Welcome to the sixth edition of the CDPC News

Hi everyone

Welcome to our last newsletter for 2016, as we wind down for the Christmas break.

Thank you all for making it such a very good year for the CDPC.

The Annual Meeting in mid November was a wonderful opportunity for everyone involved in the CDPC to come together. It is a time to showcase our achievements and that certainly occurred during this meeting. There is so much happening and we are trying to ensure that everyone involved in the CDPC is aware of what work is occurring, and that people have the opportunity to contribute to each other’s activities.

As you will see from the various reports in this newsletter we have a number of new projects beginning, lots underway, and several projects nearing completion or finished. Examples include the Consumer Companion Guide to the Clinical Practice Guidelines which was launched in November this year and has been very well received. It is an excellent example of consumer involvement at all levels. We will look at disseminating it widely in 2017. Another example is the project looking at the effect of state and federal regulations on care for people with dementia. It is a very interesting and important area and you can read more in this newsletter. Falls occur more often in people with dementia than in those without dementia and the results of one of our projects showing that exercise can improve balance is described in this edition.

I would like to wish you all a happy and peaceful Christmas break and all the best for 2017.

Sue
The CDPC comes together

It is always a valuable time when the CDPC Network Members come together for our annual face-to-face meeting. Held in Sydney, over 75 attendees including consumers, academics and partner organisation members gathered to discuss their latest research findings, stories and learnings. With the CDPC now half way through its first five year funding term the theme of this year's meeting was “Translating evidence into practice”.

Professor Susan Kurrle, CDPC Director and Chief Investigator, opened the meeting with a presentation “Half way though: how far have we come?” providing an overview of the CDPC’s evolution from a small working group focused on 14 research projects to the current CDPC Network of over 250 members and 33 projects.

Sue also took the opportunity to launch the CDPC Mid-Term Report, a document that highlights our significant achievements to date and the impact that we are already having. A link to the CDPC Mid-term report can be found here or on the CDPC webpage.

Presentations from Activities that are well into the life of their projects outlined the application of their findings, while projects that recently commenced gave us a glimpse of their work through rapid fire presentations and poster session.

The meeting also provided a forum for speakers outside the CDPC Network to give their perspective on the current care environment that influences the work that we do. It was refreshing to hear from interim Director of the NHMRC National Institute for Dementia Research, Peter Schofield, who provided an overview of the current state-of-play for distribution of NNIDR funding for dementia research based on Government Policy. CEO of Presbyterian Aged Care NSW and ACT, Paul Sadler, provided an insight into “What is happening in Aged Care in 2016” and acting CEO of Alzheimer’s Australia, Maree McCabe, highlighted the importance of partnerships and community action to create a dementia friendly Australia.

A real success of the CDPC has been the involvement of consumers, those living with dementia and their care partners. At this year’s annual meeting nine consumers attended and we were lucky enough to hear two very personal stories. Jane Thompson, whose husband was diagnosed with younger onset dementia, recounted what this meant for her family and how much has changed with the availability of support, understanding and resources for the person with dementia and their families. Jane also described the shift towards consumer driven research, not just as a token gesture but as a true and valued contribution.

John Quinn, who is living with a diagnosis of dementia, shared how he has adapted his day-to-day routine so he is able to live the best life even with the significant challenges such a diagnosis brings. Glenys Petrie also shared her experiences as John’ partner and full-time carer, their tireless advocacy work and commitment to involvement in dementia research.

Hearing these stories focussed all attendees of the significance the research that we do in the CDPC and the importance of translating our findings into having a real impact for people living with dementia.

Sally Grosvenor, Communications Officer CDPC
A consumer companion guide entitled “Diagnosis, treatment and care for people with dementia” was launched at Parliament House on November 9, 2016. This resource uses accessible language to provide practical guidance about important aspects of the Clinical Practice Guidelines and Principles of Care for People with Dementia for people living with dementia.

Australia’s first clinical practice guidelines for people with dementia were released early in 2016 and while guidelines are primarily intended for use by health professionals, they are also valuable for consumers as they provide details regarding the expected level of care. It was therefore important to develop a companion guide for members of the public to complement the Clinical Practice Guidelines and Principles of Care for People with Dementia.

As part of the Activity 13 project, a collaborative working group including five consumer representatives (four care partners and one person with dementia) was formed to determine the aims and desired format of the consumer guide.

"The objective of this project was to develop a companion guide for members of the public to complement the Clinical Practice Guidelines to ensure that the information in the Guidelines is more accessible to those who need it most, regardless of their varied levels of health literacy," Activity 13 Project Officer, Dr Kate Laver.

The guide includes information about the ten Principles of Dignity of Care, ensuring timely diagnosis, advance care planning, accessing services in the community, rehabilitation services, supporting carers, strategies to manage symptoms, and end-of-life care. It includes links to further information and suggested question prompts to facilitate discussions with health professionals. This consumer version of the guidelines is a valuable resource that will allow consumers to be fully informed when being investigated or treated for possible or diagnosed dementia. The Consumer Guide is currently available on the CDPC website at http://sydney.edu.au/medicine/cdpc/resources/consumer-companion-guide.php, and through Alzheimer’s Australia national and regional offices.

"Dr Kate Laver presents the Consumer Guide at Parliament House, Canberra"

"Launch of the Consumer Companion Guide at parliament House, Canberra"

Sally Grosvenor, Communications Officer CDPC
Older people living with a diagnosis of dementia have a high risk of falls, with more than 60% falling annually and 40 percent having multiple falls. A quarter of hospital admissions for people living with dementia are due to falls and there is an increased risk of other adverse events such as mortality, morbidity and pavement in aged care facilities after a fall.

A recent study conducted by Dr Morag Taylor, Activity 19, published in *International Psychogeriatrics*, pp. 1–11. doi: 10.1017/S1041610216001629, has shown that a home-based exercise program can significantly improve balance in older people with cognitive decline. Poor balance and depressive symptoms have been shown to increase the likelihood of falls in older people with dementia. In cognitively intact older people exercise has been demonstrated to reduce falls and improve mood; however there is little information available for people living with dementia.

This preliminary six-month study examined a home based, carer supported exercise program and measured mood and balance in people with mild to moderate dementia who were over 60 years of age. The study also examined concern about falls, physical activity and quality of life indicators.

All participants had an individually tailored exercise program that was primarily centered around balance and strength exercises. A physiotherapist visited regularly over the six month period and adherence to the program was monitored using exercise diaries.

The results of this pilot study found that following the six month intervention there was significant improvement in balance and although there was no detected improvement on mood, concern about falling was reduced.

As part of dementia awareness month, CDPC researchers took part in a number of speaking events across Australia. Professor Maria Crotty and Professor Craig Whitehead delivered the Alzheimer’s Australia Dementia Awareness Forum on “Rehabilitation and dementia: the evidence on maintaining independence” in Darwin, Hobart, and Adelaide and “Dementia: ‘Prescribed disengagement or active engagement’” in Perth.

On World Alzheimer’s Day, 21 September 2016, Alzheimer’s Australia Dementia Research Foundation held a panel discussion event titled “Quality dementia care: What do we value?”. Invited speakers included Dr Ron Petersen, Director of the Mayo Alzheimer’s Disease Research Center and the Mayo Clinic Study on Aging in the U.S, with Professor Elizabeth Beattie, Ms Therese Adami, Ms Maree McCabe, Mr Trevor Crosby and Professor Susan Kurrle.

The expert panel came together to discuss the care needs of people living with dementia and their carers and ways to improve quality of care for people with dementia.
Evidence of effects of regulation in aged and dementia care help target valuable resource allocation.

As one of the CDPC’s initial projects approaches its final stages some interesting findings are emerging. This three year study aimed to examine the role and effects of regulation in aged and dementia care and gain a greater understanding of why we regulate care.

During the early stages of research, regulatory systems were mapped to reveal the uneven spread of regulation throughout the system, showing how regulation clusters around particular individuals, care sites and care-related activities.

This clustering takes place in four ways:

1. Through the overlap and duplication of different government responsibilities, jurisdictions and regulatory authorities.
2. By accretion as more regulation has been added over time in response to risk, scandal and system failings.
3. The interplay of multiple regulations at care transition points.
4. Differing levels of regulation depending on the care activity.

While these findings may come as no surprise to those involved in aged and dementia care, they provide evidence on where resources and efforts to improve care amidst regulation are best targeted.

Our research is now using and expanding these findings to explore the different ways aged care organisations respond to the regulatory environment. Interviews with senior managers, facility managers and care workers (PCA or equivalent) across a range of residential care settings have been conducted.

Responses reveal how the interpretation and application of regulation differs at three distinct levels of the organisation. The various organisational and operational strategies developed to translate regulation into action are currently being examined, and will form the basis of planned dissemination activities. Significantly, future publications will outline how organisational strategies and approaches to regulation reveal what is specific about dementia care and thus its regulation.

The final stages of the project will focus on the experience of care-users, and collect information on what this stakeholder group see as the pros and cons of regulation. This stage of the research, alongside ongoing work with the industry partners and other stakeholders, will help to shape a series of policy and practice recommendations.

Overall, the most important message of our research is that debates about more versus less, good versus bad regulation fails to capture the complexity of care governance, the need to balance various stakeholder interests and the various ways regulation can both enable and prohibit different aspects of care practice.

Moreover, ‘good’ regulation should leave room for innovation while maintaining the ‘intent’ behind regulatory rules.

In the context of proposals for a lighter touch approach to regulation we would do well to recognise the critical role of regulation in mixed economy care and recognise both its benefits and drawbacks.

More information can be found in two Research Insight documents produced by Professor Simon Biggs and Ashley Carr: (http://sydney.edu.au/medicine/cdpc/research/attitude-culture.php)

Ashley Carr, Activity 7 Project Officer

Ashley Carr presented his results at the CDPC Annual Meeting

Activities in Action
The Consumer Voice

Dementia in the public domain

Tara Quirke and Danijela Hlis (members of the CDPC Consumer Group) were privileged to attend the recent Anglicare conference and with our thanks to the CDPC for sponsoring us, Anglicare for having us and Dr Irja Haapala and Prof Simon Biggs for including us in the running of the workshop, we are happy to share this with you.

There were some great speakers at the conference. My favourite was the charismatic Charlie King, sports commentator on ABC and great advocate for Aboriginal people and their fight against domestic violence and addiction. Charlie’s mother is a Gurindji woman and he is the founder of the NT born campaign NO MORE. Prof Simon Biggs also gave a great talk that made us really reflect and look at things more closely.

Day 2 of the conference was for the delivery of the CDPC Activity 18 workshop: “Public perceptions of dementia and general intelligence.” The aim of the session was to examine the role of intergenerational relationships in the way that dementia is described in the public domain. The outcomes will be used to inform research for the CDPC and will include input from our consumer and provider advisory group.

We had four tables of participants of various ages and while Irja and Simon have a full feedback on all questions raised, I personally noted that some believed that perception of dementia, as well as awareness of this condition, may not have so much to do with our age, alone, but also our exposure. For example a professional lady of CALD background who works in the field was very well informed, aware etc. but she told us that her family and friends who work in different fields and are of the same age-are not.

To the question: how can a campaign on dementia engage better and what types of campaigns to look at: we mentioned that many already exist but the general community is unaware of them (the problems of knowledge translation). Suggestions included more accessible avenues such as more plays, soap operas for TV, radio etc., where people with dementia play a role; engaging church, school, social clubs, bi cultural social clubs to participate, etc.

I would have liked to hear from a few consumers, those who receive Anglicare help/assistance, as well as their carers, cleaners, all people who make up Anglicare. And I had an idea:

Could AA, and all those associated with it, including high profile people, researchers etc., give themselves a task of spending a day in a home of a person with dementia and his/her family? TO LIVE IT FOR 24 HOURS?

Charlie King introduced his friend Kevin (with two cultural backgrounds), who told us his personal sad story; and also we were given the pleasure of watching two dance groups (one with children, and the other one with Aboriginal men from a nearby prison facility), perform native dances, with joy and pride.

On the front page of The Review (Anglicare Australia 2016), THE FIRST CAPTION READS: “Leaving no one behind.” I did feel that people with dementia and their carers have sometimes been left behind.

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Informal interviews conducted by the CDPC Evaluation team over the last quarter revealed that the CDPC is having an emerging impact on policy and practice. While the CDPC has made some considerable progress, the interviews revealed that some Activities are more advanced than others in thinking about how their work will impact future policy and practice.

The CDPC aims to improve the care of people with dementia through supporting the implementation and evaluation of tested models of care; synthesising and disseminating research on best practice in the care of people with dementia; undertaking collaborative new research that explores innovative ways of caring for people with dementia; and building capacity to do applied research and to use research in practice. The work undertaken by the CDPC will result in progress against nine impact areas, which were identified in the original work plan.

The CDPC Evaluation team undertook informal interviews with 20 people to document the progress Activities are making towards achieving policy and practice impact.

The interviews uncovered that, even though many Activities are still in the beginning stages of their projects, the majority of lead investigators recognised that achieving broader impact is critical to the CDPC’s continuing success. For example, Dr Susan Koch, from Activity 3 and 4, believes that these Activities are meeting the CDPC goal of building workforce capacity in the sector:

“...new researchers have been an asset to the research projects – having fresh perspectives & cultivating new researchers for the future of the field is important.”

Eleven new CDPC Activities began in 2016. Several of the lead investigators from these Activities were also actively thinking about how they will impact policy and practice in the future. Megan Corlis, from Helping Hand, is hopeful that Activity 29, which is evaluating the implementation of exercise prescription in Aged Care, will give her organisation:

"... hard evidence to show that exercise does enhance the quality of life of older people, and this will have a significant impact in the future.”

Some of the lead investigators also reflected on the fact that the short term impacts in more innovative projects may not always be positive (1). For example, Len Gray, from Activity 20, hopes that this work will:

“Empower people who are providing the primary care to have all the information that experts bring without the price that comes with doing that…”

However, he recognizes that telehealth also has the potential to:

“...depersonalise a process that may feel very personal.”

The interviews uncovered that a few lead investigators were not actively thinking about how their Activity would have broader policy or practice impact beyond their individual project. As a result, it is important the CDPC continues to clarify that impact is an expectation of all projects, and to provide support to Activities to ensure that projects can achieve this. More emerging impact statements from our lead investigators are featured in the CDPC Mid-Term Report.

Panel discussion on “What is impact and how do we measure it?”

If you have any questions or comments please email the Evaluation team (Shannon McDermott and Alexandra Nikitas Kitching) on sms.cdpc@sydney.edu.au.

Maximising Communication to Accelerate Implementation of Improvement in the Lives of People Living with Dementia

We all want to increase the spread and speed of improvements in care for people living with dementia. Improving communication of robust, actionable knowledge to industry partners helps us apply and share CDPC findings to the benefit of large numbers of people affected by dementia. Each CDPC partner organisation reaches thousands of people through their marketing communication programs, each with a stake in improving the lives for people living with dementia.

Combining exploratory, knowledge-creating academic research with implementation research offers opportunities and also presents communication challenges. At the request of the Executive Committee Jan Van Emden (Helping Hand), Sally Grosvenor (CDPC Communications Officer) and Kate Hayes (CDPC Management of Change and Workforce Enabling Sub-Unit) have been working with industry partner key contacts (Designated System Based Investigators/DSBIs) to maximise opportunities for knowledge translation, dissemination and implementation.

Distributing a discussion document summarising opportunities and challenges to improving communication to the lead DSBI at each aged care partner organisation was followed by a phone interview, which in some cases included partner marketing communication and research personnel.

Improvement Opportunities

Frequent, structured and unstructured communication between DSBIs enables a good understanding of the activities involving individual DSBIs. However it may not provide the key points needed for wide publication to a broad audience. Requirements exist to collect and transform information into forms that suit each audience.

Changes that create a simple, reliable process with clear understanding of CDPC and partner roles and responsibilities include:

- Activity summaries, provided by the CDPC Directorate followed by DSBI joint discussion, will identify opportunities to leverage research findings in practice and potentially create new services.
- Regular contact between CDPC Communications team and each partner’s marketing communication and media personnel to support opportunities to rebroadcast links through social media and avoid duplication
- Tailored communications will be provided for identified audiences
- New Expressions of Interest for funding will be forwarded to the DSBI representative on the CDPC Executive Committee for distribution to all DSBIs.
- Summaries of each activity at key stages will be prepared and distributed to the DSBIs and the nominated Marketing/Communication person for each partner organisation. Each item distributed by the CDPC Directorate will also list the outlets sent to avoid duplicating marketing communication activities.
- Each Activity Lead will be supported by CDPC Communications and DSBIs to identify target audiences, and summarise each activity’s findings appropriately for these audiences. The Consumer Enabling Sub-Unit will be invited to review the suitability of language and content. The activity summaries will then be sent to CDPC partner marketing and communications contacts.

If you have any comments on this work, including ideas to improve or expand it we’d be pleased to hear from you.

Sally Grosvenor (Sally.Grosvenor@sydney.edu.au)
Jan Van Emden (JVanEmden@helpinghand.org.au)
Kate Hayes (Kate.Hayes@griffith.edu.au)
CDPC Directorate/Operations Update

The CDPC Directorate/Operations team congratulate Ali Kitching (nee Nikitas) our Project Administrator on graduating recently with her Masters in Public Health, and Dr Emily Reeve, NHMRC-ARC Dementia Research Fellow and Activity 11 team member (Quality Use of Medicines) who was a finalist for the BUPA Emerging Health Researcher of the Year. Our CDPC congratulations also go to Kate Swaffer, dementia advocate, who won South Australia’s Australian of the Year award for 2017, making her a nominee for Australian of the Year, with results to be announced on 25th January 2017.

Over the past months our team have been busy attending a number of events and conferences to present, participate, and talk about the CDPC’s work. These events have included: the 2016 Ministerial Dementia Forum – Redesigning Dementia Consumer Supports (by invitation); the 5th Annual NHMRC Symposium on Research Translation – Embedding Research into Health Care: Building a Culture of Quality; the Australian Clinical Trials Alliance (ACTA) Summit 2016 – IMPACT, Maximising the health and economic benefits of investigator-initiated clinical trials & registries; the COTA Strengthening Dementia Services – Reform & policy driving cutting edge & competitive dementia care; and, we were separately invited to take part in a teleconference with our Department of Health, Dementia Section partners to discuss the direction of consumer support programs prior to the Dementia Forum.

I am working closely with Anne Cumming (Lead, Policy & Legislation Enabling Sub-Unit) to ensure the outcomes and outputs of our CDPC Activities are fed into the appropriate policy and legislation areas, and part of this is encouraging all CDPC Activity Leads to create a communication / dissemination plan for their Activities that outlines who the audience for the outputs are, and how they will be approached. Sue Field is also working with Anne and myself in this Sub-Unit and we are meeting regularly via teleconference to discuss the Sub-Unit strategies for Activity team engagement, and dissemination.

In November, I attended a one-day workshop on Knowledge Translation for Researchers which was run by Public Health Insight (incorporating Cochrane Public Health) at the Centre of Health Equity, University of Melbourne. The workshop included insights into current thinking in: knowledge translation planning, goals, and strategies; engagement for research; communicating your research; planning for dissemination strategies; measuring research impact, and evaluating knowledge translation. I came away inspired to encourage our CDPC researchers and collaborators to aim high, and be strategic, when communicating your results. If anyone wants guidance in the area of impacting policy & legislation I do encourage you to contact Anne, Sue or myself.

In 2016 we had eleven (11) new Activities commence with funding from the CDPC and six (6) Activities are due for completion by the end of the year. We have one (1) Activity scheduled to commence in early 2017 and another nine (9) Activities due for completion by the end of that year. So, next year is looking to be another intense year of operational activity and promotion for our team, the Enabling Sub-Units, our researchers, and our consumers and our partner organisations. I wish you a relaxing summer and holiday season and look forward to working with you all next year.

Jennifer Thompson, Operations Manager
(sms.cdpc@sydney.edu.au)
What is your role in the CDPC?
I am a Principal Investigator on Activity 29, the Exercise Prescription in Aged Care evaluation project.

What did you do prior to joining the CDPC?
I have worked at Uni SA's School of Health Sciences as an Associate Professor in Sport and Exercise Psychology since 2011. Previously, I held positions in the School of Sport and Health Sciences at Exeter University, England (2004-2011) and the School of Health and Exercise Sciences at Bangor University, Wales (1989-2004).

My early research was in the area of anxiety and performance, during which I worked with a number of international squads. More recently, my research has focused upon the chronic effects of exercise on psychological health; methods to motivate exercise behaviour change within community and rehabilitation environments; and mechanisms associated with the affect-exercise intensity relationship. My research with sedentary and active children and adults has employed quantitative and qualitative methodologies to understand the mechanisms and processes integral to psychological health and exercise behaviour.

What has surprised you most about working for the CDPC?
I'm not sure that there is anything in particular that has surprised me, but I have been very impressed by the collaborative nature of the CDPC, and the opportunity to network and disseminate project-related information at functions such as the November Annual Meeting.

What do you like to do when you are not at work?
I try not to think about work, and instead have fun with the family; lots of outdoor activity; music, theatre, and film; and house renovation.

Tell us one thing about yourself that we might not know?
In the 1990’s, I broke my neck skiing.

Describe yourself in three words:
Tenacious, passionate, loyal.

What is your best achievement?
Raising healthy, happy children, and maintaining a successful academic career whilst doing so, is my best achievement!
Reframing Dementia as a Social and Cultural Experience (Sydney, 14-15 February)

8th National Dementia Conference (Adelaide, 23 -24 February)

32nd International Conference of Alzheimer’s Disease International (Kyoto, 26-29 April)

21st IAGG World Congress of Gerontology and Geriatrics (San Francisco, 23-27 July)

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