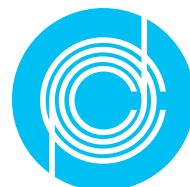


# CDPC INTERIM EVALUATION FINDINGS



COGNITIVE  
DECLINE  
PARTNERSHIP  
CENTRE

# IMPROVING THE CARE OF PEOPLE WITH DEMENTIA

The mission of the Cognitive Decline Partnership Centre (CDPC) is to develop and communicate research to improve the care of people living with dementia. The CDPC was awarded \$25 million under the Partnerships for Better Health scheme in April 2013, with contributions from the NHMRC, the Department of Health and Aging, and four industry partners: Brightwater Care Group, HammondCare, Helping Hand Aged Care and Alzheimer's Australia.

The CDPC is improving dementia care by adopting a knowledge-to-action framework which involves consumers, industry providers, academics and policy makers throughout the research process.



The CPDC is conducting 32 activities with the aim of influencing policy and practice impacts across 9 areas:

1. Aged care providers and health decision makers throughout Australia will have a measure of the **real cost of caring** for people with dementia, enabling them to plan services and shape policy more effectively and efficiently.
2. The CDPC will **evaluate respite models in multiple locations throughout Australia** to 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 substitute decision-making policies and practices**, enabling and empowering staff to respect and uphold the wishes of older people with cognitive decline.
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 CDPC 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.

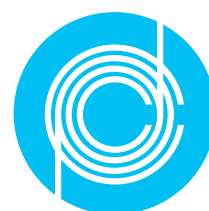
# INTERIM EVALUATION REPORT 2017

The CDPC is conducting an internal evaluation to better understand how well the CDPC is operating and the overall impact of its research activities. The evaluation provides the CDPC with important information that is being used to improve the CDPC's processes and outcomes over time.

THIS DOCUMENT REPORTS ON THE RESULTS OF THE INTERIM EVALUATION OF THE CDPC. IT REPORTS ON THE PROGRESS OF CDPC ACTIVITIES, THEIR OUTPUTS, NETWORK MEMBERS' PERCEPTIONS OF THE CDPC'S OPERATION, INFLUENCE AND IMPACT.

The analysis in this document draws on 35 qualitative interviews and 70 surveys with network members carried out in early 2017, and compares this data to that collected in the baseline CDPC evaluation in 2015.

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COGNITIVE  
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PARTNERSHIP  
CENTRE



# OUR PERFORMANCE

## MILESTONES & ACHIEVEMENTS

**95 %**  
OF MILESTONES  
ACHIEVED IN 2016

**82 %**  
OF MILESTONES  
ACHIEVED ON TIME

**246 %**  
INCREASE IN THE NUMBER  
OF ORGANIZATIONS  
INVOLVED IN WORKING  
WITH THE CDPC TO  
IMPLEMENT SYSTEMS  
CHANGE SINCE 2014

**160 %**  
INCREASE IN THE  
CDPC'S MEMBERSHIP  
RATE SINCE 2014.

## How well are CDPC Activities performing?

Since 2014, the CDPC has funded 30 activities with budgets ranging from \$9,167 to \$3.5 million, and partnered with two additional activities that were granted external funding. To date, 12 of the 32 activities are now complete.

Overall, CDPC Activities are operating exceptionally well. The CDPC's operational data shows that CDPC activities have markedly improved in their performance over time: they are meeting most milestones, working with more organizations to promote systems change, and achieving increased rates of publication. Evaluation data show that Activities have stayed on track due to the clear processes established by the CDPC Directorate to monitor the research activities. This, combined with an increase in enthusiasm for achieving the CDPC goals has led to increased performance.

## What have we learned?

Overall, members have a high level of satisfaction with the administrative processes of the CDPC. The reporting structure operates effectively and provides a system for monitoring research milestones and outputs. Some members expressed dissatisfaction about the demanding reporting requirement (currently quarterly) and provided the suggestion that a bi-annual report structure would suit the projects better. It was noted it might be helpful if there was more clarity about how the reports are utilised to ensure that the researchers feel that their work is purposive.

## CDPC activities and budget

| Activity    | Primary NHMRC Objective Activity Works Towards  | Name  | Total Budget |
|-------------|---|---|--------------|
| Activity 02 | Implementation  | Confused Hospitalised Older Persons Study (CHOPS)   | \$439,935    |
| Activity 04 |   | Alternative Respite Models  | \$413,590    |
| Activity 12 |   | Implementation of Vit-D Supplements in Residential Aged Care Facilities   | \$303,548    |
| Activity 20 |   | Telehealth Enabled Prescribing in Dementia  | \$586,555    |
| Activity 21 |   | Implementing Care of Older Persons with Dementia (COPE) in Australia  | \$877,991    |
| Activity 22 |   | Supporting and Caring for Residential Care Staff (extension)  | \$783,329    |
| Activity 24 |   | Supported Decision Making in Dementia Care  | \$669,354    |
| Activity 26 |   | Dementia Delirium Care with Volunteers  | \$0          |
| Activity 27 |   | National Quality Collaborative  | \$537,332    |
| Activity 28 |   | Implementing and Embedding Interprofessional Learning, Education and Practice (IPE) Across the Aged Care Sector                 | \$212,974    |
| Activity 29 |   | Implementation Evaluation – Exercise Prescription (EP) in Aged Care Project   | \$215,526    |
| Activity 30 |   | Do socialisation robots facilitate increase social engagement in aged care?   | \$97,708     |
| Activity 37 |   | Development of evidence-based Dementia Reablement Guidelines and Programs deliverable to people with early – moderate dementia. | \$219,603    |
| Activity 38 |   | Intervene Stage 2 - Pain management - best practice in residential aged care  | \$624,002    |
| Activity 03 | Synthesis and Dissemination   | Key Worker Role   | \$372,855    |
| Activity 05 |   | National Advance Care Planning  | \$575,543    |
| Activity 08 |   | Living with Dementia in the Community   | \$172,333    |
| Activity 10 |   | Supporting and Caring for Residential Care Staff  | \$372,799    |
| Activity 13 |   | National Australian Dementia Guidelines   | \$503,567    |
| Activity 14 |   | Primary Care Consensus Guide  | \$306,729    |
| Activity 01 | Collaborative New Research  | Long Term Care Configurations   | \$3,563,081  |
| Activity 06 |   | Financial Institution Policies / Practices  | \$132,956    |
| Activity 07 |   | Regulation of Aged Care Services – Effects  | \$458,711    |
| Activity 11 |   | Quality Use of Medicines  | \$1,795,848  |
| Activity 16 |   | Healthy Ageing in Australian Physicians   | \$0          |
| Activity 17 |   | Psychosocial Impact of Having a Parent with Dementia  | \$65,787     |
| Activity 18 |   | Dementia in the Public Domain   | \$517,050    |
| Activity 19 |   | Understanding risk and preventing falls and functional decline in older people  | \$472,118    |
| Activity 25 | Consumer Journey Modelling – Ideal State Project                                      | \$41,167  |              |
| Activity 33 | Validating and evaluating a quality of life (QOL) instrument for people with dementia | \$523,238   |              |
| Activity 09 | Capacity Building   | Evaluation of Interprofessional Education (IPE) in Residential Aged Care  | \$597,736    |
| Activity 15 |   | Modelling for Estimation of Cost Effectiveness of Aged Care   | \$9,167      |



# OUR PARTNERSHIPS

## How well is the CDPC building and sustaining partnerships?

**The CDPC is built on a model of collaboration between industry partners, consumers, academics, and clinicians.**

The survey and qualitative interviews show that these partnerships have strengthened with time, along with members' perceptions of the goals and visions for the CDPC. People also feel more positively about committing their time to the CDPC. Compared to the baseline (2015) findings, more people feel respected, see value in committing their time to the CDPC, and believe there is a clear vision for the CDPC. The majority of people in both surveys agreed that there is trust among partners and there is enthusiasm for achieving our goals. These data support the idea that the CDPC is becoming a more cohesive group and is working well together in partnership.

“ I think that as a whole, people are working together in partnership quite well. I think that silos existed at the beginning of the CDPC have been broken down, so people are working with people they might not have worked with before.

*Participant 23, Qualitative Interviews 2017*

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 to be 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:

“ I would say that's one of the strengths of the CDPC, is that people are listening to, we take on all the different thoughts of people, from the researchers through to the consumers. And for me that works really well.

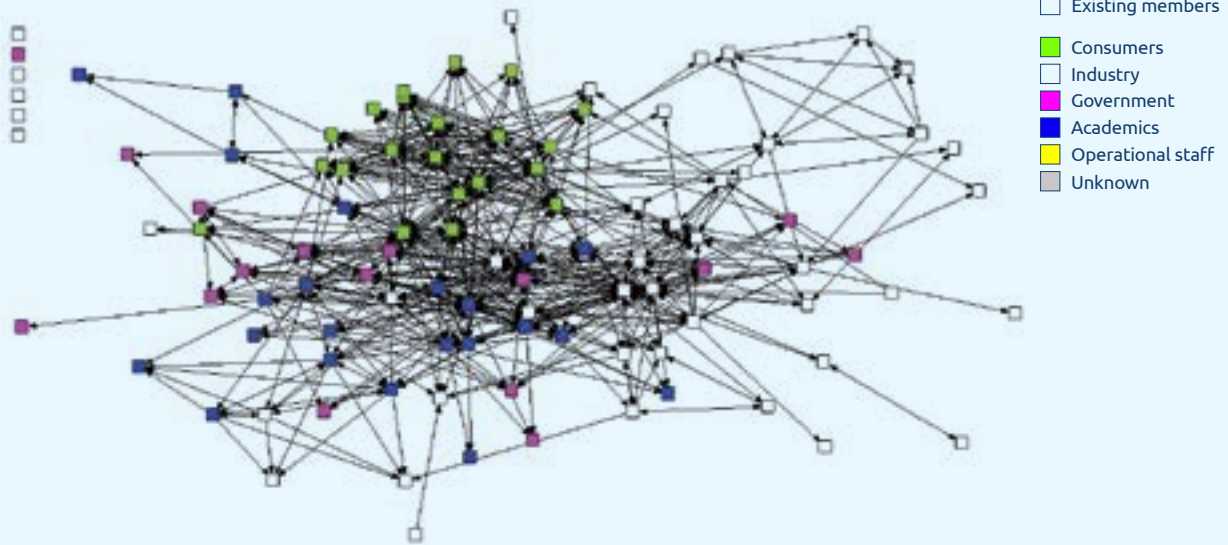
*Participant 47, Qualitative Interviews 2017*

“ ...we've been able to collaborate so closely and I think that's really improved our research questions and also the quality and the conduct of the actual research project. So, we've been working with [Industry Partner] really closely from the start, so they helped us refine our research questions and helped us to make it more relevant – even more relevant to them and to people with dementia and also to policy makers.

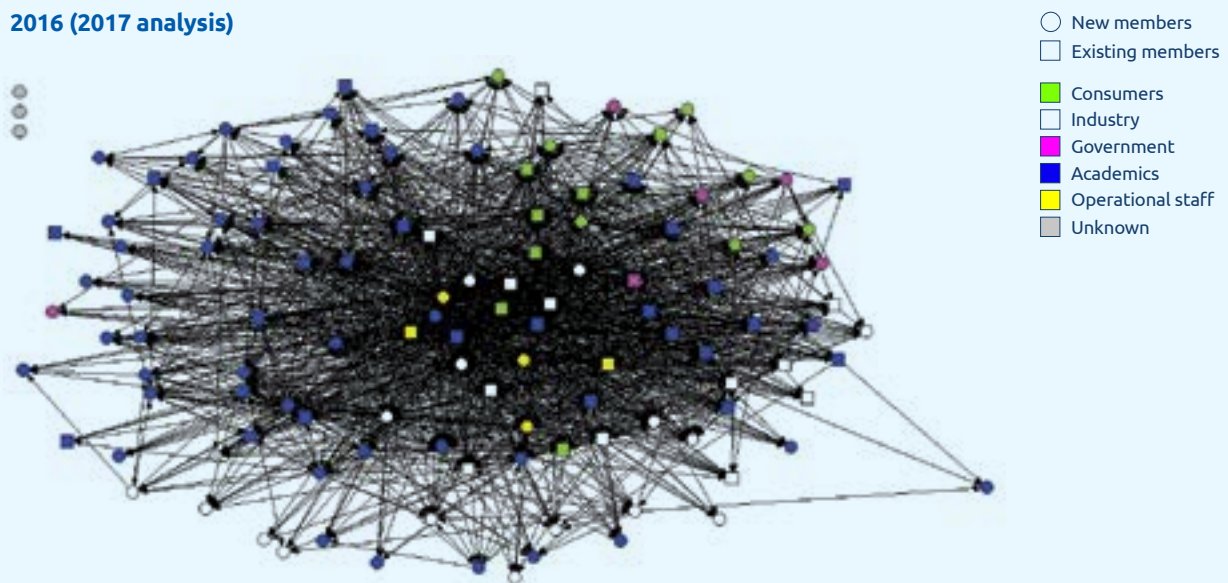
*Participant, Qualitative Interviews 2017*

# Social network analysis

## Baseline (before 2014)



## 2016 (2017 analysis)

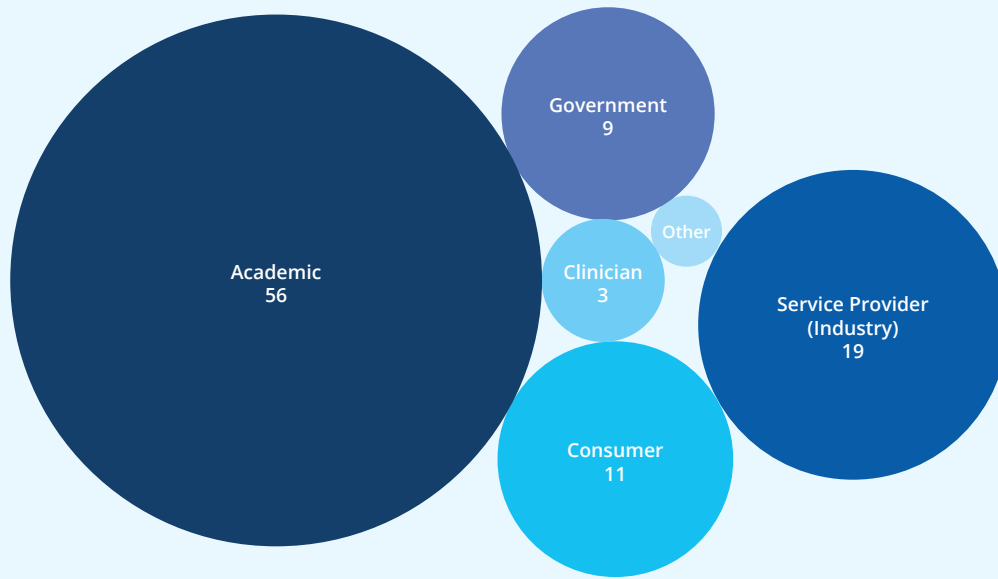


Social network analysis is the mapping of specific relationships. Within this context, the relationships are collaborations between CDPC network members. Social network analysis was conducted through the 2017 Network Survey. These results are compared to the Baseline (2015) results.

The minor decrease in density between the 2015 survey and the latest survey is expected to be due to a large amount of new members joining the network and the number of network members leaving the network since the last data collection. There is no significant pattern of collaboration exclusively within sectors which means that there is good inter-sectoral collaboration.

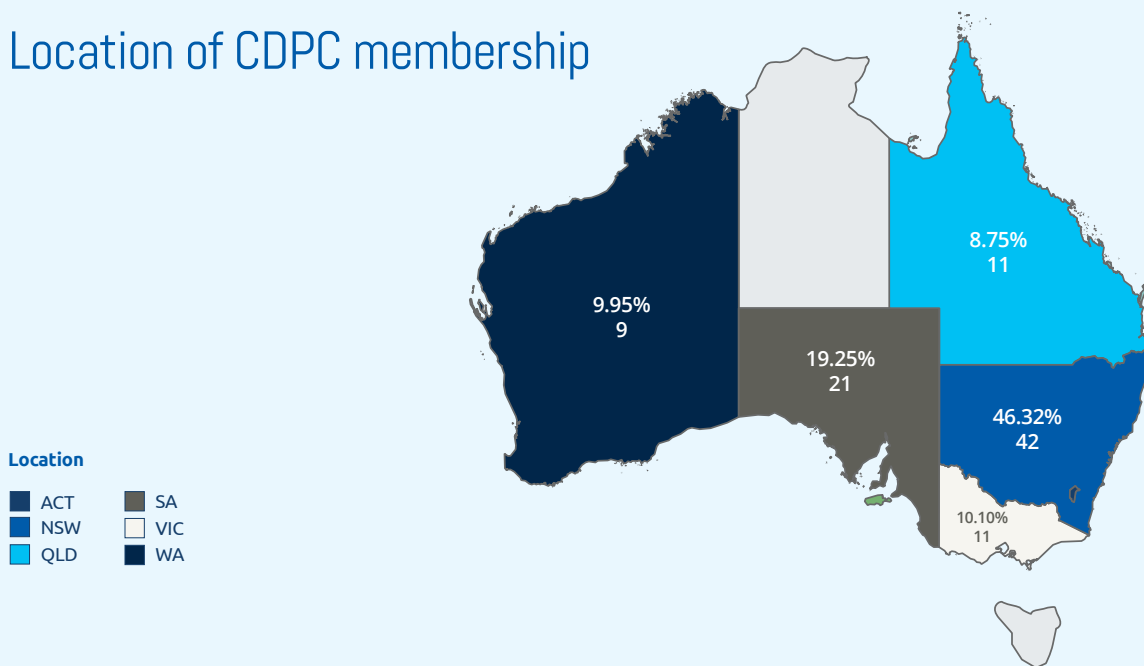
| Baseline (before 2014)                               | 2014 (2015 analysis)               | 2016 (2017 analysis)                                    |
|--|------------------------------------|---|
| 98 members were linked (6 had no connection)         | All 104 members were linked        | 119 linked together (3 had no connection with others)   |
| 699 individual links                                 | 2360 individual links              | 2294 individual links                                   |
| Density was low (6.7%)                               | Density was medium (22.7%)         | Density is medium-low (15.5%)                           |
| More ties within sectors rather than between sectors | Ties equally spread across sectors | There continues to be good inter-sectoral collaboration |

## Sectors involved in the CDPC



Sector. Colour shows distinct count of CDPC Id. Size shows distinct count of CDPC Id. The marks are labeled by Sector.

## Location of CDPC membership



## What have we learned?

CDPC partnerships have strengthened over time as people have learned how to work together. CDPC network members have built successful partnerships on trust, respect, a common purpose, and shared expectations. Working in partnership with people from different backgrounds can sometimes be challenging, so clear communication and joint problem solving are also important elements of sound partnerships.







# OUR OPERATIONS

## How well is the CDPC being administered and governed?

**The CDPC's operations – which are led by Professor Sue Kurrle and the CDPC Executive Team with support from the CDPC Directorate – are running well and have improved over time.**

Compared with the first round of the evaluation, satisfaction in the CDPC Directorate increased slightly, with 91% of survey respondents reporting that they are satisfied with the Director and Directorate team, and 81% stating that they are satisfied with the Executive Committee.

“ The communication with the administrative team has been excellent.

*Researcher, 2017 Network Survey*

“ The [Directorate] team seem really cohesive and work well together. They always have time to answer questions.

*Consumer, 2017 Network Survey*

“ I think [CDPC Directorate] have all done a brilliant job in trying to bring together a group of people that don't generally work very well together.

*Participant 34, Qualitative Interviews 2017*

**The Directorate Team has been responsible for improving the operation of the CDPC over time. Since the first round of the evaluation, the CDPC's operation has improved so that there is now better clarity around the CDPC's vision, roles and responsibilities, and what the CDPC is trying to achieve.**

Since 2015, there has been a considerable increase in satisfaction with Consumer and Industry involvement in the CDPC. 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 of the CDPC to date:

“ Giving consumers a real voice in research about their care. Now we need to learn to really listen.

*Researcher, 2017 Network Survey*

“ [The CDPC has] Improved opportunities for consumers to be effectively involved in dementia research as equal partners.

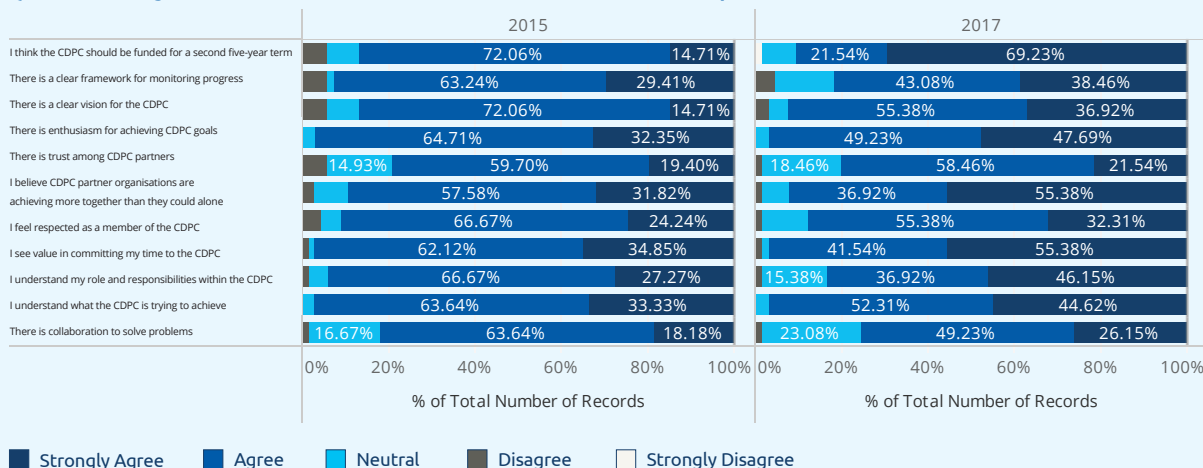
*Consumer, 2017 Network Survey*

While there were generally high levels of satisfaction regarding the consumers and industry enabling sub units, there continued to be some confusion among the CDPC network about the roles, responsibilities and achievements of the Policy and Legislation, Technology and Telehealth, Research Methodologies, Health Economics and Change Management Enabling Sub units. Some respondents are unsure how to utilise these resources or do not feel that the areas of expertise are relevant to their projects.

## Satisfaction with CDPC Operation

### Question wording

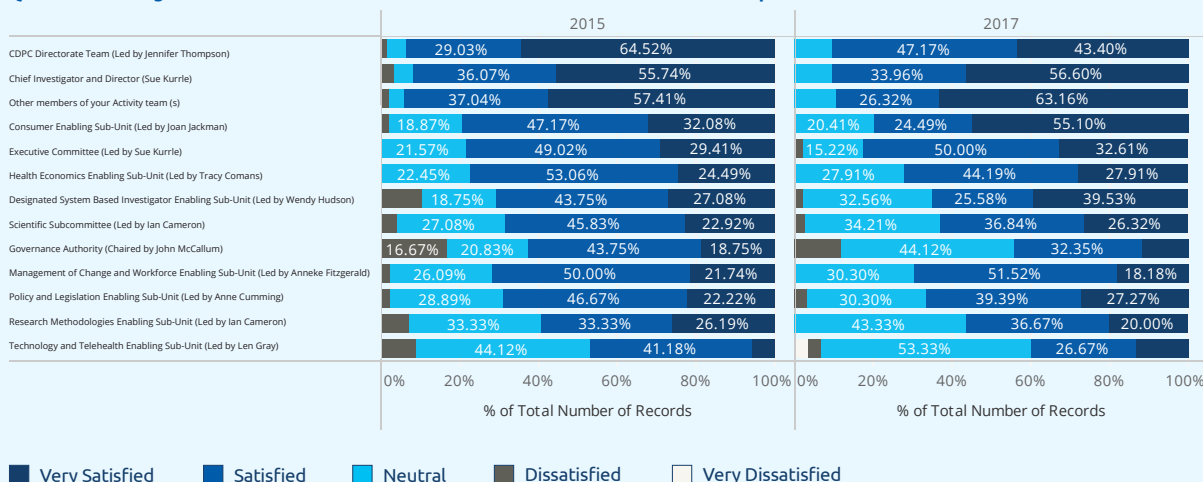
### Completion date



## Satisfaction with CDPC Units

### Question wording

### Completion date



The strategic leadership of the CDPC is provided by the Governance Authority, which is made up of leaders from each of the CDPC's four partner organizations, the NHMRC, and an independent chairperson. The evaluation survey and qualitative interviews found that there continued to be lower levels of satisfaction regarding the performance of the Governance Authority, with several qualitative interviewees expressing concern about the lack of consistent and supportive leadership provided to the CDPC by this group.

## What have we learned?

Beginnings are extremely important. When the CDPC began, the investigator team was selected after the research priorities had been established by the Governance Authority. The CDPC's priorities may have been clearer if they had been established in collaboration with academics, industry partners, policy makers and consumers. Furthermore, the ambiguity around the roles and responsibilities of the enabling sub-units may have been reduced if clear expectations and outcomes for enabling sub units, tied to the strategic priorities of the CDPC, had been established at the outset.

# OUR IMPACT

## What impact and influence has CDPC work had to date?

To date, the CDPC has had the largest influence on clinicians, consumers, academics and industry partners who are directly involved in the CDPC; the groups that have not been as consistently influenced by CDPC work so far have been policy makers, academics and health care practitioners external from the CDPC. Several of the qualitative responses to the survey and interviews suggested that the CDPC could do more to influence outside groups:

“ [The CDPC could] better target research findings to provider organisations, healthcare professionals and policy-makers, and develop long-term strategies for connecting research with practice.

*Researcher, 2017 Network Survey*

“ It would be great to see if we can have a push on how to influence policy makers... [we were] told to go to a [government] department which basically told us to go away. We didn't really have anywhere to go. It is difficult because Commonwealth departments have constant changes in staff that mean you lose contacts as they leave.

*Researcher, 2017 Network Survey*

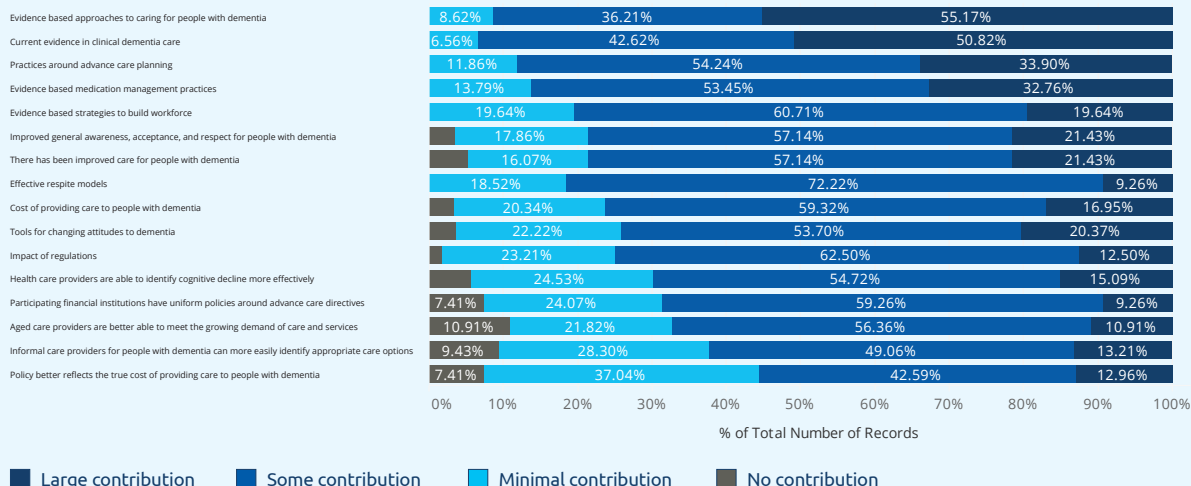
According to the survey, the CDPC's largest impact to date has been in the areas of gathering and disseminating evidence on the practice of providing care to people with dementia, clinical practice, and medication management.

The CDPC has had a smaller impact on broader policy change, the ability of informal carers to identify respite options, and the ability of aged care providers have a better ability to meet the increasing demands for their services. From both the qualitative interviews and the survey data there is disconnect between policy makers and the broader CDPC network. Policy changes take time to develop, so it is unlikely that CDPC research would have resulted in major policy change by this time in the funding period. A more targeted and strategic approach to involving policy makers and the government could leader to greater impact in this area in the future:

“ [The CDPC could have] better engagement in planning activities and the development of strategic frameworks, but where they actually want to go. And, I think, the – looking more at the context of where government policy.

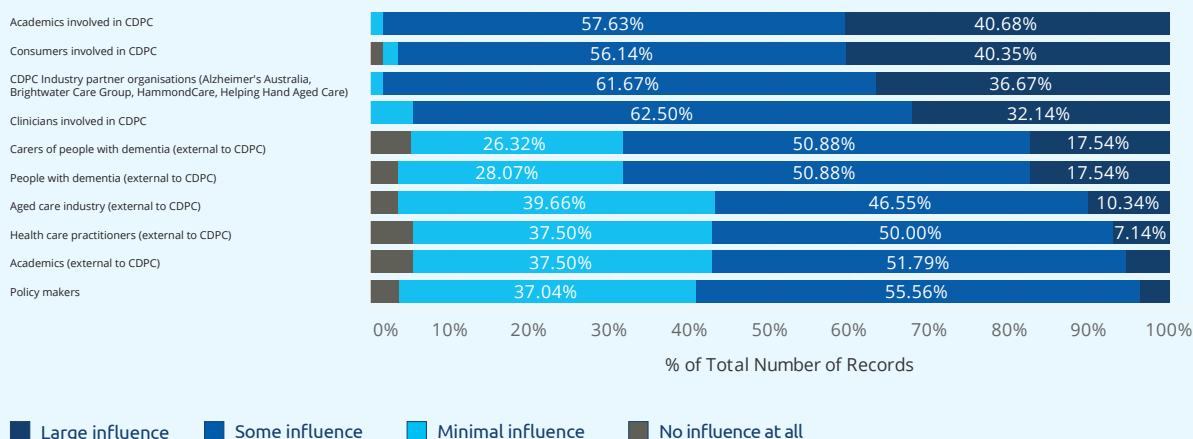
## What impact has the CDPC had on the following areas?

### Question wording



## What influence has the CDPC had on the following groups?

### Question wording



## What have we learned?

Research impact is a long term endeavour. The CDPC's end date is April 2019, and there is a considerable risk that the impact of the Centre will be diminished as network members move on to other activities. For the CDPC to maintain and maximize its impact, it is important for the Governance Authority, Executive Committee, and Enabling Sub-Units (along with support from the CDPC Directorate) to plan its closure carefully. Future Partnership Centres will benefit by establishing outcomes at the beginning that are realistic in terms of their scope and timeframe, and agreed upon by all key stakeholders.

# CONCLUSION AND ACKNOWLEDGMENTS

As the first partnership centre in Australia, the CDPC has successfully overcome bureaucratic and logistical challenges to bring together a network of researchers, consumers and industry partners who are united in a strong commitment to improving the quality of care for people with dementia.

The research activities being undertaken by the CDPC are performing well – the vast majority are achieving their milestones on time and within budget – and the CDPC’s profile has grown over the past three years. The CDPC has thoughtfully integrated consumers into almost all aspects of the research, which is still relatively rare in the Australian research context. In this way, the CDPC has so far met the objectives established by the NHMRC at the beginning of the scheme.

The challenge facing the CDPC going forward is how to solidify the impact of its research beyond the CDPC and into the broader community of clinicians, consumers and aged care providers. To date, the CDPC has had less influence externally and has not resulted in substantial changes in the policy, practice, and regulatory framework within Australia.

This is to be expected given that much of the CDPC’s research is ongoing or recently concluded. With the CDPC having just a five year term, there is a considerable risk that the momentum for achieving impact will falter, therefore reducing the potential impact of the CDPC. The CDPC Directorate and the Enabling Sub units should work together, along with the Executive Committee and the Governance Authority, to solidify impact over the next 18 months.



## Acknowledgements

Thank you to all who took the time to participate in the qualitative interviews and the network survey. We would also like to acknowledge the support of the co-investigators on this project:

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**Ms Joan Jackman**

**Prof Susan Kurrle**

**Dr Katrina Radford**

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