FINAL EVALUATION REPORT

COGNITIVE DECLINE PARTNERSHIP CENTRE

THE UNIVERSITY OF SYDNEY

DEVELOPING, COMMUNICATING & IMPLEMENTING RESEARCH TO IMPROVE CARE

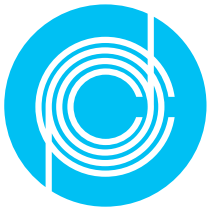
The Cognitive Decline Partnership Centre (CDPC) is a unique research centre in which industry, research and consumer partners work together to improve the quality of care for people living with dementia by developing and communicating high quality research. As the first of three Partnership Centres for Better Health funded by the National Health and Medical Research Council (NHMRC) in 2013, the CDPC received $25 million in funding from six partner organizations: the NHMRC, Department of Health and Ageing, three industry partners: Brightwater Care Group, HammondCare, Helping Hand Aged Care, and one peak body: Dementia Australia.

This is the final report of the internal evaluation of the CDPC. It provides a summative assessment of the CDPC's performance over time, including an overview of the Centre's activities and outputs. It also includes network members' perceptions on the CDPC's operation, influence and impact over the funding period.

The evaluation found that the CDPC achieved high levels of outputs and communication, thereby contributing to the collective knowledge on effective approaches to caring for people living with dementia. Individual CDPC activities achieved national influence in the areas of supported decision-making and evidence about the true cost of caring for people living with dementia. There is a strong potential for future national impact in the areas of clinical decision-making and appropriate medication management. The CDPC's experience also uncovered several lessons that could inform and improve future partnership models. Some of these lessons include ensuring that expectations are clear from the beginning, fostering open, direct communication among members, and building trust among partners.

THIS IS THE FINAL REPORT OF THE INTERNAL EVALUATION OF THE CDPC. IT PROVIDES A SUMMATIVE ASSESSMENT OF THE CDPC'S PERFORMANCE OVER TIME, INCLUDING AN OVERVIEW OF THE CENTRE'S ACTIVITIES AND OUTPUTS. IT ALSO INCLUDES NETWORK MEMBERS' PERCEPTIONS ON THE CDPC'S OPERATION, INFLUENCE AND IMPACT OVER THE FUNDING PERIOD.

FINAL EVALUATION REPORT



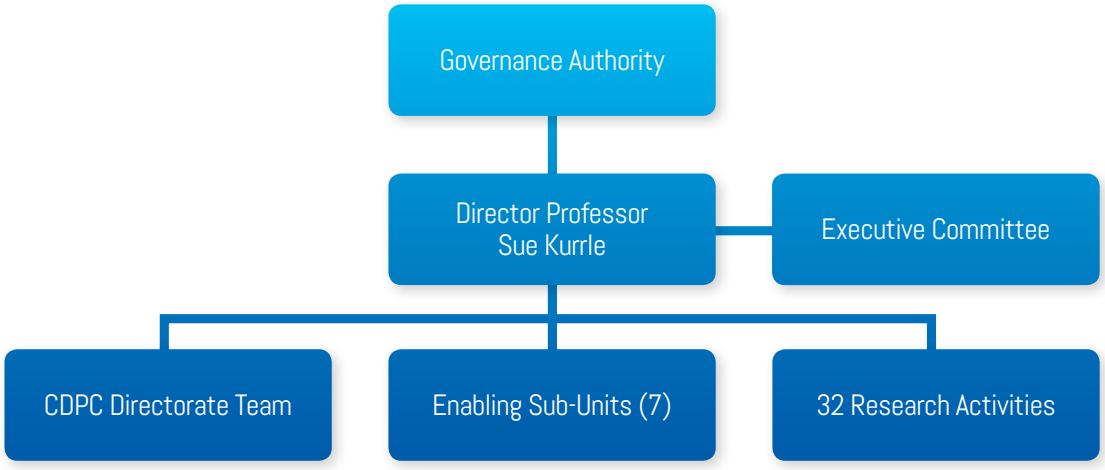
COGNITIVE DECLINE PARTNERSHIP CENTRE

THE COGNITIVE DECLINE PARTNERSHIP CENTRE

Overview

The CDPC brings together academics, clinicians, service providers and consumers to conduct applied research and knowledge translation activities around effective models of care and support for people with cognitive and related functional decline. The work of the CDPC is underpinned by a knowledge to action model, meaning the end users of the research (both consumers and funding partners) are integrated into research from the earliest stages to ensure that research generates relevant and easily transferable knowledge *(Graham et al. 2018 & Wilson et al. 2011).*

The CDPC is led by Chief Investigator (CI) and Director, Professor Susan Kurrle, who is responsible for providing the overall leadership and management of the CDPC, including overseeing the Directorate team, enabling sub-units, activities and other initiatives. The CI receives advice regarding the operation of the CDPC from the Executive Committee which is made up academic and systems-based investigators and a representative from the Consumer Enabling Sub-Unit. The CI reports to the Governance Authority, which is comprised of representatives of the four Funding Partners – Dementia Australia, Brightwater Care Group, HammondCare, Helping Hand Aged Care, and the NHMRC.



CDPC activities

From 2014–2019, the CDPC conducted **32 research activities** to explore eight thematic areas regarding dementia care, including: Service Model Options, Pathways and Navigation, Planning for Later Life, Attitude and Culture; Workforce Development and Education; Medication Management, Clinical Guidelines, and Functional Decline. Specific activities, time frame and budget is provided in the following table.

Activity	Name	Start Date	End Date	Total Budget
Activity 01	Long Term Care Configurations	13/1/14	31/12/18	$3,563,081.00
Activity 02	Confused Hospitalised Older Persons Study (CHOPS)	1/7/13	12/31/2015 (ONGOING WITH ADDITIONAL FUNDING)	$461,410.00
Activity 03	Key Worker Role	13/1/14	31/12/16	$372,705.00
Activity 04	Alternative Respite Models	13/1/14	12/4/16	$413,590.00
Activity 05	National Advance Care Planning	13/1/14	31/3/17	$575,543.00
Activity 06	Financial Institution Policies / Practices	13/1/14	12/01/2015 (ONGOING WITH ADDITIONAL FUNDING)	$137,956.00
Activity 07	Regulation of Aged Care Services – Effects	13/1/14	31/12/17	$447,711.00
Activity 08	Living with Dementia in the Community	13/1/14	30/6/16	$172,333.00
Activity 09	Evaluation of IPE in Residential Aged Care	1/2/13	31/1/16	$597,736.00
Activity 10	Supporting and Caring for Residential Care Staff	1/7/13	30/9/15	$372,799.00
Activity 11	Quality Use of Medicines	13/1/14	12/01/2019 (ONGOING WITH ADDITIONAL FUNDING)	$1,819,848.00
Activity 12	Implementation of Vit-D Supplements in Residential Aged Care Facilities	13/1/14	30/9/17	$303,548.00
Activity 13	National Australian Dementia Guidelines	13/1/14	30/9/17	$503,567.00
Activity 14	Primary Care Consensus Guide	13/1/14	30/6/17	$306,729.00
Activity 15	Modelling for Estimation of Cost Effectiveness of Aged Care	13/1/14	12/6/16	$9,167.00
Activity 16	Healthy Ageing in Australian Physicians	13/1/14	12/1/15	$-
Activity 17	Psychosocial Impact of Having a Parent with Dementia	13/1/14	12/4/15	$31,143.00
Activity 18	Dementia in the Public Domain	1/1/16	31/12/18	$528,050.00
Activity 19	Understanding risk and preventing falls and functional decline in older people	1/7/15	31/12/18	$472,118.00
Activity 20	Telehealth Enabled Prescribing in Dementia	1/1/16	31/12/18	$586,555.00
Activity 21	Implementing COPE in Australia	31/3/16	31/12/2018 (ONGOING WITH ADDITIONAL FUNDING)	$883,991.00
Activity 22	Improving residential dementia care through staff	1/10/16	31/12/18	$783,329.00
Activity 24	Supported Decision Making in Dementia Care	1/1/16	31/12/2018 (ONGOING UTILISING EXISTING FUNDING)	$669,354.00
Activity 25	Consumer Journey Modelling – Ideal State Project	1/7/16	30/4/17	$41,167.00
Activity 26	Dementia Delirium Care with Volunteers	1/3/15	31/12/2018 (ONGOING WITH ADDITIONAL FUNDING)	$22,502.00
Activity 27	National Quality Collaborative	1/9/17	31/12/2018 (ONGOING WITH ADDITIONAL FUNDING)	$556,530.00
Activity 28	Implementing and embedding interprofessional learning, education and practice across the aged care sector	12/4/16	17/7/17	$212,974.00
Activity 29	Implementation Evaluation – EP in Aged Care Project	1/4/16	31/12/18	$215,526.00
Activity 30	Innovation Research – understanding human-robot interaction	1/8/16	17/7/17	$95,012.00
Activity 33	Validating and evaluating a quality of life (QOL) instrument for people with dementia	15/9/16	31/12/2018 (ONGOING UTILISING EXISTING FUNDING)	$523,238.00
Activity 37	Development of Dementia Reablement Guidelines and Programs	16/1/17	31/05/2018 (ONGOING WITH ADDITIONAL FUNDING)	$243,865.00
Activity 38	Intervene Stage 2 – Pain management – best practice in residential aged care	1/11/16	31/10/2018 (ONGOING WITH ADDITIONAL FUNDING)	$632,202.00

CDPC EVALUATION

An evaluation was undertaken by CDPC staff to monitor the centre's progress on research activities, inform improvements and measure the overall impact of CDPC research against its intended impact areas.

The evaluation adopted a longitudinal, mixed methods research design to answer three primary research questions:

1. **Stream 1** – to what extent has the CDPC met its objectives? (Monitoring)
2. **Stream 2** – what lessons have been learnt about doing research in partnership? (Process)
3. **Stream 3** – what short-term and long-term impacts have the CDPC achieved? (Impact)

The research design was chosen because stakeholders required evidence about the CDPC's impact and the lessons learnt from working in partnership. These aims were best met through a mix of qualitative and quantitative data. An evaluation of a large scale research translation scheme in Canada used a similar methodology *(Canadian Institutes of Health Research 2015 & McLean et al. 2015)*.

Qualitative and quantitative data was collected at three separate points in time (2015, 2017, 2018). All active members each year were invited to participate in a network survey. For the purposes of the evaluation, an active member of the network was defined as someone who was involved in a CDPC committee, enabling sub-unit, Activity team, or other initiative in that current year. Participants who left the network were excluded.

Overall participation in CDPC evaluation

	2015	2017	2018
Interview participants	40	33	19
Survey respondents	71 (78% response)	68 (56% response rate)	43 (38% response rate)
Total network population	91	121	113

A group of network participants were also invited to participate in qualitative interviews. Interviewees were selected in order to cover a diversity of experiences and perspectives on the operation of the CDPC, and interview data was collected until thematic saturation was reached during each round of data collection.

Participants – Qualitative interviews

Year	2015	2017	2018
Demographics	Activity leads Executive Committee Governance Authority DSBI Consumers Enabling Sub-Unit Directorate	Activity leads Executive Committee Governance Authority DSBI Consumers Enabling Sub-Unit Directorate External service providers	Activity leads Executive Committee Governance Authority DSBI Consumers Enabling Sub-Unit Directorate
Total interviewed	N = 40	N = 33	N = 19

Qualitative data was uploaded to QSR International NVivo 10, which is a piece of software that facilitates code and retrieve functions involved with qualitative data analysis *(Bryman 2012)*. Qualitative data were analysed using thematic analysis, meaning that patterns and themes in the data were identified and coded into categories, and combined to determine the underlying story of the data *(Braun et al. 2019 & Nowell et al. 2017)*. Survey data was analysed using the Statistical Package for the Social Sciences (SPSS) software *(IBM Corp., 2013)*. Non-parametric statistics were used due to the non-normal distribution among the data: data was analysed both longitudinally using the Wilcoxon Signed Rank test, and cross-sectionally, using the Kruskal Wallace one way ANOVA of variance *(Pett 2015)*. Findings from the qualitative, quantitative and monitoring data were compared against each other to understand the similarities and differences across the findings and, in some instances, were summarized as case studies to explore project impact in more detail.

STREAM ONE

MEETING NHMRC OBJECTIVES

The CDPC achieved solid operational performance against its objectives.

Evaluation data shows that the CDPC achieved a solid level of operational performance over its six-year operating period. A diversity of activities addressed each of the objectives set for Partnership Centres by the NHMRC. The CDPC's Activities met their milestones 96% of the time and communicated findings to external audiences through 1541 total outputs as well as an active communication strategy.

NHMRC objectives

NHMRC Objective	Number CDPC Research Activities
Collaborative New Research	10 Activities
Synthesis and Dissemination	6 Activities
Capacity Building	2 Activities
Implementation	14 Activities

Milestones

Milestones achieved by the end of 2018 across all CDPC funded Activities:

96%
TOTAL ACHIEVEMENT RATE BY END OF 2018

808
TOTAL MILESTONES ACHIEVED

838
TOTAL MILESTONES DUE

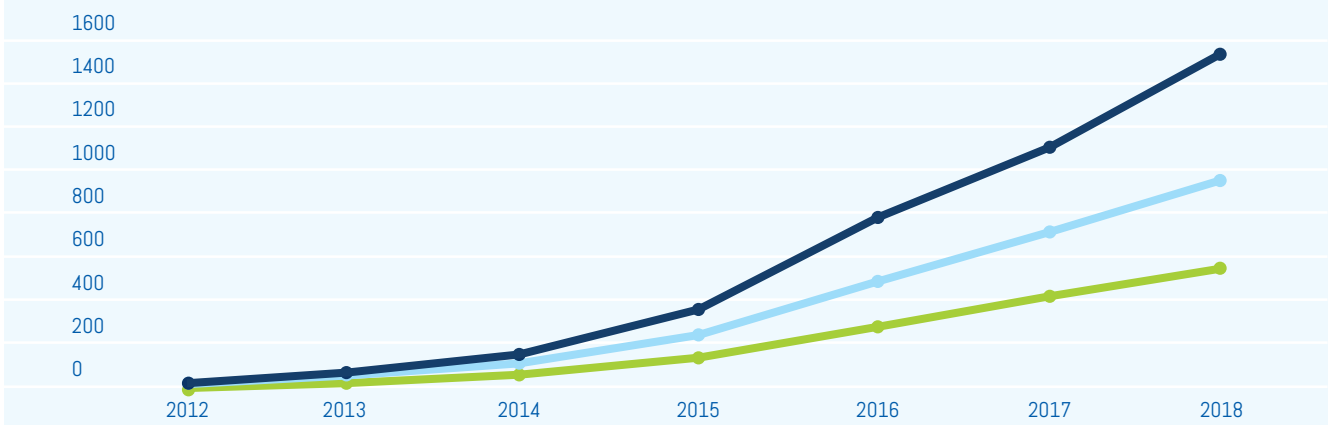
CDPC outputs

The reach of CDPC research has expanded considerably over time. The number of non-traditional outputs (n=956 total) remains higher than the total number of traditional outputs (n=585 total).

With over 1500 outputs, the audience being reached by CDPC has expanded considerably over time. Most recently the work of the CDPC was showcased on an international level at the Alzheimer's Disease International (ADI) conference in 2018. An official video, Every Three Seconds (**youtube.com/watch?v=QcgUOER1KTw**) was produced by ADI and ITN Productions and shown to all attendees at the conference held in 2018. The CDPC was asked to be part of this production to demonstrate the research that has been done and the impact that the CDPC is having on dementia care in the Australian and international context.

Total outputs (traditional and non-traditional)

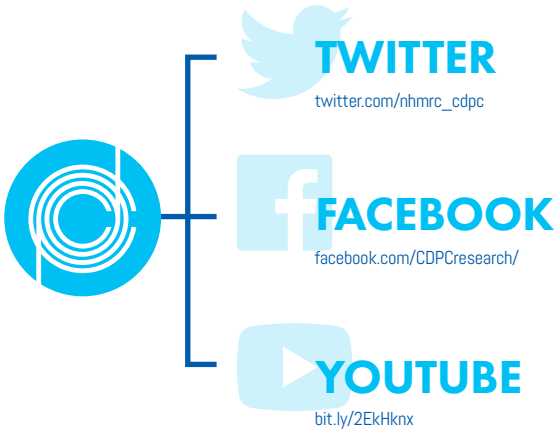
The number of outputs where CDPC research findings have been delivered has increased over the life of the CDPC



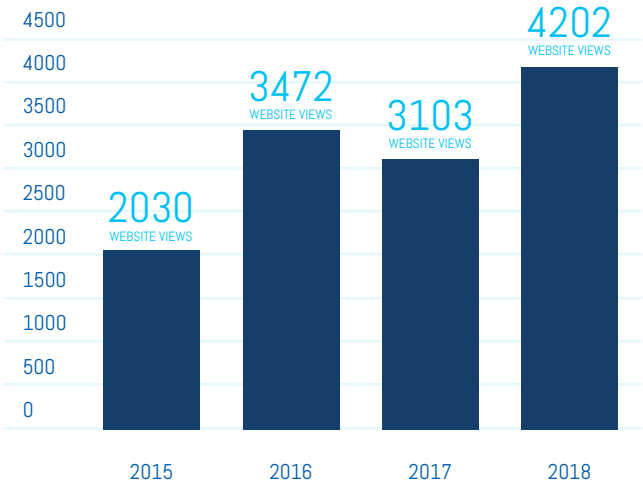
Traditional outputs (e.g. peer-reviewed)
Non-traditional outputs (e.g. publication editorials, radio interviews, technical reports)

CDPC external communication reach

CDPC has representation across several social media channels such as YouTube, Facebook, and Twitter.



Website traffic (over time):



The main CDPC social media outlet is **Twitter** where there are **748 followers**. The CDPC also has a growing presence on YouTube and Facebook.

Lessons learnt

CDPC activities stayed on track due to the clear processes established by the Centre Directorate to monitor the research activities. While the reporting structure operated effectively, some participants expressed dissatisfaction about the quarterly reporting requirement and provided the suggestion that a bi-annual report structure would have been less onerous and just as effective in keeping activities accountable.

STREAM TWO

CDPC PARTNERSHIPS

The CDPC achieved ground breaking, effective partnerships.

The CDPC Network was composed of a diversity of partners who actively worked together on research and implementation projects. The evaluation data showed that the CDPC formed ground breaking and effective partnerships between industry partners, clinicians, researchers, and consumers.

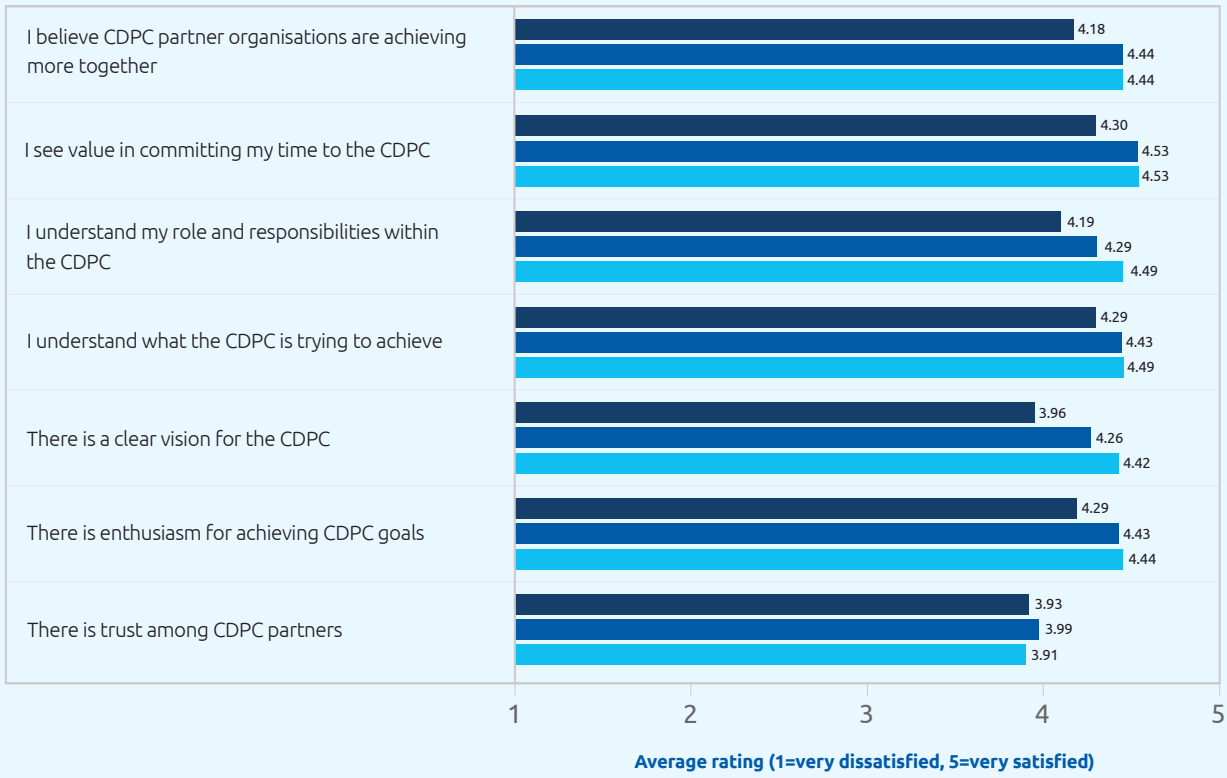
2018 – Active CDPC network members

Year	2018
Sector	62 Academics (55%) 30 Service Provider (Industry) (27%) 18 Consumers (16%) 3 Government (3%)
Region	6 ACT (5%) 44 NSW (39%) 15 QLD (13%) 24 SA (21%) 1 TAS (1%) 9 VIC (8%) 13 WA (12%) 1 International (1%)
Total active network members	N = 113

Although many CDPC members did not have prior experience conducting research in the area of dementia, most members were passionate about and committed to the CDPC's mission to improve the lives of people living with dementia. This finding was reflected in the survey data where there continued to be high levels of commitment to the CDPC vision; amongst repeated participants, there was a statistically significant increase in clarity of the vision of the CDPC over time (0.007, n=17).

Satisfaction with CDPC partnerships

Question wording



Participants said:

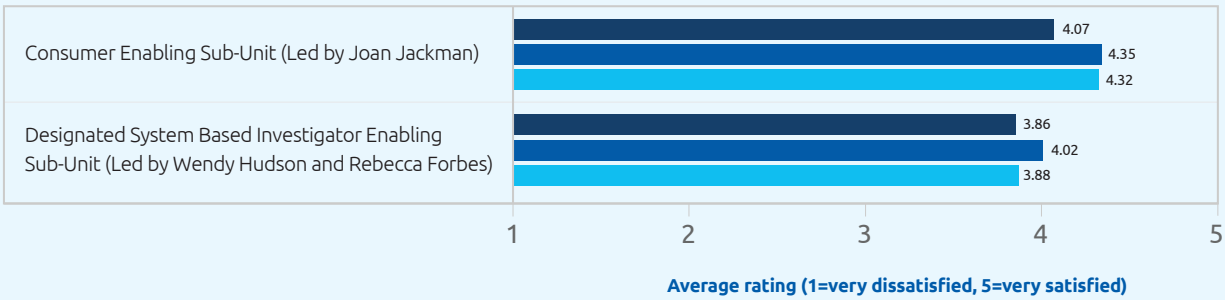
> "I think there's been a real swing to collaboratively working together right from the beginning and I think that's because we've developed relationships and like anything you trust people and you become friendly with them. And even though they are work relationships you don't have work relationships with people you don't like if they're not successful, you can have them but they're not successful."

Qualitative interview participant 2018

The majority of qualitative interviewees felt that the involvement of consumers in research from the beginning was one of the CDPC's strongest assets. Consumers and network participants who were directly involved in the CDPC research were particularly positive about the lead of the Consumer Enabling Sub-Unit whose role and approach helped to make participating in research an understandable and digestible process. Involving carers and people living with dementia in the projects was not only beneficial for the projects, but also for the consumers themselves, as this was an opportunity to build their networks *(Littlechild et al. 2015, Stevenson & Taylor 2017).*

Satisfaction – consumers and DSBIs

Question wording



Year of completion date 2015 2017 2018

Participants said:

"I would have to say [the impact of consumers being involved research projects] would be one of the [CDPC's] best assets. It ensures that the research is always reflecting their needs. It's really good expert feedback and stuff that you wouldn't think of necessarily all the time. If you've got your research hat on you might just be plugging along and not think of some real-world applications, or how something might be received or done in the real world."

Qualitative interview participant 2018

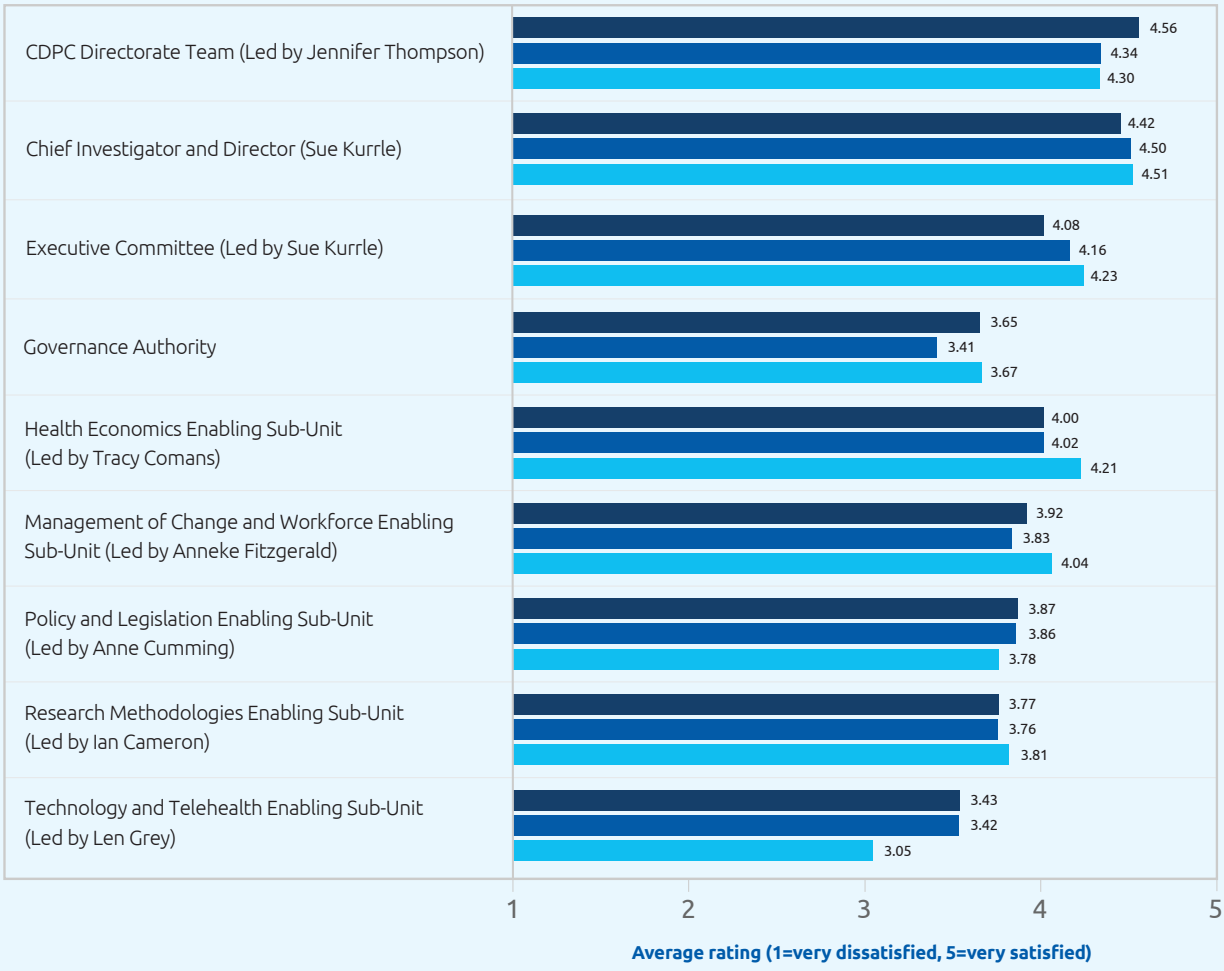
"Being involved with the CDPC, and the other advocacy work that we do, has filled a void because when [the person living with dementia] was forced to leave work, [they] fell down in a heap. But now [they] have a purpose in life again. And there's a lot of people out there with dementia who fit in to that same category. And I'm a very strong advocate for looking after other people who have also been newly diagnosed, or who would like to know about getting involved with all this sort of stuff."

Qualitative interview participant 2018

Partnerships were supported and maintained by the administration and governance of the CDPC. Most interviewees who participated across the three-year evaluation period expressed positive views about the leadership provided by the CDPC Director and the CDPC Directorate team. Many specifically touched upon how much the Director was a respected leader in the field of dementia research and how her leadership style enhanced the CDPC. There was lower average satisfaction overall regarding the Governance Authority and some of the enabling sub-units. There were no statistically significant differences in satisfaction scores over the evaluation period.

Satisfaction – CDPC administration and governance

Question wording



Participants said:

> "I think that the people involved within the management team within the Centre, [are] very skilled and very dedicated to make things work well. We've really appreciated everyone's involvement in there and it really has been quite a wonderful model."

Qualitative interview participant 2018

> "I think [the CDPC Director]'s relationships with the researchers, and the respect that they have for [her] I think always comes through with everything that we do. I think she's very highly regarded and so I think that works really well for the centre."

Qualitative interview participant 2018

The qualitative data suggest that partnerships could have been improved by clearer expectations about the scope and expected impact of CDPC work from the beginning. For example, industry partners expected that the CDPC would achieve large scale impact fairly quickly, and that they should be setting the research agenda for the CDPC alone rather than in partnership with academics and consumers. These issues were not sufficiently addressed in the early years of the CDPC and therefore they did not improve over time. There were unclear expectations about the scope and outcomes of the work of the Enabling Sub-Units, resulting in low levels of utilisation and satisfaction of the support provided by some of the sub-units.

Lessons learnt

Previous CDPC evaluation data found that partnerships worked well when there is a strong commitment to shared goals, shared expectations about direction and purpose, sound approaches to problem solving, frequent communication, appropriate resourcing, and trust *(McDermott et al. 2015).* While individual activity teams and the CDPC Directorate worked well together in each of these areas, there were lower levels of congruence between partner organizations overall regarding the expectations of the CDPC's scope and impact. There remained a level of distrust between industry and academic participants overall. As discussed in the interim evaluation report, these issues may have been mitigated if the Centre's work plan had been established in collaboration with academics, industry partners, policy makers and consumers at the Centre's outset *(Kitching et al. 2017).*

The intentional involvement of consumers was one of the most unique parts of the CDPC's structure. While the involvement of consumers was an important step in improving the inclusiveness of research on caring for people living with dementia, future consumer involvement could be improved by including more diversity, including Culturally and Linguistically Diverse and geographically remote groups which have been historically under-represented in research and policy.

Participants said:

> "I think, it was that naivety that [the industry partners] wanted to see huge changes in practise immediately, either when a project started or when it finished and it doesn't work like that, so I think, there's an education needed in relation to industry."
>
> *Qualitative interview participant 2018*

> "You had a disparate group of partners, all with their own agendas, all coming together and perhaps it wasn't balanced. The biggest mistake was that there wasn't equality within the partners so, in other words, either how much money they put in or how strong a voice they had."
>
> *Qualitative interview participant 2018*

STREAM THREE

CDPC IMPACT

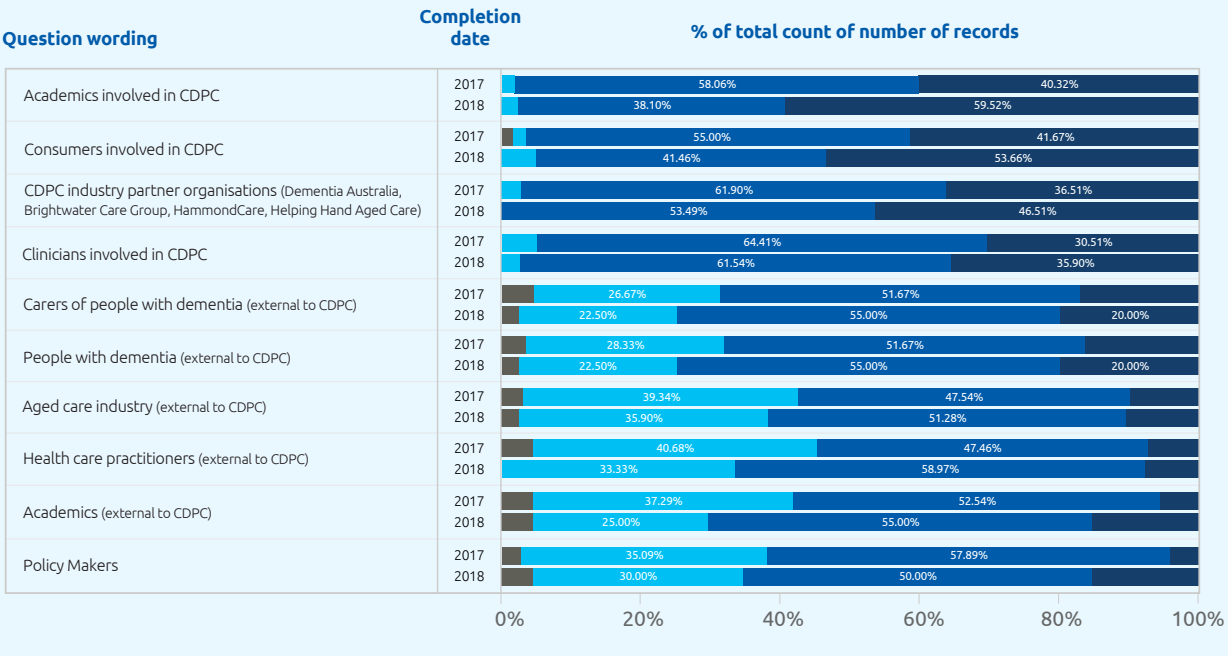
The CDPC achieved medium to large scale implementation across six of its nine impact areas.

Survey and qualitative data were used to understand the impact of CDPC activities on local, regional and national stakeholders and practices. This section summarises the overall influence and implementation reach of CDPC activities, before looking in detail at case studies under each of the nine impact areas. The case study structure and approach adopted in this section was modelled after the Research Excellence Framework in the UK, which is used to understand the broader impact of academic research activities *(Bornmann 2012 & REF Impact Case Studies 2014).*

CDPC influence

CDPC network members reported that the Centre's work has had some influence on all stakeholder groups, and that the largest influence has been on academics, consumers, industry partners and clinicians involved in the CDPC. There was a statistically significant increase in the influence of CDPC work on policy makers over time *(independent samples Kruskal Wallis test, p=0.013).*

What influence has the CDPC had on the following groups?



Implementation of CDPC research

Data collected for the evaluation shows that CDPC research has been widely disseminated and implemented. The following table shows that there have been four levels of implementation across the nine impact areas; the case studies presented later in the report are evidence based accounts of current implementation activities in each of these areas. The case studies show that the CDPC achieved medium or large scale implementation in six of the nine impact areas. Activities have not yet finished assessing the long term impact of these implementation activities on people with dementia, their carers, and the workforce.

Scale of CDPC implementation	Description	Impact area and case study activity
Pre-implementation	Collaborative research has been conducted and disseminated. While there may be future implementation of this research, there is not any evidence of current implementation activities.	Impact Area 4: Attitudes to dementia (page 28) Impact Area 6: Regulations on dementia care (page 30)
Small scale implementation	Activity results have been disseminated and changed policy or practice in: • Organizations in 1–2 Australian states • One organization in one international site.	Impact Area 5: Building Workforce (page 29)
Medium scale implementation	Activity results have been disseminated and changed policy or practice in: • Organizations across 3–4 Australian states and territories • More than one organization in two or more international sites.	Impact Area 2: Respite Models (page 26) Impact Area 7: Medication Management (page 31) Impact Area 9: Implementation of care models (page 34)
Large scale implementation	Activity results have been disseminated and changed policy or practice in: • Federal government, national non-government or advocacy organisations, or • Multiple organisations across most Australian states and territories • Foreign national governments or international peak bodies.	Impact Area 1: Cost of Care (page 24) Impact Area 3: Supported decision-making (page 27) Impact Area 8: Clinical Guidelines (page 32)

Lessons learnt

The CDPC intended to achieve nine impacts. To date, the Centre has achieved medium to large scale implementation across six of the nine impact areas, which is a significant achievement within its six-year funding period. Yet, the impact of these implementation activities on people living with dementia, carers and the industry overall has yet to be determined. In hindsight, the CDPC may have had a more measurable impact if it had scaled back the number of impact areas, focused on areas that were of most importance to stakeholders, and placed greater focus on translation and outcome measurement from the beginning.

Measuring and reporting on the overall impact of the CDPC's large scale knowledge translation efforts proved to be challenging because the breadth of policy and practice impact was not necessarily known by research teams and therefore could not be sufficiently captured by the evaluation methodology which depended on network members' knowledge of their own activity's policy and practice impact. It is possible that the time frame is too short to fully understand the impact of these activities, because policy and practice changes often take years to achieve and measure *(Roussos, S. T. & Fawcett 2000; Alexander et al. 2003)*. As the theory and practice of implementation science and large-scale impact measurement improve over time, we hope that future partnership centres can utilise methodological approaches that measure long term impact with greater confidence.

IMPACT CASE STUDIES

IMPACT AREA

1

Aged care providers and health decision makers throughout Australia will have a measure of the real cost of providing care to people living with dementia, enabling them to plan services and shape policy more effectively and efficiently.

Activities aiming for impact in this area: Activity 1, Activity 15, Activity 33

Total outputs in this impact area: 269 (109 traditional; 160 non-traditional)

CASE STUDY

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

CDPC Activity Number	Activity 1
Timeline	13/01/2014–31/12/2018
Total outputs to date	260 outputs (103 traditional; 157 non-traditional)
Budget	$3,563,081.00

Project overview

This activity provides information on the costs and consumer reported outcomes of residential aged care provided for people with cognitive decline across a range of service configurations. An Australian consumer derived outcome measure around choice and quality of care was developed and the results allow for international comparisons.

Details of impact

In mid-2018 a major publication was released by this research project in the Medical Journal of Australia (1). This publication release generated major media coverage including ABC podcasts, radio interviews, and articles in online and print media (2).
In 2017, the research team produced CCI-6D *(Consumer Choice Index – 6 Dimension)* which is a tool to measure quality of aged care and generated interest for its potential use by the Australian Aged Care Quality Agency. The Australian Aged Care Quality Agency planned to use it to develop their own consumer experience questionnaires and resources to support proposed new standards for Commonwealth funded aged care services (3). In late 2018, researchers were advised by the Knowledge Translation Program Manager at Dementia Training Australia (DTA) that the CCI-6D was adopted by them to be used in estimating impact of their tailored training packages. Researchers were informed by a member of the local health network that South Australia Health are trialling the tool in a specialist psychogeriatric unit within a state funded residential care facility. In late 2018, Group Homes Australia wrote that their innovative model of care aligns with the research produced by this project that small, clustered domestic models of care may achieve better quality of life and lower hospitalisation rates (4). Montefiore residential aged care facility now offers a new dementia model in their residential aged care facilities. They have used the MJA paper published by this project to inform these changes and to improve outcomes for their residents. In addition to the current impacts, the MJA paper published is also generating a substantial amount of potential impact through increased awareness by residential aged care facilities and large investment managers and how these findings can inform their practice. These emerging impact examples are evidenced by emails from representatives sent directly to the researchers.

Sources to corroborate impact

1. Example of online media article written in The Conversation: **theconversation.com/australias-residential-aged-care-facilities-are-getting-bigger-and-less-home-like-103521**
2. Clustered domestic residential aged care in Australia: fewer hospitalisations and better quality of life, The Medical Journal of Australia **mja.com.au/journal/2018/208/10/clustered-domestic-residential-aged-care-australia-fewer-hospitalisations-and**
3. CCI-6D User Guide: **sydney.edu.au/medicine/cdpc/documents/resources/CCI-6D-user-guide.pdf**
4. Group Homes Australia notation: **grouphomes.com.au/small-scale-communal-living-improves-residents-quality-of-life/**
5. Article on Montefiore Dementia Model (MDM) **montefiore.org.au/launching-a-new-model-for-living-well-with-dementia/**

IMPACT AREA

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.

Activities aiming for impact in this area: Activity 3, Activity 4, Activity 25

Total outputs in this impact area: 40 (24 traditional; 16 non-traditional)

CASE STUDY

Alternative respite models (WEAVERS)

CDPC Activity Number	Activity 4
Timeline	13/01/2014–12/04/2016
Total outputs to date	2 (non-traditional)
Budget	$413,590.00

Project overview

This two-year project included an initial, real-time testing of the 'Weavers' prototype with Helping Hand Aged Care in Adelaide, over a six-month period. The partner organisation's staff received training to be involved in the prototyping phase.

Details of impact

The evaluation of the Weavers model found that the respite model was effective for the carers involved (1). The Australian Centre for Social Innovation (TACSI) reported that a Queensland organisation had recently adopted the program through the open-source model (2). An article was published in Australian Ageing Agenda in February 2017 titled "Initiative to support family carers of residents will 'change lives' (3). Ian Hardy (Former CEO of Helping Hand Aged Care) was quoted in the article saying that the "program would have a profound and positive impact on family carers of residents in their facilities." Since the launch of the open source material, it has been accessed by 200 unique registrants across service providers, local, state and federal government, researchers and interested citizens. TACSI reported that they have supported the implementation of Weavers in seven sites across Australia, including adaptions to palliative care and multicultural contexts. The resources were also used by Innovation Unit (UK) to inform the Better Ending Initiative in the UK (4).

Sources to corroborate impact

1. Weavers Evaluation Report: sydney.edu.au/medicine/cdpc/documents/resources/weavers-evaluation-report.pdf
2. Open source model reference: tacsi.org.au/work/weavers-peer-to-peer-carer-support/
3. Article in Australian Ageing Agenda: australianageingagenda.com.au/2017/02/08/initiative-support-family-carers-residents-will-change-lives/
4. innovationunit.org/projects/better-endings/

IMPACT AREA

3

Participating financial, legal and health institutions in a range of locations will adopt uniform policies and practices, enabling and empowering staff to respect and uphold the wishes of older people with cognitive decline who have used substitute decision-making instruments.

Activities aiming for impact in this area: Activity 5, Activity 6, Activity 24

Total outputs in this impact area: 179 (36 traditional; 143 non-traditional)

CASE STUDY

Supported in dementia care

CDPC Activity Number	Activity 24
Timeline	1/01/2016–31/12/2018 (ongoing, utilising existing funding)
Total outputs to date	74 (18 traditional; 56 non-traditional)
Budget	$669,354.00

Project overview

This project sought to determine whether evidence-based recommendations and practical resources can be developed to aid in the implementation of supported decision-making policy frameworks across Australia. They used a mixed methods approach which incorporated multiple studies and produced resources for policy makers and people living with dementia.

Details of impact

This project produced a policy guideline for aged care providers in Australia on supported decision-making (1). These guidelines were launched at a workshop in Sydney in June 2018 and was attended by over 80 people including clinical, legal, academic, and consumer representatives. 850 copies have been disseminated to date to key health institutions and decision makers with the intention that this document will be used to inform policy making processes. In 2018, the Australian Aged Care Quality Agency included the Policy Development Guide (1) as a reference in the Aged Care Quality Standards 1 (2) & 2 (3). The CEO of Australian Aged Care Quality Agency provided the foreword in the Supported Decision-Making Guideline showing his support (1). The project also produced a consumer guidebook and a help sheet that provides tips on how to go about the process. This document has been translated into Chinese, Greek, and Italian to provide access to a wider audience (4). Recently, the National Independent Living Centre Manager of Down Syndrome Australia requested permission to adapt the 'My Decision Support Plan' for use with clients with Down Syndrome (5).

Sources to corroborate impact

1. A Policy Development Guideline for Aged Care Providers in Australia: sydney.edu.au/medicine/cdpc/documents/resources/SDM-Policy-Guidelines.pdf
2. Aged Care Quality Standards 1: agedcarequality.gov.au/providers/standards/standard-1
3. Aged Care Quality Standards 2: agedcarequality.gov.au/providers/standards/standard-2
4. Supported Decision-Making Help Sheet: sydney.edu.au/medicine/cdpc/documents/resources/SDM_Helpsheet_FA_Digital_DA.pdf
5. Supported Decision-Making resources available on Down Syndrome Australia website: downsyndrome.org.au/resources/dementia.html

IMPACT AREA

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.

Activities aiming for impact in this area: Activity 17, Activity 18

Total outputs in this impact area: 36 (21 traditional; 15 non-traditional)

CASE STUDY

Dementia in the public domain

CDPC Activity Number	Activity 18
Timeline	1/01/2016–31/12/2018
Total outputs to date	16 (12 traditional; 4 non-traditional)
Budget	$528,050.00

Project overview

The study used a variety of research approaches including one on one interviews with relevant health and care professionals and consumers; mapping of campaigns (national and international) a narrative analysis of content and intent; interviewing policy makers based on findings; and a Future Search stakeholder workshop event.

Details of impact

The Dementia in the Public Domain: Future Search workshop (1) was held in Melbourne, Victoria and the 35 attendees included carer organisations, federal and state government representatives, and industry partners. A final report incorporated these views on the social impacts of dementia. A formal report about dementia in the public domain has been produced for government and senior decision makers and has been disseminated to 250 people and organisations nationally and internationally (2). In November 2018 a Special Issue of the journal International Psychogeriatrics titled Social Aspects of Dementia and Dementia Practice was released and two of the authors, Prof Simon Biggs and Dr Irja Haapala-Biggs, were researchers on this project (3).

Sources to corroborate impact

1. Dementia in the Public Domain: Future Search Workshop Held on November 19, 2018 at University of Melbourne, School of Social and Political Science
2. Formal report (due to be released March 2019).
3. Link to the Special Edition from International Psychogeriatrics: **cambridge.org/core/journals/international-psychogeriatrics/issue/social-aspects-of-dementia-and-dementia-practice/01260B6433C9BCAC9C5970DB8506AC0B#**

IMPACT AREA

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.

Activities aiming for impact in this area: Activity 9, Activity 10, Activity 16, Activity 19, Activity 22, Activity 28

Total outputs in this impact area: 110 (63 traditional; 47 non-traditional)

CASE STUDY ONE

Evaluation of IPE in residential aged care

CDPC Activity Number	Activity 9
Timeline	1/02/2013–31/01/2016
Total outputs to date (combined)	48 (23 traditional; 25 non-traditional)
Budget	$597,736.00

Project overview

The project outcomes provide an evidence base for the benefits of inter-professional education that will assist with future workforce planning and education strategies. The results of the evaluation have been published and workshopped at industry forums.

CASE STUDY TWO

Implementing and embedding interprofessional learning, education and practice across the aged care sector

CDPC Activity Number	Activity 28
Timeline	12/04/2016–17/07/2017
Total outputs to date (combined)	48 (23 traditional; 25 non-traditional)
Budget	$212,974.00

Project overview

The main outcome of the project is to improve the well-being of residents with cognitive and functional decline through the practice of interprofessional based care and development and availability of a resource toolkit for residential aged care providers. Due to the project period being a short time frame of 12 months for development, implementation and dissemination, short term outcomes were measured.

Details of impact

These research projects developed and evaluated a "flexible, online interprofessional education in aged care (IPEAC) toolkit"(1) and implemented and disseminated this across Residential Aged Care (RAC) providers across two states. As a result of these projects, the IPEAC toolkit has been downloaded many times and is being used at Brightwater and Helping Hand aged care facilities. Additionally, staff from pilot RAC facilities have been directing students to the resources in the IPEAC toolkit.

Sources to corroborate impact

1. IPEAC Toolkit: brightwatergroup.com/research/ipeac-toolkit/

IMPACT AREA

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.

Activities aiming for impact in this area: Activity 7

Total outputs in this impact area: 43 (23 traditional; 20 non-traditional)

CASE STUDY

Regulation of aged care services – effects

CDPC Activity Number	Activity 7
Timeline	13/01/2014–31/12/2017
Total outputs to date	43 (23 traditional; 20 non-traditional)
Budget	$447,711.00

Project overview

This four-year project began with a mapping of existing regulatory frameworks and an analysis of the perception and social construction of regulation and its effects on care contexts. Semi structured interviews were conducted, targeting selected aged care senior managers and policy experts to identify key areas where end-users encounter positive and negative impacts of regulation. The team reviewed the qualitative data from the surveys and interviews to identify three areas of regulation that have a significant impact on the design and delivery of aged care services. An online survey of was conducted on these areas of significant impact.

Details of impact

This project produced a final report (1) titled 'The Organisation of Risk: How do dementia care providers adapt to regulation?'. This was released and available on the CDPC website to be accessed by anyone. Findings were circulated widely to provider organisations including Anglicare, Benetas and The Brotherhood of St Laurence, copies were also sent to the 'Standing Committee on Quality of Aged Care' and utilised through the auspices of Helping Hand. Copies were sent to The Attorney General's Office, in connection with work on elder protection. Most recently, Helping Hand Aged Care recommended the report produced by this project to inform into their submission to the Royal Commission into Aged Care Quality and Safety.

Sources to corroborate impact

1. The Organisation of Risk: How do dementia care providers adapt to regulation? sydney.edu.au/medicine/cdpc/documents/resources/CarrBiggs_Organisation_of_risk_dementia_care_2018.pdf

IMPACT AREA

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.

Activities aiming for impact in this area: Activity 11, Activity 12, Activity 20

Total outputs in this impact area: 288 (151 traditional; 137 non-traditional)

CASE STUDY

Quality use of medicines

CDPC Activity Number	Activity 11
Timeline	13/01/2014–12/01/2019 (ongoing with additional funding)
Total outputs to date	227 (133 traditional; 94 non-traditional)
Budget	$1,819,848.00

Project overview

This five-year project synthesised existing research to identify medicines that increase and decrease the risk of adverse outcomes in older people with cognitive decline in different settings. During the initial stages, this project worked to identify optimal quality use of medicines (QUM) tool(s) to guide medication selection for older people with cognitive decline. The project is assessing the factors that impede and facilitate the quality use of medicines for people living with dementia in hospital, community and residential aged care settings, before addressing those barriers.

Details of impact

This research project has two arms (one that operates out of University of Sydney and the other operates out of Monash University). It is one of the larger CDPC projects and has published numerous academic papers. The Goal-directed Medication review Electronic Decision Support System (G-MEDSS) deprescribing tool was developed as part of this project which is currently being trialled in Australia, the United Kingdom, and Canada (1). The Translational Research Grant from NSW Health has allowed the Drug Burden Index (DBI) calculator within the GMEDSS to be built into the hospital electronic medical record to identify and facilitate appropriate prescribing of high risk medications for patients. Researchers contributed to the terms of reference for the Royal Commission into Aged Care Quality and Safety. Polypharmacy has been highlighted by the World Health Organization as a focus area in its current Global Patient Safety Challenge: Medication Without Harm (2). The project has also released a policy document (3) to raise awareness of the dangers of polypharmacy as well provide a Strategic Action plan to reduce inappropriate polypharmacy, and a framework to do this. Additionally, The Medication Regimen Simplification Guide for Residential Aged CarE (MRS GRACE) was trialled with success in an aged care facility with randomly selected participants and received additional funding from the CDPC to further disseminate this tool (4).

Sources to corroborate impact

1. Canadian Frailty Network, 2017 Catalyst Grant Competition (Medication Optimization) – Improving medication use during hospital admission (CAT2017-13). cfn-nce.ca/bio/reeve-emily/
2. Hilmer, S. N., & Sawan, M. J. (2018). Discussion of patients' goals for pharmaceutical care is central to managing polypharmacy. Journal of Pharmacy Practice and Research, 48(5), 402–404.
3. Quality Use of Medicines to Optimise Ageing in Older Australians: Recommendations for a National Strategic Action Plan to Reduce Inappropriate Polypharmacy (2018). NHMRC Cognitive Decline Partnership Centre, University of Sydney, in Collaboration with the Australian Deprescribing Network and NPS Medicinewise. Sydney, NSW, Australia. ISBN: 978-0-6483658-6-3
4. 4. Chen, E. Y., Sluggett, J. K., Ilomäki, J., Hilmer, S. N., Corlis, M., Picton, L. J., ... & Grigson, J. (2018). Development and validation of the Medication Regimen Simplification Guide for Residential Aged Care (MRS GRACE). Clinical interventions in aging, 13, 975.

IMPACT AREA

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.

Activities aiming for impact in this area: Activity 8, Activity 13, Activity 14, Activity 38

Total outputs in this impact area: 222 (55 traditional; 167 non-traditional)

CASE STUDY

National Australian dementia guidelines

CDPC Activity Number	Activity 13
Timeline	13/01/2014–30/09/2017
Total outputs to date	193 (42 traditional; 151 non-traditional)
Budget	$503,567.00

Project overview

This three-year project reviewed international dementia guidelines, including the National Institute for Health and Care Excellence (NICE) guideline on dementia (United Kingdom), to establish new national clinical guidelines for dementia in Australia. As a result, up-to-date, evidence-based guidelines on care of people living with dementia have been synthesised and are being disseminated throughout Australia with a complementary training and implementation plan.

Details of impact

This project has provided local, national, and some international access to meaningful clinical guidelines reflecting the current evidence on dementia care. The project finalised in 2017, and since the guidelines launched, hundreds of hard copies of both the Clinical Practice Guidelines as well as the Consumer Companion Guide have been disseminated and requested by service providers, clinicians, consumers, and government representatives. This represents a wide range of engagement and interest in these guidelines within the Australian healthcare context. An online training course (MOOC) was developed by the team and is available on the OpenLearning platform targeting care workers and teaching them how to practically implement the guidelines into their practice (1). 147 students are currently taking the course. The Guidelines have also been included in the NSW Health Dementia Care Competency Framework online training resource so that those undertaking this course could have access to the document (2). The guidelines have had some international impacts as well: they have been translated into Vietnamese (3) and the research team have been contacted to gain permission to adapt clinical guidelines published in Columbia. The Clinical Practice Guidelines resulted in the NHMRC Boosting Dementia Research Grants Implementation round focusing on the effective implementation of research into improving practice and care (4). Additionally, according to the analysis of the CDPC website, the Dementia Guidelines resource page is the most visited page on the CDPC website with views starting at 983 (in 2015) and continuing to grow throughout the years with 7733 individual views in 2018 (5).

Sources to corroborate impact

1. Online Training Course: **openlearning.com/courses/dementia-care-for-the-care-worker/**, Accessed 17 January 2019
2. NSW Health Dementia Care Competency Framework online training resource: **dementiacare.health.nsw.gov.au/**
3. Vietnamese Translation: **sydney.edu.au/medicine/cdpc/resources/dementia-guidelines.php**
4. Boosting Dementia Research Grants: **nhmrc.gov.au/funding/find-funding/boosting-dementia-research-grants-priority-round-1**
5. Clinical Practice & Consumer Companion guide resource page: **sydney.edu.au/medicine/cdpc/resources/dementia-guidelines.php**

IMPACT AREA

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.

Activities aiming for impact in this area: Activity 2, Activity 21, Activity 26, Activity 27, Activity 29, Activity 30, Activity 37

Total outputs in this impact area: 182 (49 traditional; 133 non-traditional)

CASE STUDY

Confused Hospitalised Older Persons Study (CHOPS)

CDPC Activity Number	Activity 2
Timeline	1/07/2013–31/12/2015 (ongoing with additional funding)
Total outputs to date	64 (8 traditional; 56 non-traditional)
Budget	$461,410.00

Project overview

This two-year project built on the 12-months CHOPS pilot by expanding the implementation over two years. The focus has been on broader roll out within NSW, followed by the exploration of feasibility for expansion into other Australian states, where hospital clinicians have expressed the need for a similar intervention in consultation with the Lead Investigator. As well as evaluating the implementation program, the final stage of this Activity also includes a refinement of the education strategies developed as part of the CHOPS program, for use in other hospitals and expansion into aged care.

Sources to corroborate impact

1. CHOPS resources: aci.health.nsw.gov.au/chops
2. Principles of Management of the Confused Older Person in Metro North: A five year health plan for older people who live in Brisbane North 2017–22 pp.35–36
3. HammondCare International Dementia Conference abstract book: hsansw.org.au/2018IDC.pdf
4. nar.uni-heidelberg.de/en/youngscholars/dementia/eckstein.html

Details of impact

The principles (1) developed in this research project have gained national and international attention. In 2016, Royal Brisbane and Women's Hospital began using CHOPS and called it "Plus" because they added another principle (2). Additionally, the CHOPS program has been implemented across 12 NSW healthcare facilities including Prince of Wales Hospital, Gosford Hospital, Lismore Base Hospital, Wollongong Hospital, Broken Hill Base Hospital, Nepean Hospital, Springwood Hospital, Orange Base Hospital, Maitland Hospital, Hornsby Ku-ring-gai Hospital, Fairfield Hospital and Coffs Harbour Hospital. In 2017, the CHOPS principles were used in the South German PAWEL study exploring patient safety, cost effectiveness and quality of life and the reduction of delirium risk and post-operative decline in elective surgery in the elderly. Hospitals RBK Stuttgart and Mannheim Hospitals in Germany have both translated CHOPS resources into German with plans to implement these principles into their practice. In 2018, Brianna Walpole presented at HammondCare International Dementia Conference in Sydney, Australia about Monash Health developing a Dementia and Delirium initiative that was based on the CHOPS program (5). The first three months of implementation showed improvements in recognition and management of patients with delirium and dementia. Recently, the Chief Investigator on this project met with Claudia Eckstein, a nurse from Germany who is working on her PhD at Heidelberg University incorporating CHOPS principles into practice (5).

CONCLUSION

The evaluation showed that the CDPC has achieved solid performance, groundbreaking partnerships, and medium to large scale implementation across six of nine impact areas.

The CDPC overall achieved high levels of outputs and communication, contributing to the collective knowledge on effective approaches to caring for people living with dementia. Individual CDPC activities achieved national influence in the areas of supported decision-making and evidence about the true cost of caring for people living with dementia. There is a strong potential for future national impact in the areas of clinical decision-making and appropriate medication management.

The CDPC's experience also uncovered several lessons that could inform and improve future partnership models. Some of these lessons include ensuring that expectations are clear from the beginning, fostering open, direct communication among members, and building trust among partners. Facilitating genuine consumer involvement can be challenging, and future partnership centres may benefit from ensuring that under-represented groups are involved.

Impact assessment is complex, and research on how to best measure impact continues to evolve. Measuring the impact of knowledge translation activities can also be challenging because changes at the level of policy and practice often takes years to achieve. *(Roussos, S. T. & Fawcett 2000).* It is critical that the impact statements of future partnership centres are realistic in scale and scope, and that partners have shared expectations regarding the time frame and scope of impact.

Limitations to research design

There some important limitations to this research design. There is limited generalizability of survey findings due to non-random sample, decreasing response rates and difficulty collecting data on impact. Engagement in the evaluation network survey dropped significantly with the survey participant rates beginning at 78% in 2015; 56% in 2017; 38% in 2018. Declining engagement through the years in the qualitative interviews, evident by participants who declined to participate (first years, all invitees accepted invitation and each year the amount who agreed to participate decreased). There is also potential conflict of interest in conducting an evaluation as internal, rather than external evaluators. This may have led to hesitancy of respondents to be fully candid in their responses. The evaluation team tried to overcome this by assuring participants that only the evaluation team had access to the named version of the data and that only aggregate information was to be shared more broadly, but this still could have influenced the results.

We would like to conclude the evaluation by thanking all who took the time to participate in qualitative interviews and the network survey. We appreciate your time and effort through the years. We would also like to thank the co-investigators for their support on this project:

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