Welcome to the third edition of the CDPC News

Hi everyone and welcome to our third newsletter. We also welcome our new Operations Manager, Jennifer Thompson, who has taken over from Amy. I will leave it to Jenn to tell you more about herself in this newsletter.

It is great to be able to report that we are definitely getting some runs on the board. Activity 2 (CHOPs- Care of the Confused Hospitalised Older Persons Program) is concluding with successful roll out of the program in hospitals across NSW. Activity 13’s Clinical Practice Guidelines for Dementia in Australia are awaiting final approval and sign off by the NHMRC, and we are looking forward to the launch of those next year.

In this newsletter we take a look at a number of other activities underway or nearing completion, ranging from medication use to the role of regulation in dementia care. We also give an update on our very active consumer representatives, and their national and international involvement.

We look forward to seeing many of you at our Annual Meeting in Adelaide on 16 and 17 November.

Sue
Overuse of medicines in older Australians: what can we do?

National Stakeholders Meeting: Quality use of Medicines to Optimise Ageing in Older Australians.

Gaining a clearer understanding of how much overuse of medicines occurs in older Australians is key, according to experts at the National Stakeholders Meeting: Quality use of Medicines to Optimise Ageing in Older Australians held at the Kolling Institute of Medical Research on 3 August 2015.

As our population ages there is an associated major increase in people living with multiple chronic diseases, including dementia. There has been a rapid increase in polypharmacy (multiple medicines use) in Australia over the past decade and the prevalence continues to rise, especially in older adults. There are many consequences of polypharmacy including adverse drug reactions as well as being a burden to the person taking them.

Taking multiple medicines is time consuming and costly to older adults and adverse drug reactions can be mistaken as disease or as a symptom of ageing itself. Use of harmful or unnecessary medicines also impacts the health system through the high cost of medicines and treating patients with adverse drug effects.

More than 80 representatives including consumers, clinicians, academics, policy makers, and health and aged care professionals attended the meeting hosted by the NHMRC Cognitive Decline Partnership Centre and NPS MedicineWise, to discuss strategies to improve quality use of medicines for older Australians, with an emphasis on avoiding the harms of multiple medicines use.

The meeting was opened by Ms Carol Bennett, CEO of Alzheimer’s Australia who used the example of people with dementia to highlight some areas in which we can improve. People with dementia often take more medicines than those without which means there is greater chance of drug interactions and adverse drug reactions.

Optimisation of medicines in this group is complicated because of these issues as well as the involvement of surrogate decision makers (family and friends). She highlighted that medications to treat the behavioural symptoms of dementia should only be used short term due to the harm they can cause in older people and discussed a need to support use of non-pharmacological therapies in this population.

“Polypharmacy, usually defined as the use of five or more drugs, is a real issue for the ongoing overall health of older Australians,” says Professor of Geriatric Pharmacology at Sydney Medical School, Activity 11 Lead Investigator and meeting organizer, Professor Sarah Hilmer.

There is emerging evidence that supervised withdrawal of harmful or unnecessary medicines is safe and may improve quality of life in older people. When surveyed, over 90 per cent of older Australians said that they would like to stop one of their medicines if their doctor said it was possible.

Strategic areas including policy change, increased education and awareness of consumers and clinicians on the benefits of quality use of medicines, use of technology and eHealth, as well as evidence-based research, were then identified during the meeting as real opportunities to improve the health of older Australians.

Over the next 12 months working groups will come together to develop a Strategic and Action Plan that will provide a way forward to achieve a reduction in the prevalence of harmful or unnecessary medication in older Australians.

Key findings from the meeting can be found in the recently released Outcomes Statement.
Why advance care planning needs to be different for people with dementia

A draft report titled “Future care planning for individuals with cognitive decline” has been released for public consultation.

The draft report (http://sydney.edu.au/medicine/cdpc/documents/about/future-care-planning-for-individuals-with-cognitive-decline-final-draft.pdf) has been developed by the NHMRC Cognitive Decline Partnership Centre with researchers from funding partner HammondCare. The report examines how Advance care planning (ACP) systems can be improved to meet the needs of people with dementia, and other forms of cognitive decline.

Many people living with dementia will live for an extended time when they are unable to make or express their own choices about matters that are important to them. ACP is an important mechanism that facilitates a person's involvement in planning for the future, at a time when that person cannot make or communicate his or her decisions.

Dementia poses unique challenges for ACP because incapacity to make decisions is more certain than in other diseases and such incapacity is progressive over a long period. If ACP is left until near end-of-life it will be too late for those with dementia to be able to fully participate. The types of decisions that need to be made as a person’s cognitive function deteriorates are wider than just medical decisions near end of life. Family members and carers are called on to make ongoing decisions, and these decisions relate to a range of financial, lifestyle and health issues.

Ideally ACP discussions should commence before an individual is diagnosed with dementia. However, when ACP has not been discussed prior to diagnosis it should occur as soon as possible after diagnosis, usually within a few months.

“In developing this report we spoke with a lot of stakeholders, including consumers; there was overwhelming support for the need to engage people earlier in life, before a diagnosis of dementia, or shortly afterwards. It was also identified that the most important part was supporting the person with dementia to have ongoing conversations with family about what is most valued” says Associate Professor Meera Agar, Director of Palliative Care HammondCare and CDPC Lead Investigator.

This draft report recognises the good work that is being done in the different jurisdictions of Australia and includes recommendations that can be adapted into existing programs or can be used to develop new programs that aim to increase the uptake of ACP in a sustainable way. The recommendations are relevant for policy makers and individuals in government, aged care and community care, primary care and acute care.

Consultation has been an important element in the development of the report and recommendations and broader feedback is now sought to ensure it reflects the experience of a wide range of stakeholders.

The CDPC requests your feedback on the draft report using the online feedback form. The form encourages you to direct your feedback to precise areas and make specific suggestions for improvement. The consultation process will remain open until Monday 2 November.

Draft Report:
Future care planning for individuals with cognitive decline

Additional information:
Future care planning for individuals with cognitive decline-companion document
Please provide your comments in the form at: http://sydney.edu.au/medicine/cdpc/advanced-care-planning-report.php
Written submissions can be send to acp@hammond.com.au
For further information on the project please contact Adele Kelly or Gail Yapp (above address)
Dementia and Delirium Care with volunteers Program

The Dementia and Delirium Volunteer program is based on a volunteer program implemented and evaluated at Bega Hospital in NSW in 2009 by CDPC Lead Investigator Cath Bateman (Southern NSW LHD), in partnership with Barbra Williams (Alzheimer’s NSW).

The program has been sustained at Bega Hospital for six years.

It was included as a model supporting care of hospitalised patients with dementia in the NSW Dementia Services Framework 2010-2015 and was showcased on the Innovations Exchange web sites in Australia and the US. Replication has occurred in a number of other Australian hospitals.

In 2014 the NSW Agency for Clinical Innovation Care of Confused Hospitalised Older Persons Program (CHOPs) funded Cath Bateman to develop a comprehensive training and implementation package to assist other NSW hospitals wishing to implement the program.

The volunteer role provides similar support to that of a family carer. In this way the volunteer program can be of support and reassurance to families and carers when they are not able to be with their loved one.

Volunteers provide emotional security though one to one interaction with patients and engagement in therapeutic activities. A personal profile is completed by volunteers with the patient and/or family carers to gain information about the patient’s background and personal preferences. Volunteers also provide practical assistance, including assisting with eating and drinking; ensuring patients are wearing vision and hearing aids and encouraging patients to walk when it is safe to do so.

The funding is part of the Commonwealth Government’s Aged Care Service Improvements and Healthy Ageing Grants. This Volunteers Program is also now part of the CDPC Work Plan.

Project officers (Clinical Nurse Consultants or Allied Health Professionals) will be recruited at each site to establish and implement the program; recruit, train and support volunteers, and assist in collecting data on the program.

Training, supervision and support of the site project officers will be provided by Cath Bateman (as Program Co-ordinator). The ACEU will assume project management responsibilities and research services. The research will analyse patient, staff and volunteer outcomes and include a cost analysis and evaluation of the implementation and training resource.

Ethics approval has been obtained and recruitment of the project officers is underway. A governance steering committee has been established with Elaine Todd representing the CDRN. It is expected that Project Officers will begin implementation of the program in October, with volunteers trained and working with patients from January to December 2016. The project is due for completion in June 2017.

The project had an abstract accepted and was recently presented at the DCRC National Dementia Research Forum in Sydney in September.

Cath Bateman

The Southern NSW Local Health District Aged Care Evaluation Unit (ACEU) and Cath Bateman (SNSWLHD Dementia/Delirium Acute Clinical Nurse Consultant) have secured funding from the Department of Social Services to implement and evaluate the program at seven SNSWLHD Hospitals (Moruya, Batemans Bay, Goulburn, Crookwell, Yass, Cooma and Queanbeyan).
The Role of Regulation in Dementia Care

Regulation is an ever-present feature of the aged care system and is a key mechanism through which government interacts with providers and the users of care services. While ‘red tape’ is a growing topic of public interest, so is the quality of care. From building design and fire safety through to food and hygiene, a host of regulations guide aged care providers and their staff, influencing the dynamics and quality of residents’ experience and their living environments.

However, we lack a detailed understanding of how these regulations affect the quality of life of people living with cognitive decline specifically, and the degree to which services can innovate in meeting their needs. Activity 7 addresses these issues in collaboration with three leading Australian Providers and the Consumer Dementia Research Network, based at Alzheimer’s Australia.

Our research aims to reveal how regulation shapes the provision of care for people with dementia. What are the intended and unintended consequences of current regulations? What are the positive, negative, or ambiguous effects? By answering these questions, and by developing a deeper understanding of how regulation works in practice, we will be able to make recommendations to improve future care policy.

We define regulation as an intentional attempt to guide behaviour, which goes beyond individual pieces of legislation to look at how organisations interpret, shape and are shaped by the everyday experience of a regulated environment. In aged care, this works in several ways: guaranteeing rights, setting out provider and employee responsibilities, promoting safety, providing standards of care, protecting consumers and care workers, and reducing risk. “Regulation matters” is the message we have heard from care providers, workers and consumers. But, there are different views on why and the effects it has on the practice of care. How different people understand and experience regulation often depends on where they sit in the system.

The research has progressed in three stages:

During the first stage, we mapped the many regulations that apply in aged care. This showed a complex web of regulatory arrangements and departmental relationships. Demands sometimes overlapped, regimes differed on purpose and effectiveness and the degree to which regulation specified.

In the second stage, we interviewed multiple stakeholders in aged and dementia care. We asked for their opinions on how regulation works, and we talked through their concerns and priorities for change. One important finding was that regulation has often been developed as a reaction to scandal rather than to facilitate best practice in care. Another finding was that providers need to interpret regulations before they can put them into practice – and this is not always simple or standardised. On one hand regulation may restrict good care. On the other it may allow innovation.

Taken together the mapping and stakeholder consultations gave us a ‘big picture’ of the role of regulation in the dementia care system.

The third stage is currently underway. We are interviewing staff from different levels of the partner organisations: senior managers, facility managers, and personal care workers. This will help us to see how regulation works throughout the whole organisation. We hope to have a particular emphasis on the point at which care is delivered and the amount of flexibility given to experienced care workers.
Activities in Action

The Role of Regulation in Dementia Care (cont).

We will also be focusing on three particular points of care delivery: food, daily care routines, and decision-making. From this we hope to understand how regulation can sometimes restrict and sometimes enhance best practice.

Presentations based on this project have been given in New Zealand, at the Brotherhood of St Laurence, and the Alzheimer’s Disease International Conference and the Australian and New Zealand History of Medicine Conference. Publications are underway in two academic journals in health and social sciences. We will soon release a discussion paper on our first findings.

Simon Biggs, Ashley Carr and Bryonny Goodwin-Hawkins.

The Consumer Voice

Members of the Consumer Dementia Research Network (CDRN) in action

Recent opportunities to which some Members have been invited to contribute, include:-

Presentations:
Kate Swaffer  -  was invited to deliver the Consumer Address on Day 2 of the recent Dementia Collaborative Centres (DCRCs) Forum in Sydney, titled - Making a difference in dementia: My perspective on the international landscape.

Jane Thompson  -  was invited to deliver an Oral Presentation on Day 2 of the same Forum. Jane’s Paper, titled Incorporating consumer preferences and values into the new Australian Clinical Guidelines for Dementia, was based on the involvement of Consumers in the development of the National Dementia Guidelines, as undertaken in CDPC Activity 13.

Jane Thompson  -  also had an Abstract accepted for a Poster Presentation at the forthcoming NHMRC Symposium titled, Partnering with consumers to develop the Australian Clinical Guidelines for Dementia in Australia, will be presented by Louise Heuzenroeder.

Appointments:

The Minister for Health has recently approved appointments to the Board of Directors for the NHMRC National Institute for Dementia Research (NNIDR).

Jane Thompson  -  has been appointed as a Member of the Board of Directors.

Louise Heuzenroeder  -  has been appointed to the Expert Advisory Panel.

Representation/Consumer Advocacy:

Ron Sinclair  -  has been appointed as a Consumer/Carer Advocate on the Department of Social Services (DSS) Carer Gateway Advisory Group, which will lead the Government’s $33.7 million initiative to build a National Carer Gateway.

Joan Jackman  -  has been involved with the Australian Commission on Safety and Quality in Health Care (ACSQHC) - Cognitive Impairment Program, through Consumer Representation on the NSQHS Clinical Care Standard for Delirium Working Group; the Cognitive Impairment and Review of the NSQHS Standards - Roundtable Meeting; the recently convened Cognitive Impairment Advisory Group – to advise and support the Commission’s Cognitive Impairment Program – and specifically the dementia and delirium Call for Action Campaign.

Louise Heuzenroeder  -  was also involved in her professional capacity, in the Cognitive Impairment and Review of the NSQHS Standards – Roundtable Meeting.

Christine Bryden  -  (former CDRN member) – is also a Consumer Representative on the Cognitive Impairment Advisory Group.

Joan Jackman
The Consumer Voice

World Alzheimer Report 2015

Encouragingly this report has incorporated new research evidence which gives us more accurate projections of prevalence and cost and thereby a stronger advocacy base.

In 2015 it is estimated there will be:

- 46.8 million people living with dementia rising to 131.5 million in 2050
- 9.9 million new cases of dementia, one every 3 seconds
- a global cost of dementia of US$818 billion
- an Australasian cost of US$ 15.1 billion, an increase of nearly 40% over 2010

What is very positive is the call for dementia planning at the global and country level aiming to support the person with dementia to stay in the community as long as possible. Elements include:

- Awareness raising
- Creating dementia friendly communities
- Promoting risk reduction measures
- Improving diagnosis
- Supporting family carers
- Access to long term community and residential care services and to enhanced care in hospitals
- A commitment to person centred care with minimal use of restraint
- Workforce strategies
- Use of technology in the home and to extend service reach in rural areas
- Recognition that people with dementia deserve good quality end of life care.

We must use these as a focus of our own actions in the dementia research and knowledge translation arenas.

Tony Ramshaw

UN Convention on the Rights of People with Disabilities (CRPD) drives Kate’s speech

2015 definitely looks like becoming a landmark year for people living with dementia. At the World Health Organisation’s (WHO) inaugural Ministerial Conference on Dementia in Geneva in March, in a speech by Kate Swaffer, access to the UN Convention on the Rights of People with Disabilities (CRPD) was a key point. Marc Wortmann, CE of Alzheimer’s Disease International (ADI) later received unanimous support for an ADI “Nothing About Us Without Us” resolution, also incorporated into the Concluding Call for Action by WHO Director, Dr Margaret Chan.

In my plenary speech representing people with dementia, three key points were made and included in the Final Call To Action:

- our human right to a more ethical pathway of care
- being treated with the same human rights as others, under the Disability Discrimination Acts and UNCRPD
- and that Research does not only focus on a cure, but on care, including rehabilitation

We have been working to gain full access to the CRPD for the global dementia community alongside international NGOs working for people with other disabilities. We have not previously used our legal right to the CRPD; we now need the support of all to ensure that the voice of people living with dementia is heard when decisions that affect us are being made nationally and globally. The CRPD will hold our governments accountable for translating its Principles and Articles into reality in our own community.

Kate Swaffer
6 Essential Elements of Effective Partnerships

A core concept in the CDPC is partnership. Most people involved in the CDPC implicitly understand that working in partnership has a number of potential benefits: it can, for example, help us to leverage skills and resources that we may otherwise not have at our disposal, or help us to solve complex problems that one person or one organisation cannot tackle alone. But, as in all human relationships, maintaining partnerships can also be challenging.

The CDPC evaluation aims to understand how well CDPC members are working in partnership, and the key elements that need to be present for us to work well together. This article outlines the six elements that are essential to effective partnerships identified in the data. The end of the article discusses how the evaluation team will elicit your feedback on the overall evaluation findings in the coming months.

6 essential elements to partnerships

**Commitment:** Commitment to a shared goal forms the foundation of all partnerships. In the case of the CDPC, members have an exceedingly strong commitment to improving the lives of people living with dementia. Remaining focused on and committed to this shared goal is crucial because it helps people to prioritise the partnership over other personal and organisational priorities.

**Trust:** Trust is a crucial element required to sustain a partnership over time; without it, people will have a hard time working together effectively. Relationships of trust develop when people show respect to each other and are generous with their time. CDPC members show respect for each other through numerous small actions, such as actively listening to others, turning up on time and being prepared for meetings, and demonstrating good manners (even saying thank you helps earn others’ trust!)

**Research cultures:** The CDPC is made up of people from industry, academia, advocacy and policy, all of whom have different perspectives of how research should be conducted and used. It is important to recognise that members have different experiences of research and have honest negotiations about how research questions should be developed and prioritised.

**Problem solving:** Challenges are inevitable when doing research in partnership, and it is crucial that problems are resolved in a way that preserves relationships and does not impede Centre progress. Problems are successfully resolved when there is honest, respectful communication; willingness of all parties to compromise; and strong support from the Centre administration team.

**Resourcing:** The majority of people involved in the CDPC have multiple professional responsibilities, of which the CDPC is only one. The extent to which people can focus on partnership responsibilities depends on whether there is appropriate support and resources provided by the organisation they are affiliated with.

**Communication:** Communication is essential for building relationships of trust, solving problems, overcoming different research cultures, and maintaining commitment to the common goal of the partnership. Communication works well when it is frequent, targeted to the audience, and respectful. Effective communication can be particularly difficult to achieve in a dispersed network such as the CDPC.

**Next steps**

The evaluation team looks forward to sharing more evaluation findings with the CDPC network over the coming months. We will share findings with you in two ways: first we will produce some short discussion papers detailing findings specific to the Governance Authority, Executive Committee, DSBI Enabling Subunit, Consumer Enabling Subunit, and Activities. Second, we will be hosting a workshop at the CDPC Annual Meeting that will provide you the opportunity to give us your ideas about how the CDPC can improve how we work in partnership.

In the meantime, if you have any questions for us, please do get in touch! (sms.cdpc@sydney.edu.au)

Shannon McDermott, Anneke Fitzgerald, Katrina Radford
CDPC Member Profile

Jennifer Thompson

What is your role in the CDPC?
As Operations Manager of the Administration team, I believe that my collaborative management style will help me get to know all of the Activities and Activity teams, consumers and industry partners. I hope that this will assist in making everyone’s goals achievable and ultimately improve the lives of those with cognitive decline.

What did you do prior to joining the CDPC?
I came to the CDPC after 2 years as the Centre Manager of the Clinical Research Centre at The Children’s Hospital at Westmead. Prior to that I spent 4 years as a Trial Coordinator at the NHMRC Clinical Trials Centre at the University of Sydney, and 5 years in the research department at Pfizer Australia.

I have three adult children and a wonderful husband who has put up with me for over 27 years. My mother is 88 years old and lives in New Zealand. As she has been diagnosed with dementia I have been her decision maker for the past 2 years so you’ll quite often find me spending my weekend in New Zealand.

What has surprised you most about working for the CDPC?
This questionnaire came to me only 4 days into my first week and so far what has surprised me the most is that there is a decent coffee shop near to the office. Apart from that, there’s not been a lot of surprises as yet because everything is new to me.

What do like to do when you are not at work?
In the summer my husband and I like to spend one morning every weekend at the beach. Since we live quite a distance from any beaches we make an effort to get up and head off early so we can have coffee and beach time and then be home before lunch.

I also enjoy computer gaming in my spare time. Mario Cart will always be my favourite…

Tell us one thing about yourself that we might not know
I’m collecting citizenships. My Australian citizenship is the third I’ve held throughout my life. I consider myself to be a citizen of the world and I love travelling.

Describe yourself in three words

What is the best advice you were ever given
“This is the true joy in life, the being used for a purpose recognized by yourself as a mighty one; the being a force of nature instead of a feverish, selfish little clod of ailments and grievances complaining that the world will not devote itself to making you happy.

I am of the opinion that my life belongs to the whole community, and as long as I live it is my privilege to do for it whatever I can. I want to be thoroughly used up when I die, for the harder I work the more I live. I rejoice in life for its own sake.

Life is no “brief candle” for me. It is a sort of splendid torch which I have got hold of for the moment, and I want to make it burn as brightly as possible before handing it on to future generations.”

What is your best achievement?
My best personal achievement is my science degree. It took me 9 years to complete part-time. Studying at least 1 subject every semester while bringing up our three children, working full-time, and going through a cancer diagnosis and successful treatment. A grad cap never felt so good.
Where you find the CDPC?

48th AAG National Conference

“ViDAus: Implementing Vitamin D to reduce falls in Australian residential aged care” Ian D Cameron, Amanda Miller Amberber, Pippy Barnett

“Quality residential care from a consumer perspective: importance of personhood” Rachel Milte, Wendy Shulver, M Killington, Clare Bradley, and Maria Crotty

IPA International Psychogeriatric Association International Congress 13-16 October 2015

“Quality in residential care from a consumer perspective: the importance of personhood” Rachel Milte, Wendy Shulver, M Killington, Clare Bradley, and Maria Crotty

“Powers of attorney- are they worth the paper they are written on” Sue Field

Visit the CDPC Website at: http://sydney.edu.au/medicine/cdpc/

Follow us on twitter at: https://twitter.com/nhmrc_cdpc

CDPC Intranet https://workspaces.usyd.edu.au/sites/partnership/

Contact us at: sms.cdpc@sydney.edu.au

Call for Abstracts

AAG & ACS Regional Conference 7 & 8 April 2016 Dubbo

31st International Conference of Alzheimer’s Disease International
21-24 April 2016, Budapest, Hungary
Dementia: Global Perspective - Local Solutions

2016 International Dementia Conference
Grand Designs Are we there yet?

International Federation on Ageing
13TH GLOBAL CONFERENCE
Disasters in an Ageing World | Brisbane, Australia | 16 – 23 June 2016

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