Welcome to the second edition of the CDPC News

Hi everyone and welcome to our second newsletter.

This edition covers CDPC activities over the past few months including a summary of our Policy Engagement Workshop, the 30th International Conference of Alzheimer’s Disease International and two perspectives on consumer involvement.

Several of the CDPC Activities are showcased to let everyone involved in the CDPC know what is happening in different Activities and the impact we are already having to improve the lives of people living with dementia, their families and carers. More will be covered in our next edition.

Please let us know what you think of the newsletter and what else you would like included.
Linking research with policy

In February 2015 the CDPC held a Policy Engagement Workshop with an aim to increase awareness and understanding of the policy development process, its complexities, and how members of the CDPC Network can maximise their opportunities for having impact. Close to 50 members of the CDPC Network attended the Workshop as well as representatives of policy agencies including the Department of Social Services, SA Health, WA Health, QLD Health, NSW Health and ACT Health.

The full-day workshop was opened by Carol Bennett, CEO of Alzheimer’s Australia. Carol eloquently set the scene outlining the importance of working together in partnership to drive change and how shared values are crucial in an effective partnership. Carol pointed out that evidence alone does not drive policy or practice and that involvement of consumers at the beginning of the research process helps to focus the key issues.

The morning session focused on providing attendees with a better understanding of how research can impact policy and the ‘evidence’ base for what factors influence the likelihood of research informing policy change. Sue Hunt, from the Department of Social Services, presented from the perspective of policy-makers, outlining the need for researchers to keep policy agencies informed throughout the process and be aware of opportunities for influencing change. Sally Redman, from the Sax Institute, highlighted the importance of policy makers and researchers working in effective partnerships.

Individual case studies describing the success, challenges and lessons learnt along the way were shared by some CDPC Network members. Anne Cumming, CDPC Policy and Legislation Enabling Sub-Unit Lead, described the role of policy makers and researchers in addressing cognitive impairment in hospitals and the development of the ‘A better way to care’ resources. Activity 11 Lead Investigators, Sarah Hilmer and Simon Bell described the implementation of the Drug Burden Index as a tool for optimising quality use of medicines and the need for policy engagement for enduring change. Ian Cameron, who is leading CDPC Activity 12, also presented on his experiences with government regulators in improving outcomes for people with motor vehicle injuries.

The afternoon involved a session on how to ‘write for policy impact’ presented by Krister Patel from the Deeble Institute, as well as an opportunity to break into smaller groups with policy-maker representation to workshop the ‘key messages/audiences’, ‘obstacles’ and ‘strategy’ around each CDPC Activity underway, with the goal of improving our chances of success in relation creating change through policy.

After the event, as part of the feedback survey, participants were asked to rate the event overall with 95 per cent of attendees feeling the event was good or excellent. They were also asked whether the workshop had enhanced their awareness and how they would modify their approach in order to increase the chances of success in achieving policy impact.

“…I will be much more proactive in my relationships with policy makers, keeping them informed of the research that I am working on and how it is aiming to address current gaps in services…”

“…we will identify key policy makers at state and national level, establish a good relationship, and keep them informed of events, etc. that could be useful to them…”
Alzheimer’s Disease International Conference- A CDPC review

This year’s 30th International Conference of Alzheimer’s Disease International ‘Care, Cure and the Dementia Experience – A Global Challenge’ held in Perth on April 16 provided an opportunity for attendees including people living with dementia and their carers, government, service providers, and researchers to hear about the current successes, latest findings and challenges facing dementia both at a national and international level.

A pre-conference screening of the film ‘Still Alice’ set the scene for what was to be a forum that provided real insight into living with a diagnosis of dementia. Edie Mayhew and Anne Tudor gave the opening plenary and described the experience of being in a relationship where one person is given a diagnosis of dementia. Edie and Anne so bravely described their initial loss, grief, guilt and frustration during and after the time of Edie’s diagnosis and how they have worked as a couple towards acceptance and understanding.

“…I choose not to allow dementia to dictate my thoughts and feelings. I have this moment in time and that’s enough…,” said Edie

Over 100 people with the lived experience of dementia attended the conference. Dementia advocates Kate Swaffer (you can read Kate’s report of the conference in this newsletter) and Helga Rohra told of the importance of putting the person first and the diagnosis of dementia second and the importance of making all communities places that foster well-being for all individuals that are not merely ‘friendly’ but “inclusive”.

Plenaries by Professor Martin Prince and Harry Johns focused our attention to the international context, where low and middle income countries and communities are expected to have the highest rates of people living with a diagnosis of dementia by 2050. The importance of examining better models of care was also highlighted, confirming the importance of the work being progressed through the CDPC.

Senator Mitch Fifield opened the second day outlining the government’s current strategy to address the growing health challenge of dementia. He highlighted the $200 million commitment to research into finding a cure and supporting those living with a diagnosis of dementia as well as their carers and families. The focus of the government towards a more consumer directed market in terms of aged care services as evidenced through the development of the ‘My Aged Care Gateway’, was also highlighted.

The CDPC had a strong presence at the ADI Conference. Karla Seaman, Lead Investigator for Activity 9, presented her latest findings into benefits of interprofessional education. You can read more about Karla’s work in this edition of the newsletter. Karen Hutchinson from Activity 17 also gave a presentation on her study examining the social implications on young people of having a parent with dementia, complementing the strong focus on Younger Onset Dementia at this year’s Conference.

As well as the oral presentations, Activity 3, 7, 10 and 14 as well as CDPC partnership fellowship with Dementia Training Study Centre presented posters of their findings to date.

- “Revision of the 2003 Australian ‘Care of Patients with Dementia in General Practice’ Guidelines” Dimity Pond, Jill Philips, University of Newcastle (Activity 14)
- “Risk, freedom, regulation and experience: a study of dementia care” Ashley Carr, Simon Biggs, Bryonny Goodwin Hawkins, University of Melbourne (Activity 7)
- “Improving quality of residential dementia care and promoting change by supporting and caring for staff: What can we learn from the literature?” Katrina Anderson, Mike Bird, Sarah MacPherson, Annaliese Blair, Southern NSW Local health District (Activity 10)
- “Key Worker roles for people with Dementia: A Systematic review” Susan Koch, Dianne Goeman, Emma Renehan, Royal District Nurses Service (Activity 3)
- “Physical comorbidities of dementia: an interprofessional educational program” Roseanne Hogarth
Activities in Action

Draft Clinical Practice Guidelines for Dementia in Australia

In May 2015, the first clinical practice guidelines for dementia in Australia were released for public consultation.

CDPC Activity 13 have developed the draft guidelines in consultation with an expert multi-disciplinary Guideline Adaptation Committee that included health professionals, researchers and consumers. Currently there are no NHMRC approved guidelines for dementia in existence.

“These guidelines will assist in informing our response to dementia, and improving quality of care for people with dementia and their carers…” says Professor Kurrle, Chief Investigator and Director of the CDPC.

Intended for use by medical specialists, general practitioners, nurses and allied health professionals, the guidelines provide health professionals the information to respond appropriately to the needs and preferences of the person living with dementia.

Key recommendations include medication management of cognitive symptoms of dementia and communicating with the person with dementia, their carers and families about disease progression, treatments and services offered by Alzheimer’s Australia.

The importance of education for health professionals, carers and families is also outlined. It recommends that carers should be offered education and training to better manage the symptoms of dementia, be offered respite when needed and provided with information about strategies to enable them to maintain their overall health and well-being.

Approximately 70 submissions were received in response to the call, from policy makers, health and aged care organisations, specialist colleges, health and aged care professionals, as well as people with dementia and their carers.

Overall, feedback was positive with many respondents commenting on the need for Clinical Practice Guidelines and the quality of the document. The Guideline is currently being modified based on the feedback received and is on track for submission to the NHMRC for consideration of endorsement later in the year.

Caring for confused older people in hospital

Sharing practical ideas and strategies in caring for older people who are in hospital and who have confusion, delirium or a diagnosis of dementia was the focus of a recent forum in Sydney.

Hosted by the Agency for Clinical Innovation (ACI) on 11 June, the knowledge sharing forum brought together nurses and clinicians from each of the 12 Care of Confused Hospitalised Older Persons (CHOPs) sites to share learnings from the implementation and evaluation of the CHOPs program.

CHOPs aims to improve the experiences and outcomes of confused older people in hospital. Seven key principles have been developed as a framework for improving care and outcomes. These principles have been informed by the initial CHOPs pilot program in 2011 and the existing evidence base.

The day showcased the great work that has been implemented in the phase 1 sites (Gosford, Lismore and Prince of Wales) as well as outcomes of the program to date.

Interactive workshops and knowledge cafe sessions were held focussing on the 7 CHOPs ‘Key Principles’ to identify challenges and share practical solutions to promote knowledge sharing and learning between colleagues.

The day was valuable in bringing people together who are working towards the same objectives to learn what has and hasn’t worked well and to celebrate the achievements of participating hospitals to date.

Overall, feedback from the day was overwhelmingly positive. “So many ideas and stories, great strategies, lessons learnt, sharing experiences and many light bulb moments,” said one participant.
Activities in Action

INSPIRED study to improve quality of care

The Investigating Services Provided in the Residential care Environment for Dementia in Australia (INSPIRED) study, brings together CDPC researchers from Flinders University and the Repatriation General Hospital (SA), consumers and CDPC Funding Partners to provide evidence-based information for the development of innovative models of care that emphasise consumer-directed care and more effective and efficient service provision.

Currently, there is very little accurate information about what providing quality care for people with dementia or related cognitive decline really means. With an ageing Australian population and increased pressures on aged care services, it is critical to get a better understanding of what factors influence the ability for providers to deliver quality care. This information can then be used to assist in future care planning efforts by service providers and government.

The INSPIRED study has been undertaken in South Australia and New South Wales with CDPC Funding Partners, Helping Hand Aged Care and HammondCare. Residents and their families from eight facilities have been involved in interviews about their quality of life and quality of care, and the aspects of residential care they value most. Information about the model of care provided in these facilities and the resources required to provide this care has also been collected.

Through one-on-one interviews with consumers, the study is examining the variation in current aged care services, differences in resource use, quality of care, and the quality of life associated with different models of care offered by these services.

“The study is a rare one in that it does not exclude people on the basis of being cognitively impaired, on the contrary INSPIRED is designed to include these people,” explains Professor Maria Crotty, Director of Rehabilitation at Repatriation General Hospital, and Lead Investigator for CDPC Activity 1.

“Participants in our INSPIRED study at Helping Hand Aged Care had a wide range of cognitive abilities and even those with moderate cognitive decline were able to participate in the data collection for the study with the assistance of a family member or carer” Professor Crotty said. Interviews at HammondCare were primarily conducted with the family members of residents due to the severity of the residents cognitive impairment.

The researchers are now planning to undertake data collection at selected facilities managed by CDPC Funding Partner Brightwater Care Group in Western Australia and other residential aged care service providers nationally. At completion of the study, the INSPIRED team will be equipped to analyse the data to produce work that will help inform policy and service delivery decisions.

Back row L to R: Tiffany Easton, Rachel Milte, Rebecca Bilton, Enwu Liu
Front row L to R: Wendy Shulver, Lua Perimal-Lewis, Clare Bradley. Absent Maria Crotty and Angela Basso
Innovative program highlights career opportunities in aged care

It has been long recognised that there is disparity between the numbers of university students choosing employment in residential aged care once their studies are completed and those who choose other seemingly “exciting” clinical settings such as acute care.

Those involved in aged care are acutely aware that with the ageing population it is vital that we create a sustainable workforce that is adequately trained to assist older people. To do this, we need to demonstrate that aged care is a stimulating work environment, highlighting the clinical challenges involved in working with those with complex care needs, and ultimately challenge student perceptions of working in aged care.

An innovative interprofessional education (IPE) program in Western Australia is addressing this misconception by highlighting residential aged care as a progressive, challenging and economically viable alternative for future employment.

The IPE program in progress at a Brightwater Care Group’s aged care facility since 2010, and sees students from seven disciplines and three universities conduct their student placement in an interprofessional environment facilitated by coordinators who facilitate opportunities for collaborative practice within a multidisciplinary team.

The students participate in numerous training sessions on a diverse range of topics with a particular focus on cognitive decline.

The CDPC is funding an extensive evaluation of the IPE program to provide an evidence base for the benefits of interprofessional education in residential aged care that will assist with future workplace planning and education strategies. The evaluation includes surveys, focus groups and semi-structured interviews with perspectives from residents and families, staff and students.

“IPE has been invaluable in helping me understand the roles of allied health professionals and how to work as a team. I will, in future, know when/to whom to report health statuses out of my scope. I will carry this throughout my working career,” responded one IPE student after placement.

“I am very grateful for this clinical placement within aged care. It definitely has enhanced my nursing skills and [I have] become more confident to work in aged care in the near future. The enhancing experience of interprofessional learning and share skills and knowledge with my IPE peers has been beneficial,” another student commented.

The evaluation will provide data to determine if the IPE program demonstrates the value of learning from and working with other health disciplines, allows students to overcome initial perceptions of aged care, and increases the likelihood of students seeking employment in the sector on graduation.

One striking outcome of the evaluation so far is an increase in students considering employment in the aged care sector on graduation. Across 2013 to 2014, 11 percent reported interest in employment in aged care prior to their place, with this rising to 60 percent following their IPE experience.

This model of interprofessional education is setting the scene for collaborative care among aged care professionals of the future. If more aged care providers adopt this model, it will help create a sustainable dementia workforce for the future and may provide better outcomes for the residents.
CDPC Evaluation update

Welcome to the evaluation corner of the CDPC newsletter! I would like to begin by welcoming Heather Middleton to our team. Heather has a diversity of research and evaluation skills, but she particularly excels in doing qualitative interviews, analysing qualitative data, and communicating with a wide variety of audiences. She will be working closely with me to collect and analyse evaluation data and also to report on our findings.

The CDPC is committed to improving how we operate and understand the impact of our work. The CDPC evaluation provides an opportunity to assess the performance and operation of the Centre. Key questions the evaluation aims to answer are:

• Is the CDPC doing what it said it was going to do?
• How well is the CDPC operating and what can we do to improve?
• What outcomes is the CDPC achieving?

We will answer these questions using a combination of methods, including conducting interviews and surveys with network members, reviewing the results of evaluations from individual Activities, and analysing data that is already being collected across the network.

We have just finished our first round of data collection and are pleased to report that 40 members participated in interviews and 60 members completed the first survey. We are busy analysing the results of the interviews and surveys, and a full report of our findings will be ready in September 2015. We will be collecting data again in 2016 and 2017.

Thank you to everyone who contributed to the evaluation, we appreciate your feedback and look forward to sharing our findings with you in the newsletters to come!

Helping Activities into action

The Management of Change and Workforce Enabling Sub-Unit has been busy assisting with the conduct of the CDPC Evaluation, as well as provide advice and consultation to many other Activities.

Knowledge translation or implementation of CDPC Activity outcomes is key to the CDPC achieving its goal to improve the lives of people with dementia, their carers and families. One area where we can support CDPC Activities is with development of an implementation strategy. Implementation is often difficult, particularly when it involves shifting people’s behaviour from one state to another.

The Management of Change and Workforce Enabling Sub-Unit can help by providing you with key strategies for success and working with you in this implementation process. Some of the questions we can help you with include (but are not limited to):

• What does the implementation of my Activity look like?
• How do I disseminate my outcomes from here?
• How do I get people on board with my Activity?
• What strategies should/could I use to change behaviours?
• How will I manage the change that is needed for my Activity to be successful?
• How can I maximise my impact more broadly?
• and more!

Our team consist of people who have a psychology, organisational behaviour, human resource management, general management, information technology, logistics, operations management, and clinical background.

We look forward to hearing from you.

Anneke Fitzgerald, Kate Shacklock, Joanne Curry, Katrina Radford (absent: Kate Hayes)
Jane Thompson’s review:

The ADI Conference was an opportunity to showcase how consumer involvement has been embedded into the CDPC since its inception. On behalf of the Consumer Dementia Research Network, I gave an oral presentation entitled ‘Consumer Involvement in Dementia Research in Australia: Past Present and Future’. In the presentation, the evolving landscape of involvement of consumers (people with dementia and carers) in dementia research in Australia was documented along with the increasing recognition that our involvement can lead to research with greater relevance, improved quality and outcomes and also facilitate research translation.

Based on my experience as Consumer Lead on CDPC Activity 13, I illustrated how consumers have been involved in the development of the new Clinical Practice Guidelines for Dementia for Australia. I also discussed how consumer involvement was planned and implemented early with consumers represented on both the ‘Organising’ and ‘Guideline Adaptation’ Committees. The role of consumers was clearly defined and their involvement resourced by the Activity team. Accessibility issues were also addressed and involvement documented. Consumers provided significant input across a broad range of issues including use of appropriate language and incorporation of principles of dignity of care. Overall, the consumers involved in this Activity were positive about their involvement. In addition, the public consultation phase offered a wider group of consumers to provide input. Based on the principle that clinical guidelines developed with attention to the public good and incorporating consumer preferences and values better inform public policy, I suggested that the involvement of consumers in Activity 13 has contributed to the development of relevant, high quality guidelines which will better inform policy and practice in Australia.

Kate Swaffer’s review

A strong focus for ADI Conference in Perth this year was of consumers and professionals, from the perspective of the CDRN and other Alzheimer’s Australia consumer groups. Over 1100 attendees representing 49 different countries were welcomed to ADI conference. Over the course of the three days delegates had the opportunity to attend over 40 different presentations relating to the latest developments in diagnosis, treatment and care, as well as hear some of the experts in the field.

Significantly, ten per cent of the registered delegates were people with dementia; hence at least ten per cent of the delegates were supporters of people with dementia. This was the biggest conference Alzheimer’s Australia has ever hosted, and the highest number of consumers ever to attend an ADI conference. The voice and attendance of family carers has been a strong one, especially as they started the Alzheimer’s Associations and organisations around the world, and so it is excellent to finally see people with dementia given the same opportunities, as three people with dementia were invited as keynote speakers, and another ten had abstracts accepted.

Executive Director of ADI, Mr Marc Wortmann spoke about their current strategic plans now and into the future. He reminded attendees that the current global cost of dementia is US $600 billion or 1% of global GDP and every four seconds a new case of dementia is diagnosed. So how do we reduce this number? Mr. Wortmann explained that ADI is advocating for all countries to set up national dementia plans and public health approaches to fighting dementia and welcomes the work of local Alzheimer’s advocacy to achieve this.

Mr Wortmann also said to keep an eye out for two reports being released later this year by ADI updating on the number of people living with dementia around the globe, as well as the global cost of dementia, and that there would be a special report released specifically focusing on women and dementia, very recently released here.

As co-chair of the CDRN and Chair of Alzheimer’s Australia’s Dementia Advisory Group (AADAC),
I was invited to speak about dementia friendly communities, and my work in developing and consulting on the dementia friendly community projects around Australia and globally. Dementia friendly means including us, and therefore “nothing about us should be without us”. It is less about being friendly, and more about full inclusion, respect, autonomy, equality, accessibility, and supporting our disabilities. It is also about the use of language that is respectful, empowering and enabling, and for organisations and communities to be dementia friendly, this is one of the first steps. It is important for everyone to embrace the Alzheimer’s Australia dementia language guidelines in your workplace and practice.

Finally, at the end of the conference, Mr. Glenn Rees AM, former CEO of Alzheimer’s Australia was welcomed as the incoming Chair of ADI; as consumers we expect, following his commitment to us in his CEO role here, that the global voice of all consumers will be strong.

Indigenous performers at ADI conference (image courtesy of Kate Swaffer)

CDPC Member Profile

Shannon McDermott

What is your role in the CDPC? I work with the CDPC Administration team and am responsible for developing, conducting, and overseeing the CDPC evaluation. I provide advice to CDPC Network members on doing program evaluation and am also responsible for communicating evaluation findings to the Network so we can improve how the CDPC is operating.

What did you do prior to joining the CDPC? I am passionate about doing social research that is both rigorous and applicable to the ‘real world’. Before joining the CDPC I was a Research Fellow at the Social Policy Research Centre at UNSW where I worked across numerous applied social research projects. I also worked as a Lecturer in Policy Studies where I trained students in the art of doing social research. Long ago, I worked as a social worker at Meals on Wheels in San Francisco.

What has surprised you most about working for the CDPC? I am continually impressed at the extraordinary amount of goodwill people have towards the CDPC. Working together in partnership can be very difficult but people within the CDPC remain extremely committed to making it work. I think this is because everyone shares a strong desire to improve the lives of people living with cognitive decline and their carers.

What do like to do when you are not at work? When I’m not at work, I spend a lot of time wrangling my two small children, visiting local parks, bushwalking, reading and catching up on my favourite TV shows (some good ones to check out if you haven’t already are Silicon Valley, Game of Thrones, Veep, and House of Cards).

Tell us one thing about yourself that we might not know My PhD examined the ethical dilemmas when people hoard or live in squalor and how professionals resolve these dilemmas. It is an area that still fascinates me to this day!

What is your best achievement? My most life changing achievement was when I won a competitive Rotary Ambassadorial Scholarship to study in Australia for a year. It brought me to Australia from San Francisco in 2003. After arriving I promptly fell in love with the country and am still here 12 years later, now married and with two young children!

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“Working towards a sustainable aged care workforce through interprofessional education” Karla Seaman, Jennifer Lawrence, Jane Harrup-Gregory, Rosemary Saunders, Helen Loffler

“Key worker roles for people with dementia: a systematic review” Dianne Goeman, Susan Koch, Emma Renehan

“It’s one place for people to actually be given a clue as to what they might need in the future” - Key Worker Models for People with Dementia and their Carers/ Family, Emma Renehan, Dianne Goeman, Susan Koch

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

Call for Abstracts:
2016 International Dementia Conference: Grand Designs. Sydney, Australia 16-17 June 2016