=10	Name	Start Date	End Date	Status	Funded Institution and Investigators	Funded State	Primary Objective
CDPC 1301	Long Term Care Configurations	13-Jan-14	31-Dec-18	Ongoing – Milestones still to complete	Flinders University Prof. Maria Crotty	561BSA	Collaborative New Research
CDPC 1311	Quality Use of Medicines	13-Jan-14	12-Jan-19	Ongoing – Milestones still to complete	University of Sydney / Monash University Prof. Sarah Hilmer; A/Prof Simon Bell	NSW / VIC	Collaborative New Research
CDPC 1319	Understanding risk and preventing falls and functional decline in older people	01-Jul-15	31-Dec-18	Ongoing – Milestones still to complete	University of Sydney / NeuRA at UNSW Prof. Jacqui Close; Dr. Morag Taylor; Prof. Susan Kurrle	579BNSW	Collaborative New Research
CDPC 1320	Telehealth Enabled Prescribing in Dementia	1-Jan-16	31-Dec-18	Ongoing – Milestones still to complete	University of Queensland Prof. Len Gray	588BQLD	Implementation of Research Informed Change
CDPC 1321	Implementing Care of Older Persons with Dementia (COPE) in Australia	31-Mar-16	31-Dec-18	Ongoing – Milestones still to complete	University of Sydney / Flinders University Prof. Lindy Clemson	597BNSW	Implementation of Research Informed Change

CDPC 1322	Supporting and Caring for Residential Care Staff (extension)	1-Oct-16	31-Dec-18	Ongoing – Milestones still to complete	Southern NSW Local Health District Dr. Katrina Anderson	606BNSW	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	Ongoing – Milestones still to complete	Flinders University Dr. Kate Laver	614BSA	Implementation of Research Informed Change
CDPC 1329	Implementation Evaluation - Exercise Prescription (EP) in Aged Care Project	1-Apr-16	31-Dec-18	Ongoing – Milestones still to complete	Helping Hand Aged Care Ms. Megan Corlis	623BSA	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	Ongoing – Milestones still to complete	Griffith University (to 31-Oct-17) now University of Queensland (from 01-Nov-17) Dr. Tracy Comans	632BQLD	Collaborative New Research
CDPC 1338	Intervene Stage 2 - Pain management - best practice in residential aged care	1-Nov-16	31-Oct-18	Ongoing – Milestones still to complete	Hammondcare Prof. Colm Cunningham	641BNSW	Implementation of Research Informed Change

**ALIGNMENT OF RESEARCH ACTIVITY WITH RESEARCH OBJECTIVES**

In 2018 the number of total approved CDPC driven Activities and Initiatives increased very minimally from 40 to 43 (Figure 1, Table 1: 25 research Activities and 11 Initiatives) with the only growth being in number of Initiatives and no growth in number of Activities. The growth occurred under the Capacity Building and Implementation of Research Informed Change Objectives. This lessened growth was expected, as the CDPC funds for new Activities and Initiatives has been fully allocated with no extension of funding for the Centre by the NHMRC. While the Centre has performed well against all objectives, the lack of a visible long-term source of continued grant revenue or funding will result in the Centre discontinuing at the end of 2019.

**Figure 1 (left and above): Alignment of all 43 approved CDPC research**



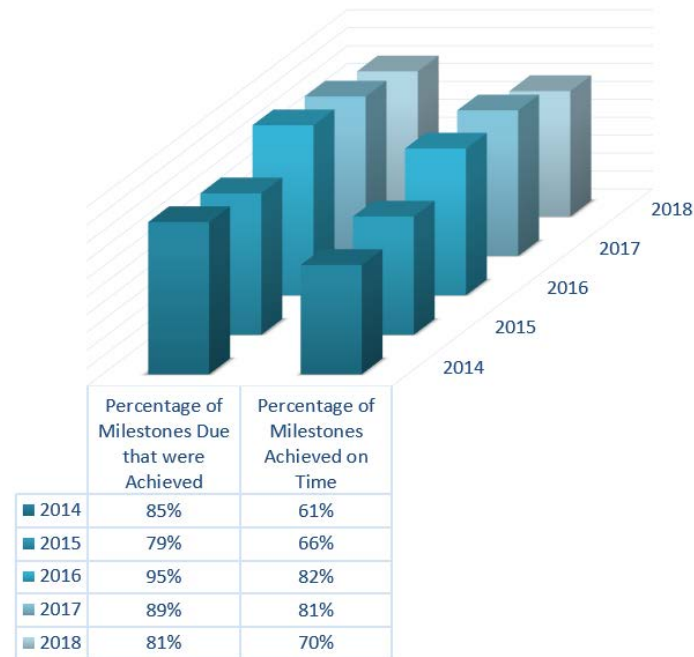
**Activities and Initiatives (All Priorities) against NHMRC Objectives (2014-31 December 2018)**

**MEETING MILESTONES**

For the period 1 January 2018 to 31 December 2018, a maximum of thirteen (13) Activities were In Conduct, with one (1) Activity Completed between 1 January 2018 and 31 December 2018. For the Activities In Conduct during this year, 81% of milestones due were met by 31 December 2018, and 70% of those milestones due were achieved on time (Table 2, Figure 2).

**Figure 2: CDPC Activity Specific Milestones Achieved (2014-2018)**

Year	Quarter	Activities	Due	Achieved (on time)	Percentage Achieved (on time)
2018	1	13	30	26	87%
	2	13	35	29	83%
	3	12	29	21	72%
	4	12	35	14	40%
<b>Total / Percentage</b>			<b>129</b>	<b>90</b>	<b>70%</b>



**Table 2: Activity Specific Milestones Due and Achieved Per Quarter (2018)**

### **IMPLEMENTATION OF RESEARCH INFORMED CHANGE**

In 2018 there were 18 CDPC Activities that reported implementation of change into institutional practice compared to 16 in 2017 (Table 3). Between 2014 (12 institutions / organisations) and 2018 (>740 institutions / organisations) there has been an increase of 728 sites known to have implemented change as a result of CDPC funded evidence created through the research Activities.

Continued increase in this area is indicative of the CDPC's ongoing commitment to encouraging and supporting research implementation into practice and it is envisaged the number of sites implementing change will continue to increase incrementally each year, even beyond the lifespan of the Centre. These numbers are challenging to accurately track as implementation into practice occurs outside the CDPC and we rely on Centre staff and CDPC members hearing and recording stories of impact and implementation. Therefore, while we ask that Activity teams report implementing sites they are aware of there may be more instances of implementation than are reported.

Activity Number and Description	Number of Organisations (2014)	Number of Organisations (2015)	Number of Organisations (2016)	Number of Organisations (2017)	Number of Organisations (2018)
Activity 1301 - Long Term Care Configurations	0	0	0	0	3
Activity 1302 - Confused Hospitalised Older Persons Study (CHOPS)	7	13	17	17	18
Activity 1304 - Alternative Respite Models (WEAVERS)	0	7	2	4	8
Activity 1307 - Regulation of Aged Care Services	0	0	5	5	50
Activity 1308 - Living with Dementia in the Community	0	5	6	0	0
Activity 1309 - Evaluation of Inter-Professional Education (IPE) in	0	11	3	3	0
Activity 1311 - Quality Use of Medicines	2	33	104	106	110
Activity 1312 - Implementation of Vit-D Supplements in Residential	3	55	42	42	42
Activity 1313 - National Australian Dementia Guidelines	0	0	100	160	200
Activity 1314 - Primary Care Consensus Guide	0	9	6	0	0
Activity 1320 - Telehealth Enabled Prescribing in Dementia		0	7	5	7
Activity 1321 - Implementing COPE in Australia			0	10	15
Activity 1322 - Improving residential dementia care through staff			0	11	12
Activity 1324 - Supported Decision Making in Dementia Care			0	0	100
Activity 1326 - Dementia Delirium Care with Volunteers		7	7	51	79
Activity 1327 - National Quality Collaborative				0	36
Activity 1328 - Implementing & Embedding Interprofessional Learning, Education and Practice Across the Aged Care Sector			6	6	6
Activity 1329 - Exercise Prescription in Aged Care			2	6	7
Activity 1330 - Understanding human-robot interaction			5	5	5
Activity 1333 - Validating and Evaluating a QOL instrument for people			0	3	38
Activity 1337 - Development of Reablement Guidelines and Programs				0	0
Activity 1338 - Intervene 2 (Pain Management)			0	4	4
<b>Total Reported Number of Organisations Implementing Change (2014 - 2018)</b>	<b>12</b>	<b>140</b>	<b>312</b>	<b>438</b>	<b>740</b>

**Table 3: Number of Organisations/Institutions Reported by Activity teams as Implementing Change as a Result of CDPC Research (2014-2018: n=740)**

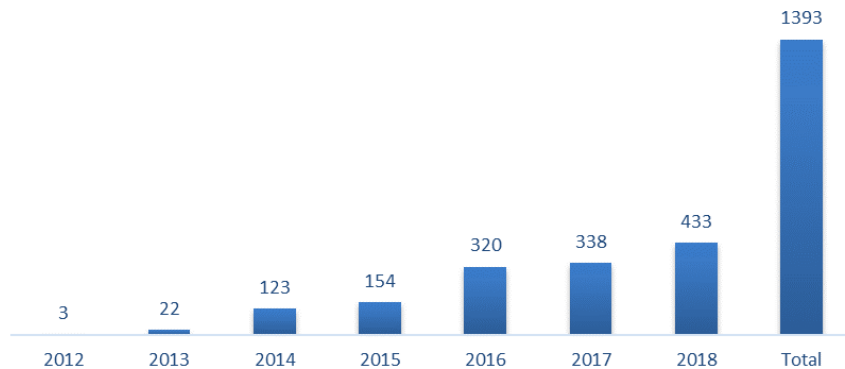


**SYNTHESIS AND DISSEMINATION**

The first CDPC Activities received their funding payments from January 2014, however there were a number of Activities that commenced activity prior to 2014 and therefore reported CDPC associated Outputs for 2012-2013 (Figure 3). The number of Outputs/Syntheses across all CDPC Activities increased significantly in between 2013 and 2014 and then again between 2015 and 2016, while it remained reasonably static between 2016 and 2017. In 2018 the number of Outputs / Syntheses again rose significantly from 338 in 2017 to 433 in 2018. The total number of recorded Outputs/Syntheses from the CDPC had reached 1393 by the end of 2018, giving evidence that the CDPC continues to meet its Research Synthesis and Dissemination Objective (Figure 3).

**Figure 3: Total CDPC Outputs/Syntheses 2012-2018 (n=1393)**

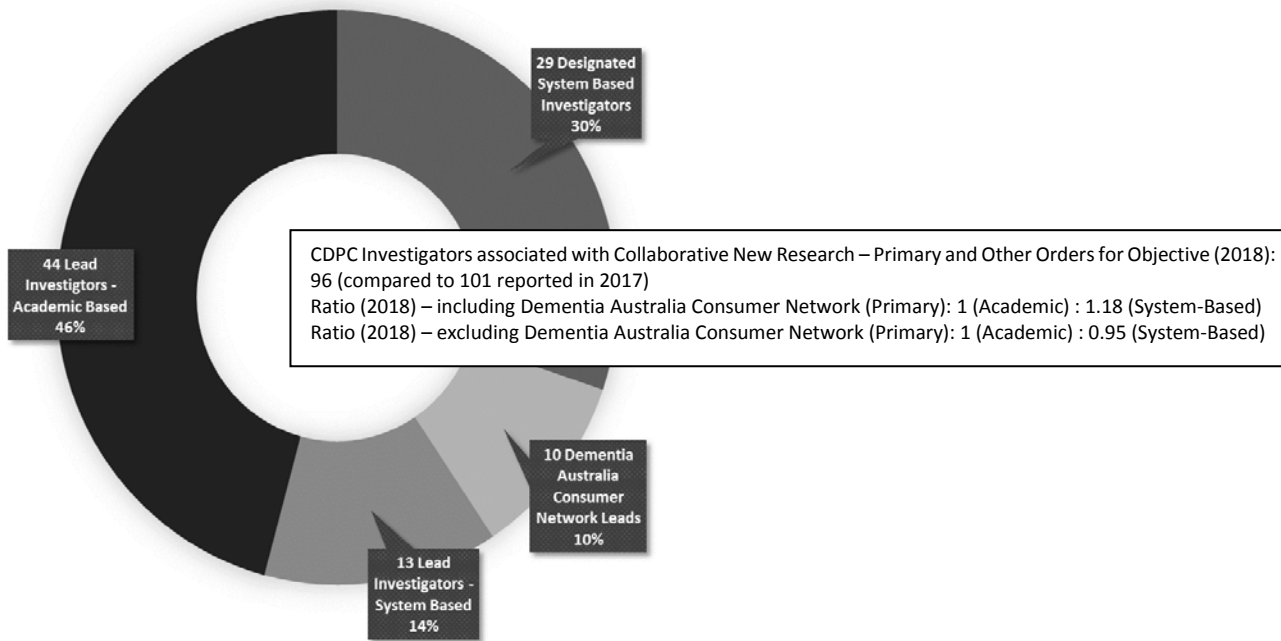
**Total CDPC Outputs/Syntheses (2012-2018)**



While creating and disseminating Traditional Outputs/Syntheses remains a key strength of the CDPC as a whole, the combined Non-Traditional Outputs (Table 10) in the areas of knowledge creation and knowledge impact significantly outnumber the number of Traditional Outputs. We continue to believe that the larger number of Non-Traditional Outputs/Syntheses being disseminated gives measure of evidence that the CDPC is performing well against its original nine (9) impacts, with the CDPC remaining focussed on end-users and consumers having measures of cost; availability of plans and guidelines to inform improved practice in community, primary care, residential aged-care and acute care settings; research-informed guidance for people with dementia and their carers on appropriate care options and pathways; and tools and resources to change attitudes, increase awareness, build workforce, improve medication management, and identify appropriate care options (Appendix A).

**COLLABORATIVE NEW RESEARCH**

As expected and reported in the 2017 Annual Report, with no further funding available for new CDPC research Activities, this report reflects a shrinking number of research investigators associated with CDPC research for 2018/2019. However, we believe the data continues to provide evidence that sustained, role-appropriate engagement of cross sector investigators can be encouraged through effective funding of collaborative Centres like the NHMRC Partnership Centres. Partnerships between Government, consumers and industry can increase collaboration between academic, system-based researchers, and consumers. And consumers can be successfully included as real partners into research. The inclusion of consumer advocates sourced through the Dementia Australia Consumer Network has always been a priority for this Centre, and that inclusion has continued right through to completion of research projects, and beyond. Indeed, the impact that consumers / end-users can have on dissemination success, and their effectiveness as disseminators for research outcomes, outputs and resources. continues to be one of the most important strengths of the CDPC to date, and this will remain a priority until the Partnership Centre grant funding completes at the end of 2019.



**Figure 4: 2018 CDPC Investigators associated with CDPC research Activities with a component of Collaborative New Research**

If all Activities with Collaborative New Research being at least one of their identified Objectives are reviewed, the number of In Conduct Activities aligned against this NHMRC objective in 2018 decreased to thirteen (13) (Figure 4, Table 4) compared to sixteen (16) reported for 2017. The positive outcome that can be noted from the 2018 data is the ratio of Academic to System-Based Investigators changed across all Activities aligned with this Objective and each open Activity had almost even numbers of System Based and Academic Based Investigators associated with the project.

**Table 4: CDPC Activities associated with NHMRC objective 'Collaborative New Research' (2018, n=13)**

CDPC Activity Number	Activity (short) Name	NHMRC / CDPC Objective	Objective Priority	Start Date	End Date
CDPC 1301	Long Term Care Configurations	Collaborative New Research	Primary	13-Jan-14	31-Dec-18
CDPC 1311	Quality Use of Medicines	Collaborative New Research	Primary	13-Jan-14	12-Jan-19
CDPC 1318	Dementia in the Public Domain	Collaborative New Research	Primary	01-Jan-16	31-Dec-18
CDPC 1319	Understanding risk and preventing falls and functional decline in older people	Collaborative New Research	Primary	01-Jul-15	31-Dec-18
CDPC 1333	Validating and evaluating a quality of life (QOL) instrument for people with dementia	Collaborative New Research	Primary	15-Sep-16	15-Nov-18
CDPC 1322	Improving residential dementia care through staff	Collaborative New Research	Secondary	01-Oct-16	31-Dec-18
CDPC 1329	Implementation Evaluation - EP in Aged Care Project	Collaborative New Research	Secondary	01-Apr-16	31-Dec-18
CDPC 1320	Telehealth Enabled Prescribing in Dementia	Collaborative New Research	Tertiary	01-Jan-16	31-Dec-18
CDPC 1324	Supported Decision Making in Dementia Care	Collaborative New Research	Tertiary	01-Jan-16	31-Dec-18
CDPC 1327	National Quality Collaborative	Collaborative New Research	Tertiary	01-Sep-17	31-Dec-18
CDPC 1337	Development of Dementia Reablement Guidelines and Programs	Collaborative New Research	Tertiary	16-Jan-17	31-May-18
CDPC 1338	Intervene Stage 2 – Pain management - best practice in residential aged care	Collaborative New Research	Tertiary	01-Nov-16	31-Oct-18
CDPC 1321	Implementing COPE in Australia	Collaborative New Research	Quaternary	31-Mar-16	31-Dec-18

**CAPACITY BUILDING – MEETINGS, WORKSHOPS, CONFERENCES AND SUPPORT FOR EARLY CAREER RESEARCHERS**

The CDPC Directorate office asks CDPC research Activity teams to report on the total number of researchers, community members and other non-academic audiences who have been exposed to CDPC training and information that encourages system-based awareness and change. As training initiatives are provided centrally by the CDPC, as well as delivered via the Enabling Sub-Units, conducted by Activity teams, and conducted as part of external meetings and conferences, it is not possible to capture details and origin of all audiences exposed to such initiatives, however we believe that we have captured the majority of events of training through our data reporting requirements for research teams. In 2018 there were a total of 141 training sessions by Activity teams and the CDPC Directorate team compared to 129 in 2017.

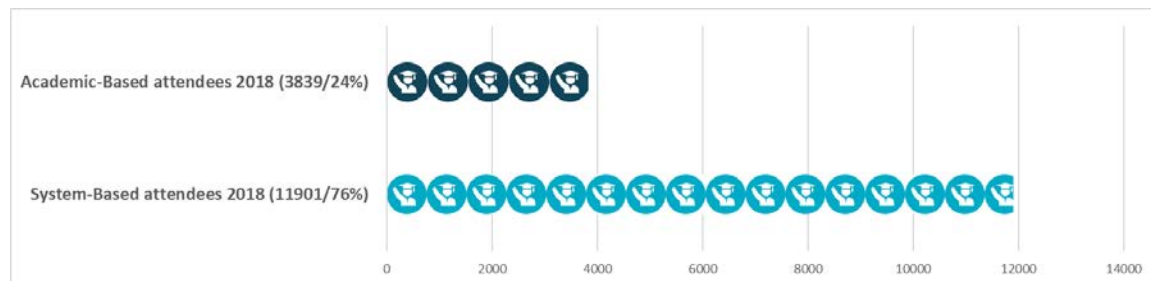
**Figure 5: CDPC training sessions (2018, n=141)**



For reporting purposes each CDPC training event is centrally categorised as having a systems-based audience, academic audience, or both. The data provided to us is used to report the proportion of system-based vs academic researchers exposed to CDPC training and information each reporting year. The majority of training sessions given between 1 January 2018 and 31 December 2018 were given to an audience comprised of both system-based attendees and academic based attendees (Figure 5). We are pleased to see the CDPC training events continues to have broad reach into health systems and community across Australia, and Internationally.

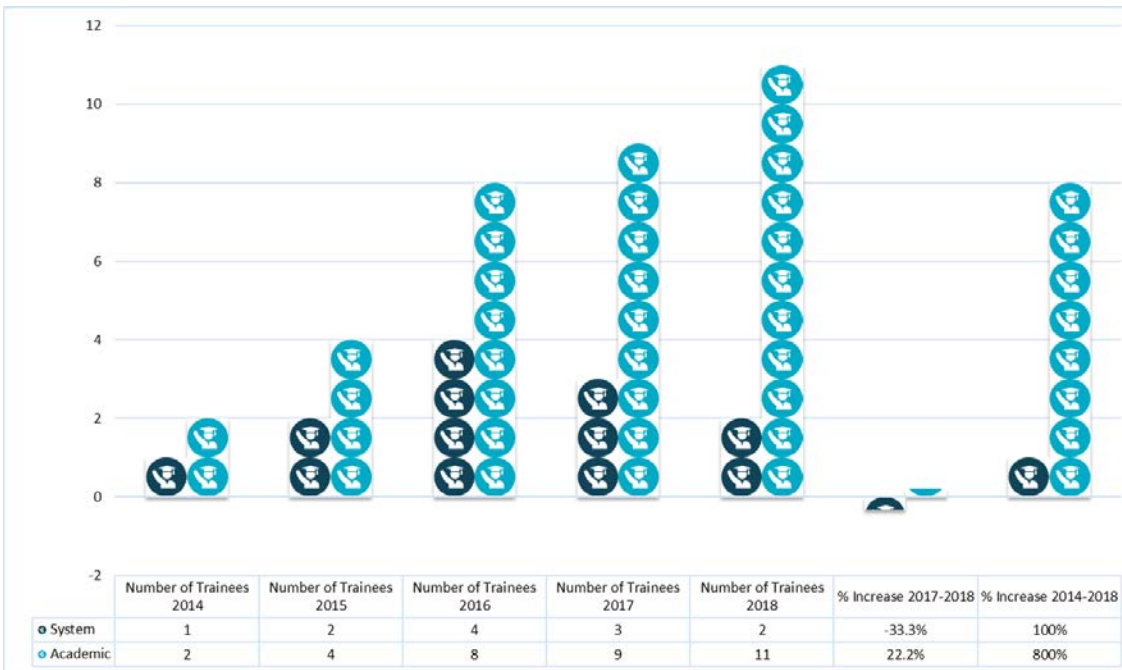
An estimated 15,740 people were exposed to CDPC training in 2018 (Figure 6) compared to 6113 in 2017. Of these, 11901 were classed as system-based (76%) and 3839 were academic-based (24%). This continues to reflect the CDPC’s commitment to embedding research informed change into the community, including into acute, primary-care, and residential aged-care settings.

**Figure 6: Number of academic and system-based researchers exposed to CDPC Training (2018, n=15740)**



Encouragement and economic involvement of early career researchers (ECRs) in the work of the CDPC has continued throughout the lifespan of the CDPC. CDPC funds utilised in this capacity building context reduced in 2018. This was expected as a result of the Centre not having additional input of funds to continue to support additional research and research staff, whether academic or system-based. (Figure 7).

**Figure 7: CDPC Trainee Placements Percentage of Academic vs System Based Placements (2014-2018)**



By the nature of the positions available, the trend is usually for early career researchers to be primarily involved in academic only placements. This trend continued to be reflected the capacity building support data for 2018 with 86% of trainees being completely based in academia and 14% of CDPC trainees having placement not only in academia but also in systems-based contexts.

With the CDPC's tenure as a NHMRC Partnership Centre for Better Health completing in 2019 the students who have been supported by CDPC funded research Activities had mostly completed by the end of 2018 and moved on to new positions to further their careers. We wish them good speed and believe that they will carry the learnings around improving care for people with dementia with them throughout their careers.



## CDPC PEER-REVIEWED PUBLICATIONS TO 31 DECEMBER 2018 (n=98)

1. **Harrison, S. L., Cations, M., Jessop, T., Hilmer, S. N., Sawan, M., & Brodaty, H.** (2018). Approaches to Deprescribing Psychotropic Medications for Changed Behaviours in Long-Term Care Residents Living with Dementia. *Drugs & aging*, 1-12. [\[More Information\]](#)
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11. **Standfield, L., Comans, T., & Scuffham, P. A.** (2018). Simulation of health care and related costs in people with dementia in Australia. *Australian Health Review*. [\[More Information\]](#)
12. **Ofori-Asenso, R., Ilomaki, J., Tacey, M., Curtis, A. J., Zomer, E., Simon Bell, J., ... Liew, D.** (2018). Prevalence and Incidence of Statin Use and 3-Year Adherence and Discontinuation Rates Among Older Adults With Dementia. *American Journal of Alzheimer's Disease & Other Dementias*®. [\[More Information\]](#)
13. **Haapala, I., Carr, A., & Biggs, S.** (2018). Differences in priority by age group and perspective: Implications for public health education and campaigning in relation to dementia. *International Psychogeriatrics*, 1-9. [\[More Information\]](#)
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16. **Taylor, M. E., Lord, S. R., Delbaere, K., Wen, W., Jiang, J., Brodaty, H., ... & Close, J. C.** (2018). White matter hyperintensities are associated with falls in older people with dementia. *Brain imaging and behaviour*, 1-8. [\[More Information\]](#)
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## APPENDIX A: CDPC 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.