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

submission to the Royal Commission into Aged Care Quality and Safety

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Executive summary

The NHMRC Partnership Centre on Dealing with Cognitive and Related Functional Decline (CDPC) has been undertaking dementia research over the last five years. Its strength has been the involvement of end users from the beginning. It is in now in a timely position to be able to offer wide reaching research evidence, tools and resources relevant to the terms of reference of the Royal Commission into Aged Care, particularly addressing how best to deliver services for people with dementia.

The CPDC submission offers the following:

- Direction for aged care providers on how to develop policies upholding the right of people with dementia to be supported to make decisions that affect their lives
- Clinical Practice Guidelines and Principles of Care for people with dementia and an accompanying consumer guide so that consumers, clinicians and aged care planners and providers can expect, recognise and provide good dementia care
- Evidence that a home-like model of residential aged care provides a better quality of life, better meets the needs and preferences of residents and their families and is associated with fewer use of psychotropic medicines
- A validated consumer rated quality of care instrument to evaluate the quality of care in residential aged care facilities from a consumer perspective
- Examples of models of care that maintain a person’s functioning to enable a person to remain at home for longer as well as effective carer support models
- Recommendations for a national strategic action plan to reduce polypharmacy
- Evidence for strategies to reduce the use of chemical restraint
- A tool to ease the burden of drug administration in residential care and clinical decision software to achieve person-centred medication management
- Suggestions for increasing prescribing of Vitamin D supplements in aged care to reduce health care costs related to falls and the confirmation of the potential of telemedicine to improve the timeliness and efficiency of medication reviews
- Evidence of benefits for residents and students of an inter-professional education program and the identification of staff factors that influence quality of life.

The CDPC outputs are being widely disseminated and incorporated into practice beyond the industry partners. A research partnership approach modeled on the CDPC could develop further innovative solutions that are feasible, translatable into practice and that address the challenges presented to the Royal Commission.
Introduction

The NHMRC Partnership Centre on Dealing with Cognitive and Related Functional Decline (CDPC) welcomes the opportunity to provide a submission to the Royal Commission into Aged Care.

The CDPC’s importance lies in its integration of the end users from the beginning in the development of research evidence and resources (consumers, people with a lived experience of dementia, and industry partners). The research across a broad range of contexts has generated relevant and easily transferable knowledge with significant reach and potential impact.

The submission focuses on the Centre’s research outcomes relevant to the Commission’s Terms of Reference. It summarises background evidence, tools and resources that can facilitate improved care for older Australians and people living with dementia.

Who we are

The CDPC is a research centre in which academics, clinicians, service providers, consumers including people living with dementia, and government bodies have worked collaboratively since 2013, funding and supporting research and knowledge translation activities to improve the quality of care and quality of life for people living with dementia.

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 nearly $25 million in cash and in-kind funding from six partner organisations: the NHMRC, Department of Health and Ageing, and four industry partners: Brightwater Care Group, HammondCare, Helping Hand Aged Care, and Dementia Australia.

From 2014–2019, the CDPC has funded and supported 32 research activities across eight thematic dementia care areas. Themes have been: Service Model Options, Pathways and Navigation, Planning for Later Life, Attitude and Culture; Functional Decline; Workforce Development and Education; Medication Management and
Clinical Guidelines.

As the CDPC’s current funding term concludes at the end of 2019, many of its’ research findings are now published, and accessible tools and resources developed. These have been attracting considerable interest from policy makers, aged care and health providers, and the community.

**Relevance to the Royal Commission into Aged Care**

While much of the CDPC’s research targeted people living with dementia, many of its’ outcomes are more broadly relevant to older Australians. Its broad relevance is likely to stem from the active involvement of consumers in the design and implementation of the research.

This submission offers evidence and expert background papers in specific research areas that point to the way forward in providing high quality, safe and affordable care improving the quality of life for older people and people living with dementia. It provides evidence to support innovative models of care and provides solutions to challenges such as medication management and staff training. It highlights how we can design a system to meet the needs of people with dementia now and into the future.

The work of the CDPC aligns well with the scope of the review as defined in the Terms of Reference of the Royal Commission, with a focus on the following evidence for change:

1. How best to deliver aged care services to the increasing number of Australians living with dementia, having regard to the importance of dementia care for the future of aged care services
2. How to ensure that aged care services are person-centred, including through allowing people to exercise greater choice, control and independence in relation to their care, and improving engagement with families and carers on care-related matters;
3. How best to deliver aged care services in a sustainable way, including through innovative models of care, increased use of technology, and investment in the aged care workforce and capital infrastructure.
Research areas

**Dignity, choice and control**

The aged care system must be underpinned by fundamental principles that safeguard and support the rights of people with dementia. All too often people with dementia are not treated with dignity nor given the opportunity to exercise their rights to make their own decisions, to choice and autonomy. A diagnosis of dementia does not automatically exclude a person from decision making. Rather, a person should be supported as much as possible so that they can exercise their rights, including the right to make decisions about their lives.

The CDPC welcomes the introduction of the new Aged Care Standards in July 2019 that encapsulates this principle in the first Standard on consumer dignity and choice. The CDPC included the 10 Principles of Dignity in Care [1] in the beginning of the Clinical Practice Guidelines and Principles of Care for people with dementia.[2] They articulate a number of key points that should underpin all service delivery.

**Supported decision-making**

Supported decision-making is a progressive, rights-based approach to decision-making and this approach is aligned with the ‘social model of disability’, which identifies the root cause of disability as the failure of society to support and accommodate those with impairments. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) mandates that supported decision-making is a key ethical component of a human rights-based approach to dementia care (United Nations Enable, 2008).

The CDPC supported decision-making project concluded with creation of Supported Decision-Making in Aged Care- A Policy Development document for Aged Care Providers in Australia, [3] which provides directions to aged care providers and consumers on how to implement supported-decision making at a time when legislation and policy approaches have not provided adequate guidance in this area. The project team also developed a consumer guidebook, videos and multilingual
resources that are available here: http://sydney.edu.au/medicine/cdpc/resources/supported-decision-making.php.

Aged care staff in NSW, SA and WA, have received educational training workshops on supported decision-making using specifically developed educational tools and resources. These workshops have provided step by step guides to policy development in compliance with National Decision-Making Principles as well as aligning with the new Aged Care Quality Standards.

**Clinical guidelines and principles of care**

The Clinical Practice Guidelines and Principles of Care for people with dementia: Recommendations [2] [4] summarise current evidence on dementia care on how to better respond to the needs and preferences of the person living with dementia. The guidelines are based on the best research evidence; where there is inadequate evidence, they are based on the opinion of experts, including consumers with dementia. They cover:

- Ensuring a timely diagnosis
- Living well with dementia
- Accessing services in the community system navigation
- Supporting carers
- Strategies to manage symptoms
- End of life care.

People’s needs and response to dementia vary considerably. Person centred care, that identifies and responds to the individual needs and preferences of the person with dementia is paramount to high quality and safe care.

The guidelines and principles provide an evidence based starting point for evaluating the adequacy of existing care arrangements. It is important that these guidelines are regularly updated so that service providers and individual health professionals are able to assess their service and practice against the best available evidence.

An associated Consumer Companion Guide to the Guidelines [5] developed in collaboration with Dementia Australia affiliated consumer advocates, provides a lay version of the recommendations that enables the general public to be fully informed on current best practice when being investigated for a possible diagnosis of dementia.
Dignity, choice and control knowledge to inform the Royal Commission:

- Aged care providers can embed “Supported Decision-making in Aged Care: A Policy Development Guideline For Aged Care Providers in Australia” [3] upholding the right of people with dementia to make and be supported to make decisions about their lives.

Innovative and quality care

Residential care

The environment where care is delivered for a person living with dementia can greatly impact their quality of life. The CDPC supported an important study, the INvestigating Services Provided in the Residential care Environment for people with Dementia (INSPIRED) study, which examined and developed evidence about the different models of residential aged care in Australia with a focus on people living with dementia. http://www.flinders.edu.au/sohs/disciplines/rehabilitation-aged-and-extended-care/research/residential-aged-care.cfm

Clustered, domestic model of residential aged care

While there is increasing emphasis on home-like care environments internationally, most aged care homes in Australia are large, with the perception that this model is more cost efficient. The INSPIRED study found that living in a home-like model of residential aged care, where a facility has less than 15 people, was associated with a better quality of life and better meets the needs and preferences of residents and their families. [6] This model is associated with fewer potentially inappropriate medications, including psychotropics, and fewer hospitalisations and emergency department presentations. [7] Smaller home-like models of care may provide better health and quality of life outcomes for older people, at potentially similar or lower
The study found that the clustered domestic model of care had more personal care assistant hours, more staff training and more direct care time compared to standard models.[8]

The study also developed a validated consumer rated quality of care instrument, the Consumer Choice Index – 6 Dimensions (CCI-6D) [9] that measures six key characteristics of quality of care.

As well as a number of significant journal articles, the project team has produced a number of excellent research summaries on the outcomes of the study for industry and consumers which are available here:

Living in the community

The majority of people with dementia live in their own homes supported by family members and friends. They vary considerably in terms of their needs, preferences, symptoms and rates of progression as well as their of social, cultural and economic circumstances. However, in designing a system to meet the current and future needs of people living with dementia and their families there are some key components that should be considered. These include;

- timely access to assessment and diagnosis and ongoing clinical support
- access to culturally appropriate information, family education and flexible community support when required in order to maintain independence, social engagement and quality of life for the person and those providing support.

Maintaining independence

CDPC researchers have developed evidence-informed resources and recommendations and are implementing programs that promote independence and wellbeing of people with dementia.

One such evidence-based program is the ‘Care of People with dementia in their Environments’ (COPE) program, which is a structured occupational therapy and nursing intervention for people with dementia and their carers living at home.
CDPC researchers are undertaking a translational study [10] to implement and cost COPE in Australia within different types of government and privately funded services.

The results are promising, pointing to significant benefits if the model can be expanded further. The products from the project such as a “how to” guide, website and consumer information will assist organisations adopt the model in the Australian context http://sydney.edu.au/medicine/cdpc/resources/cope.php

Functional independence examined in the reablement resources developed through CDPC funding focuses on occupational therapy, exercise and cognitive programs http://sydney.edu.au/medicine/cdpc/resources/reablement.php. The resources include a technical guide, sector handbook and consumer information booklet. Evidence suggests that people living with dementia can maintain their functional abilities for longer through specific ‘reablement’ programs. Included in the clinical guidelines recommendations, maintaining function has the potential to increase quality of life and enable a person to remain at home for longer.

The ‘Agents of Change’ project (http://sydney.edu.au/medicine/cdpc/resources/change.php) aims to improve post-diagnosis care for people with dementia and their carers through implementing these three key recommendations from the Clinical Practice Guideline for dementia:

1. People living in the community should be offered occupational therapy
2. People with dementia should be strongly encouraged to exercise
3. Carers and family should have access to respite, and to programs to support and optimise their ability to provide care.[11]

Falls

People with dementia are at increased risk of falls [4], which can often lead to further loss of function and independence and hasten transfer into residential aged care. CDPC funded researchers are undertaking a randomised controlled trial to determine whether a tailored exercise and home hazard reduction program can reduce the rate of falls in people with dementia living in the community. A health economic analysis examining the cost and potential benefits of the program will also be undertaken. Depending on the outcome, the program has significant potential to
enable people with dementia to remain at home for longer with associated cost benefits.

There needs to be an increased focus and availability of evidence informed programs that enable people with dementia maximise their functional ability and achieve meaningful goals in partnership with the people who support them.

**Key worker model**

Delay in timely diagnosis and access to information and services increases the risk of inappropriate clinical management, functional decline, disengagement and lost opportunities to put timely arrangements in place for the future.

The Clinical Guidelines recommend that people with dementia have access to a care coordinator. Several ‘key worker’ or support models have been implemented in Australia and overseas. These are designed to assist people with cognitive impairment (and their carers) to adjust to living with memory loss, navigate the health and aged care system, and access services, information and support. Currently the model supported by Dementia Australia is only available to those diagnosed with early-onset dementia. CPDC researchers undertook an evaluation of the models and developed a key worker framework.[12] The value of a support worker for people with dementia, their family and carers came out strongly in the two phases of the evaluation; the systematic review and qualitative evaluation. A similar program available for people diagnosed with early onset dementia has had excellent results.

The CDPC recommends national implementation of the identified essential components of the key worker model, including aligning implementation with Primary Health Networks to encourage early intervention and increase geographic coverage, particularly in rural and remote areas.

**Innovative peer support model**

Personalised peer to peer support for carers, the Weavers model was positively evaluated by CDPC researchers.[13] It is an exciting innovative model that has been developed using co-design and social innovation methodologies. It provides an alternative to institutional style respite programs that often fail to meet the needs of
carers. Resources to implement the model are available to any organisation here: https://weavers.tacsi.org.au/

**Innovative and quality care knowledge to inform the Royal Commission:**

**1. Residential care**

- Policy-makers could consider incentives or funding [models of care](#) that encourage more clustered domestic models for residential care for people with dementia
- Policy-makers, aged care providers, peak bodies and consumer organisations can promote the use of the Consumer Choice Index – 6 Dimensions (CCI-6D) to evaluate the quality of care in residential aged care facilities from a consumer perspective.[14]

**2. Living in the community**

- Policy-makers, health services, and allied health providers can highlight the importance of access to programs that maintain a person’s functioning to increase quality of life and enable a person to remain at home for longer
- Policy-makers can explore options for expanding an evidence-based key worker model to provide access for all people with dementia regardless of age or location.
- Policy-makers and peak bodies can promote the [peer support “Weaver” model](#) as an effective care support model

**Medication management**

The quality use of medicines (QUM) is a balance between managing clinical conditions and preventing disease progression while reducing or avoiding medicine related harm such as side effects and medication errors.

QUM demonstrates the interplay between the health and aged care systems. Good medicine management enhances quality of life.[15] For older people who are empowered to understand their medicines and participate in decisions, medicines can support their goals and preferences. [15, 16] Harm from medicines includes falls, hospital admissions, loss of independence and the need for aged care
assistance. Unnecessary supply and complex administration of medicines adds to the cost burden of health and aged care systems.

As our population ages, more people are living with multiple chronic diseases and as a consequence are using multiple medicines. Approximately half of all older adults are taking a medicine that is harmful or unnecessary. [2]

In residential care the rate of polypharmacy is alarming, with three-quarters of all residents taking nine or more medications on a regular basis [17] pointing to the enormous potential for appropriate deprescribing.

Administering these multiple medications is also complex with different instructions and formulations that are costly for aged care providers in terms of nursing time.

For people living with a complex condition like dementia the management of appropriate medication is challenging with additional problems such as swallowing and refusal. In addition, for many people with dementia, high-risk medicines have been used inappropriately as a form of chemical restraint.

The CDPC research and activity provides possible evidence-based solutions through two important approaches:

1. Reducing polypharmacy

A cohesive, national approach is required to address the issue of inappropriate polypharmacy in older adults and promote deprescribing. There is increasing evidence that deprescribing (supervised withdrawal) of harmful or unnecessary medicines is safe and benefits the individual and the community. Harmful or unnecessary medicine use can be reduced through partnership of key stakeholders, focusing on awareness, incentives and tools to optimise quality use of medicines for older Australians.

Recommendations for a National Strategic Action Plan to Reduce Inappropriate Polypharmacy (2018) [18] is a document that provides direction through multi-pronged strategies. It was developed in collaboration with the Australian Deprescribing Network and NPS MedicineWise
Seven action items were formulated on the basis of a four-level model: overall policy and regulatory environment of health, health care organisations in which care is delivered, health care professionals, and the broader public and recipients of care:

While many committed individuals are currently implementing components of the model, supported co-ordinated action is a more effective and efficient approach.

2. Person-centred medication management

Deprescribing unnecessary or harmful medicines

At the centre of optimal use of medicines is the person’s needs, preferences and goals of care. Deprescribing is the safe withdrawal of medicines that are unnecessary, ineffective, where the potential risks outweigh the potential benefits or they don’t fit with a person’s goals of care. [19]
CDPC research has made a significant contribution to the way forward on deprescribing through examining the barriers and developing tools and resources, including the first NHMRC endorsed deprescribing guidelines to assist prescribers and consumers to take action.[20]  

CDPC researchers have developed and validated a computerised clinical decision software, (G-MEDSS) that incorporates tools appropriate for residents, with or without dementia, and family carers to achieve person-centred medication management. They have explored the utility of G-MEDSS in aged care homes, with staff confirming its usefulness.

**Reducing complexity of medication administration**

Consolidating the number of administration times in residential care or using alternative formulations may reduce drug administration time and enable nurses to have more time for other clinical needs and reduce the burden on residents.

CDPC researchers have developed and validated a tool, the Medication Regimen Simplification Guide for Residential Aged Care (MRS GRACE).[21] Implementation of the MRS GRACE tool is being evaluated in an ongoing cluster randomised controlled trial, called the SIMPLER study, in eight residential aged care facilities. This trial will test if MRS GRACE results in less administration time, improved outcomes for residents and is cost effective.

**Reducing inappropriate use of antipsychotics and other psychotropic medicines**

CDPC research has added to the evidence of the alarmingly high prescription rates of antipsychotics and other psychotropic medicines for people with dementia in residential care. The INSPIRED study found that one quarter of the residents were prescribed the common antipsychotic drug risperidone, with people with dementia nine-fold more likely to receive it over a 12-month period than those people without dementia. [22]

CDPC researchers have also collated and confirmed evidence-based practice and identified multi-strategic effective solutions for addressing overuse. These include;
• Non-pharmacological interventions that are individualised to the person and based on understanding the purpose of the behavior should be the first line management and can reduce antipsychotic use[23] [24]
• Assessment of pain should be conducted, and a stepped analgesic approach trialled when appropriate [25]
• Deprescribing psychotropic medications is possible without causing harm and re-emergence of behavioural symptoms and can be achieved by well trained and supported multidisciplinary teams, GP, pharmacist, and allied health and direct care staff, in partnership with residents and families [25] [24, 26]
• Home-like models of residential care may help to reduce the need for psychotropic medications, but further research is needed to validate these findings. [22]
• Organisational culture needs to be addressed to reduce inappropriate use of psychotropic medications as it shapes psychotropic prescribing decisions and practices of both on-site and visiting staff in aged care homes.[27]

Pain can result in changed behavior particularly when a person is unable verbally communicate their pain. Mis-diagnosis and undertreatment of pain highlights the importance of trained staff and appropriate assessment tools to effectively identify and respond to a person’s pain. The CDPC funded INTERVENE 2 project identified organisational cultural barriers and has produced educational videos that can be integrated into staff orientation processes http://sydney.edu.au/medicine/cdpc/news-events-participation/pain-management.php.

Having trained staff and pain assessment tools to effectively identify and respond to a person’s pain is critical to deliver quality care to people living in residential aged care. A CDPC systematic review has also demonstrated there is less psychotropic medication use when staff are more skilled and trained. [28]

**Increasing appropriate Vitamin D prescribing**

Low levels of vitamin D are associated with a number of chronic and complex health conditions. Older people with low levels of vitamin D have been found to be at higher risk of falling, which can lead to injury and reduced quality of life. Taking a vitamin D supplement is an effective way of reducing the rate of falls among residents living in
aged care. While all aged care residents are at high risk of Vitamin D deficiency, it is estimated that less than half are prescribed an adequate dose of vitamin D.

CDPC supported a project to test the feasibility of an intervention in aged care homes to increase the vitamin D supplement use. [29] The project provided valuable insight into current barriers and identified future action required to ensure optimal falls prevention. Direct engagement with GPs is a priority area to increase awareness of the strength of the evidence for proactively prescribing sydney.edu.au/medicine/cdpc/documents/resources/Implementation-of-Vitamin-D-in-Residential-Aged-Care-Facilities-Summary-Report.pdf.

Supporting appropriate prescribing through telemedicine

Geriatricians and pharmacists can support health professionals responsible for prescribing, dispensing and administering medicine to undertake optimal use of medicines through medicines reviews. However, visits by specialists are infrequent and expensive not occur simultaneously with GPs.

CDPC researchers have demonstrated that telemedicine is feasible for undertaking medication reviews and a paper on this will be released in 2019. With further development, telemedicine could be an effective avenue increasing prompt access to specialist medication review, including those in rural and remote communities.

Medication management knowledge to inform the Commission:

Policy-makers, clinicians, pharmacists, aged care providers, and consumers need to understand and acknowledge:

- the importance of quality use of medicines to overall quality of life of older Australians, and to cost reduction for the health and aged care systems [29]
- a cohesive national approach to reducing the burden of polypharmacy through the implementation of the Recommendations for a National Strategic Action Plan to Reduce Inappropriate Polypharmacy (2018)
- the importance of person-centered care and a non-pharmacological approach in reducing reliance on chemical restraint
- the possibility of achieving more goal-directed pharmaceutical care that takes into account older adults’ medication goals, preferences and values through the
integration of computerized clinical decision support systems into practice [16]

- the potential to reduce impaired physical and cognitive function caused by side effects of unnecessary medications by using the Drug Burden Index as a clinical risk assessment tool. [30]
- the potential for easing the burden of drug administration in residential care through implementation of the Medication Regimen Simplification Guide for Residential Aged Care (MRS GRACE)
- that increased prescribing of Vitamin D supplements in aged care could reduce health care costs related to falls [29]
- the potential of telemedicine to improve the timeliness and efficiency of medication review for residents in aged care homes, particularly in rural and remote communities.[31]

Professional education, staff variables and implementation of good practice

Staff training, resourcing, and negative career perceptions in aged care have been identified as barriers to maintaining a skilled aged care workforce. CPDC research will contribute to the focus on building a sustainable aged care workforce for the future through a number of its activities. These include evaluating interprofessional education (IPE) and understanding how staff variables can improve quality of care and quality of life residential dementia care.

CDPC funded research is also testing a national quality collaborative approach to train clinicians to implement evidence-based care and has also implemented key principles to improve delirium and dementia care.

**Interprofessional education (IPE)**

IPE programs provide training in residential aged care for students from a diverse range of health care disciplines. The IPE program, evaluated through the CDPC, was implemented over a three-year period, saw an average of 60 students receiving 182 training sessions per year with a third of the aged care staff involved in training and supervision of students. [32] The impact on the skill, productivity and experience of the staff due to exposure of the IPE program was examined over five years [http://sydney.edu.au/medicine/cdpc/resources/ipe-tookit.php](http://sydney.edu.au/medicine/cdpc/resources/ipe-tookit.php).
Of significance were the gains observed from the improved quality of life of residents. Regular interactions with the students improved the residents’ physical health and emotional wellbeing. Graduates also showed improved productivity due to enhanced skill and knowledge, while staff directly involved in student training and supervision also displayed improved productivity and greater job satisfaction, resulting in lower rates of absenteeism and turnover.

A benefit–cost analysis (BCA) [33] showed that the program was highly beneficial and recommended that universities, aged care providers and the government work in partnership to put more effort into similar projects to provide student clinical placements [33].

**Staff variables in residential care**

Another promising project, “Improving residential dementia care through staff”, is shedding light on whether increased support for staff in aged care homes through interventions such as training improves the way care is provided and, as a consequence, improves the quality of life of residents.

The systematic review [34] has shown it is more effective to focus on a specific targets, such as restraint reduction and that restraint reduction is possible through mentoring and similar support but that didactic education alone is inadequate. More complex targets such as reducing aggression in showering require a period of on-site support and practice.

Further work in this project will identify what staff factors influence quality of care for people with dementia in residential aged care and provide evidence for targeted interventions.

**The Confused Hospitalised Older Persons Program (CHOPS)**

While this implementation program targeted people with cognitive impairment in hospitals, the principles developed such as better identification, prevention and treatment of delirium, engaging with families and providing a supportive environment are all applicable to aged care homes. The CHOPs website provides valuable training resources and implementation advice [34].
Agents of change

The Agents of Change project is testing if providing training and support to health professionals through a national quality collaborative approach increases adherence to guideline recommendations. As described earlier, the project is focusing on recommended care in the areas of exercise, occupational therapy and carer interventions. http://sydney.edu.au/medicine/cdpc/resources/change.php.

Professional education, staff variables and implementation of good practice knowledge to inform the Royal Commission

Policy-makers, aged care providers and universities can:
• note the benefit–cost analysis (BCA) of interprofessional education and encourage partnership between universities, aged care providers and government to further extend the model
• note further outcomes from CPDC funded research will be released shortly that will guide future interventions with staff to improve the quality of life of residents.

Cognitive Decline Partnership Centre - Research Impact

The research funded by the CDPC is extensive, with this submission only touching on some of the research outcomes. Other research outcomes include:


The CDPC’s experience as an NHMRC Partnership Centre for Better Health can be used to guide future improvements in research. It takes time to develop trust, cooperation and partnerships amongst industry partners, researchers and consumers but the results are worthwhile. The recently released CDPC Final Evaluation [36] summarises the lessons learnt. These include ensuring that
expectations are clear from the beginning, fostering open, direct communication among members, and building trust among partners. It also notes that 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.


CDPC research demonstrated the value in investing in a research partnership model that creates valuable evidence as well as tangible, quality evidence-based tools and resources. Its’ outputs have been immediately useful to consumers, service providers and policy makers. It highlights the importance further research that involves end users including people with dementia, carers and advocates, from the beginning of the process to provide further innovative solutions to the problems confronting the aged care sector http://sydney.edu.au/medicine/cdpc/news-events-participation/consumers-in-collaborative-dementia-research.php.
References


