Welcome to the seventh edition of the CDPC News

Hi everyone,

Welcome to our first Newsletter for 2017. It has been a busy and productive start to the year and this newsletter highlights some of our achievements.

There were a number of posters presented at the recent Alzheimer’s Disease International Conference in Kyoto, Japan ranging from robots to support of staff in residential care, there were also oral presentations with Jane Thompson presenting our Consumer Companion Guide for the National Dementia Guidelines. It was a good opportunity for us to spread the word about our work beyond Australia.

We have also been involved in workshops locally with our sister Partnership Centre TAPPC, and in a University of Sydney interdisciplinary workshop on Reframing Dementia. Both are highlighted here.

Most of you will be hearing from our Evaluation Team in the next couple of months, as we pull together information on how the CDPC is meeting the objectives that we set for ourselves. It would be great if people could spend a bit of time on the survey as it provides us with useful information on how we are going and on how we can improve the way we work.

Sue
CDPC research highlighted at international forum

Alzheimer’s Disease International’s push for a Global Plan of Action on Dementia by the World Health Organisation will be realised with likely adoption later this month, attendees at the recent International Conference of ADI in Kyoto, Japan were told.

The plan will provide a worldwide framework for action, and targeted spending by governments and organisations improving the lives of people with dementia globally.

With a theme of “Togetheer towards a new era” the conference focused on the global community, as well as local communities, to work on a shared vision to achieve dementia-friendly communities, reduce stigma, appropriate language use and ensure all people have the opportunity to live well with dementia.

Within the diverse international audience Australian representatives highlighted the influence that our research is having on the global stage. In his keynote presentation Dr Faizal Ibrahim outlined the Dignity in Care Campaign and highlighted the importance of dignity for people with dementia through the Ten Principles of Care. It is these ten principles that also underpin the CDPC’s Clinical Practice Guidelines and Principles of Care for People with Dementia.

In her oral presentation Jane Thompson, a CDPC Consumer, discussed that while these guidelines were focused on health professionals they were also a vital resource for consumers. Jane described the importance of consumer involvement in the development of the guidelines and the subsequent Consumer Companion Guide. This Guide ensures that people with dementia and their carers and families have access to a relevant and easy summary of key recommendations in the Guidelines.

In another concurrent session, Jane also spoke of her own reasons for wanting to be involved in dementia research, the value of consumer involvement in research and the changing Australian landscape of support for consumers in research.

A poster presented by the CDPC Directorate also outlined consumer involvement in the CDPC from its initial stages to now having either someone with dementia or a care partner involved in every CDPC project.

Dementia Friendly Communities were a particular focus of this year’s conference with many international speakers from Japan, Canada, UK and Singapore outlining their strategies toward improving community care for people with dementia.

Culturally, the Japanese primary model of care resides in the community setting with many presentations examining how they can improve quality of life and reduce stigma for people with dementia in the community through education programs, videos and booklets.

In other oral presentations, Professor Kurrle spoke on the Northern Sydney Dementia Collaborative, a program to help a person with dementia navigate community services available to them, Kate Swaffer stressed the importance for human rights based approach for people living with dementia, and John Quinn and Glenys Petrie shared their experiences of living well with dementia.

With Japan’s expertise in technology it was exciting to meet “Pepper” a communications robot that learns, has emotions and feelings. It was no surprise that the poster from CDPC Project being undertaken at Brightwater Care Group “Understanding the impact of Socialisation Robots on the Social Engagement of Older Adults with Cognitive Decline,” was of great interest.

Other posters presented at ADI from CDPC funded projects included a collaborative project between Helping Hand Aged Care and Brightwater Care Group “Interprofessional Education in Aged care-IPEAC Toolkit” and the project led by Katrina Anderson, “Improving residential dementia care through staff: a systematic review of the evidence.”
Launch of new resources to help people plan ahead

Accessible and user friendly resources have been developed by our Advance Care Planning (ACP) project team to assist community, aged and health care staff highlight the importance of planning ahead for people in their care, particularly those in the early stages of dementia.

Launched by palliative care physician and project lead Professor Meera Agar at The Bob Hawke Prime Ministerial Centre in Adelaide on April 6 2017, the resources help health and aged care professionals engage with people who have dementia about the issue of planning ahead and also how to implement ACP across their organisation.

"Our research included interviews with over 80 people with experience in advance care planning in a variety of community, aged and health care settings from across Australia. The resources have also been developed and trialled with a number of organisations", Prof. Agar explained.

The resources include short videos discussing experiences of planning ahead and why it is important. There are also brochures, which can be used with the person living with dementia, and their carer partner, who may be called on to make decisions when someone can’t do this themselves.

"It is important to have a professional health and aged care workforce who are knowledgeable and skilled in helping older people plan ahead. The community sector, in particular, has an important role to play in raising awareness and encouraging conversations about what matters most in the years ahead," Prof. Agar said.

Kathy Williams, a CDPC consumer representative from Alzheimer’s Australia, involved in the research and development of resources described the importance of planning ahead for those with dementia and the need to focus on how the person wants to live the rest of their life, rather than just a narrow focus on end-of-life issues.

“I know that for my mum staying in control was really important and early planning helped with this," Ms Williams said.

A/Prof Josephine Clayton, a palliative care physician at HammondCare and member of the study stakeholder advisory committee, welcomed the resources and the focus on assisting those who have to make decisions for others.

“Making decisions for others can be very stressful. The resources include a pamphlet which can be given to people so they better understand their role. There is also information on how to support a person to make their own decisions as far as possible," A/Prof Clayton said.

The resources are available from http://sydney.edu.au/medicine/cdpc/resources/advance-planning.php and at www.start2talk.org.au

A podcast of the launch is also available at http://www.unisa.edu.au/Business-community/Hawke-Centre/Events-calendar/Advance-Care-Planning-for-People-with-Dementia/

Sally Grosvenor, CDPC Communications Officer
How to better care for residents and engage staff members

The first comprehensive guide for implementing an interprofessional education (IPE) program for students and staff in aged care organisations has been developed by CDPC funding partners Brightwater Care Group and Helping Hand Aged Care.

The free online Interprofessional Education in Aged Care Toolkit (IPEAC), funded through the CDPC, provides aged care managers and administrators accessible resources to facilitate interprofessional student placements and support IPE programs within their organisation.

Interprofessional education is a site based program where aged care professionals learn from and about each other in order to improve collaboration and quality of resident care.

IPE has been shown to provide numerous benefits in these settings, including:

- Increased support and social contact for residents through increased one-on-one and group activities and therapy
- Increased knowledge and capacity of facility staff through additional training opportunities and knowledge sharing by students of recent professional developments
- Increased positive perceptions of working in aged care from students, with students reporting they were more likely to consider a career in aged care following an IPE placement

The IPEAC Toolkit (‘Interprofessional Education in Aged Care Toolkit’) was developed following a CDPC project evaluating the benefits of IPE programs run within Brightwater Care Group and Helping Hand Aged Care over several years. Results from the evaluation can be found in the IPE Evaluation Report.

The implementation and dissemination phase of the project is now underway with the toolkit at five aged care organisations across Australia. Initial results from the project were recently presented at the Alzheimer’s Disease International Conference in Kyoto.

The toolkit consists of four modules and can be used in parts or as a whole.

1. IPE in aged care
2. Getting Started
3. Running an IPE student placement
4. Moving forward with IPE

Free training is also available Australia-wide to support facilities in implementing an IPE program.

The IPEAC Toolkit is available now at www.brightwatergroup.com/IPEAC-Toolkit. For more information contact IPEAC Project Coordinator Jane Harrup-Gregory on (08) 9202 2800 or jane.harrup@brightwatergroup.com.

A copy of the poster “Interprofessional Education in Aged Care - IPEAC Toolkit” can be found here. Or on our news and events webpage.

Jane Harrup-Gregory, IPE Project Coordinator

IPEAC Toolkit homepage

Snapshot of the poster presented at the Alzheimer’s Disease International conference in Kyoto
Innovative technologies helping people with dementia

A CDPC funded project being carried out at Brightwater Care Group and supported by University of Western Australia is examining the use of a socialisation robot to enhance the wellbeing of people living with dementia.

Results recently represented at Alzheimer's Disease International Conference in Kyoto are encouraging showing that both residents and staff appear to be more engaged when Alice is incorporated into group activities.

The Zorabot, named Alice, has been part of the Brightwater community for over 12 months. Alice is an interactive, humanoid, socialisation robot, and is controlled by staff members.

Jennifer Lawrence, CEO of Brightwater, said that from the time Alice first came to life at Brightwater Madeley residents have been captivated by her engaging and charismatic personality and the range of interactive activities Alice supports.

Alice co-facilitates a number of activities, including Bingo, Song and Dance, Reminiscence, Poetry and Exercise groups.

“From day one residents have loved engaging with Alice so this research is an important next step in understanding what impact she is having on older adults with cognitive and/or functional decline and how we can make the most of the opportunities she presents,” said Ms Lawrence.

The research specifically investigates the impact incorporating Alice into activities has on older adults with cognitive decline and will also explore staff attitudes to the use of Alice within a residential aged care setting.

“Alice presents some fantastic opportunities to try new activities with residents but is only as good as the therapy team trained to use her, so it is important that we understand how staff feel about adding Alice to their therapy toolkit,” said Ms Lawrence.
Partnership Centres explore ways to improve the use of evidence in policy and practice

The NHMRC’s three Partnership Centres, the Cognitive Decline Partnership Centre, the Australian Prevention Partnership Centre, and the new Partnership Centre for Health System Sustainability have a unique opportunity to contribute to the science behind increasing the uptake of evidence in policy and practice, attendees at a March 2017 workshop were told.

The workshop brought together representatives from the three Partnership Centres along with international experts to discuss practical ways to encourage the use of evidence in policy. Dr Bev Holmes, Acting President and CEO of the Michael Smith Foundation for Health Research in Canada, told the workshop that while there was a body of scientific literature around ‘knowledge mobilisation’, few organisations could draw on their practical experiences in the same way as Partnership Centres.

“You are doing the work and contributing to the science of knowledge mobilisation,” she said. “It is time to think of the larger picture, to talk to the community about what we can do better.”

Only eight to 15 per cent of research is ever used in policy and practice, and it currently takes an average 17 years between the development of research and its use.

“In many cases we have the evidence, we know what we should be doing, but we are not doing it,” said Prevention Centre Director, Professor Andrew Wilson.

The CDPC is building communication and knowledge translation strategies into the design of each of its research activities, Director Professor Susan Kurrle said. A key aspect of this is involving consumers at every step of the research process, from development to implementation and dissemination.

Workshop participants applied their strategies to a knowledge mobilisation framework developed by experts Dr Holmes and Professor Diane Finegood, a systems science expert from Simon Fraser University.

“There is a dearth of work being done that shows solutions to complex problems with empirical evidence. Your contribution to the science of complexity is very important,” Professor Finegood said.

Other key strategies suggested in the workshop included:

• Recognise that knowledge encompasses both research and practice
• Set shared goals, vision and values
• Build trust and respect among stakeholders through fostering relationships
• Consider incentives and inhibitors that inspire collaboration and manage dissent
• Provide adequate resources (funding and time) to support leadership and strategic communications
• Embrace failure: aim for continuous improvement.

Knowledge Mobilisation Workshop - Consumer Perspective

The overall context of the Workshop was based on the ‘Key Messages’ that Knowledge Mobilisation (KM) is an established field with an evidence base about what works in some contexts. However, the complexity of health systems make it difficult to know which set of KM strategies will have sufficient impact. ‘Systems thinking’ can provide a framework for selecting a set of complementary strategies.

Presentations by the two Partnership Centres highlighted the progress of each and dissemination strategies undertaken to date.

The Australian Prevention Partnership Centre targets its work specifically at policy and decision makers, with relevant advocacy organisations representing the consumers. The CDPC represented its integration and involvement of consumers in all aspects of CDPC work, with this seen as a unique feature and strength of the CDPC.

Of particular interest were Mike Kelly’s comments about the importance of ‘co-production’ in research, indicating that ‘ordinary people’ are knowledgeable about the worlds in which they live, recommending that researchers need to ‘start with people on the ground’ and not to underestimate the power of ordinary people.

For a copy of the presentations contact sms.cdpc@sydney.edu.au
The Social Reframing of Dementia: A Timely Conversation

An interdisciplinary workshop held in March 2017, *Reframing Dementia as Social and Cultural Experience*, looked at reframing the negativities surrounding the ‘dementia habitus’ and bring to it value, life, laughter and relationship.

Organised by Dr Gaynor Macdonald, Department of Anthropology, in collaboration with Associate Professor Jane Mears, Social Policy, Western Sydney University, and the CDPC, the workshop brought together academics across different disciplines, representatives from leading aged care organisations, experienced nurses, as well as people living with dementia and their carers.

This diversity made for rich discussion around an experience that is overwhelmingly framed in biomedical terms, often leaving the complex social and relational challenges of dementia unaddressed.

*The workshop was an eye-opener for me. Both my parents, and parents of several friends have died with dementia, so I have always known finding a cure is important. But after the workshop, I can see how important improving quality of life is.*

The vision of the workshop was to challenge the dominance of bio-medical approaches to dementia. Participants examined stigmas and stereotyping in the wider society that make life hard for those living with dementia, including family.

*Just how diverse the approaches to this reframing were evidenced from a number of papers presented. Presentations looked at better support for those directly involved; more effective communication with people with dementia; reconceptualising ‘care’ as a total social responsibility; and exploring ways to create a more caring society.*

*This workshop reinforced that many of the difficulties that come with a diagnosis of dementia are not medical or cognitive issues, they are social. Ignorance and stigma are issues that need more thought, and as we design interventions to address attitudes and behaviours we need to understand how they come to be formed and reinforced, and ways to create change.*

Reframing involves understanding the reasons for the negativity and fear surrounding dementia, and finding innovative ways to disrupt and move beyond these. It involves interrogating assumptions attached to dominant models of care. The search for a cure and improving quality of life need to be better balanced within the research, budgetary and policy space.

*So many talks presented a different view from what I am used to, [where] dementia issues centre around behavioural challenges and ensuring the family have an ACP in place. Patient-centred care sounds great but task orientation persists.*

The value of the social sciences in providing new and critical perspectives on social attitudes to dementia, and to dementia care, was seen by participants as an integral contribution of the workshop.

*It was refreshing to reflect on what reframing dementia can mean from the perspective of a person living with cognitive decline, their families, service managers, and researchers. It affirmed that reframing dementia means rethinking our silo-approach to research and ensuring that a whole range of voices are listened to.*

The imperative to listen to the experiences and insights of those directly impacted, including carers, was a recurring theme. Participants discussed assisting people to deal with complex relationship issues in ways that make sense to them, including raising awareness and understanding of the real impact of dementia across the whole family.

The Reframing Dementia project aims to initiate a communication network, inviting opportunities for collaboration and sharing of cross-disciplinary projects. This includes the publication of papers emanating from the workshop. Changing the negative dementia narrative is an ambitious goal but it is an urgent one which ultimately involves all of us.

*For more information on the workshop, presenters and paper abstracts, see: http://sydney.edu.au/arts/research/reframing-dementia/*

Dr Gaynor MacDonald, University of Sydney.

Presentations are available to CDPC members via the CDPC SharePoint site.
The importance of Occupational Therapists and persons with dementia

As a single male person diagnosed with dementia about ten years ago I was quite unaware of the importance of Occupational Therapists (OT) and their input in making life easier and safer for persons with dementia.

After diagnosis I carried on as usual without their assistance thinking I was ten foot tall and bullet proof. In a short time I moved into new accommodations and it was then that I was sent an OT to assess my living situation.

I must say, some years prior to this occurring I had worked in senior management in a company providing rehabilitation equipment to many individuals and facilities in Victoria and NSW. It was during this time that I had much contact with OTs, but very little association with persons with dementia.

It was then, when I had my assessment at my new dwelling that I realised the role of the OT was such a vital person for a person like me, as a single male living alone with Younger Onset Dementia.

That day of the assessment changed my life in many ways but most importantly it made me understand the need for me to be aware of my surroundings and what needed to be corrected so I was safe. I removed mats I could trip or slip on, placed on slate floors.

I had a few episodes of stove top near disasters and ovens left on plus near catastrophies with the grillers cooking, whilst I wandered off to do other chores. From that time onwards I now use an electric wok. I have a service providing wet area floor cleaning and gardening. I have removed cluttering to allow me to avoid tripping on poorly placed furniture and much more.

Without the intervention of an OT I probably would not be living well with dementia today and I always praise the invaluable service they provide for PWD, each and every time I speak and advocate for persons with Younger Onset Dementia.

Ian spoke on this subject at the Occupational Therapy Association of Australia forum in October 2016.

Ian Gladstone Chair of Alzheimers Australia Dementia Advisory Committee

A CDPC project currently in progress is examining the barriers and facilitators to the implementation of an Occupational Therapy based program called the ‘Care of People with dementia in their Environments’ (COPE) program into the Australian health system context.

The program, developed by Professor Laura Gitlin at Johns Hopkins University in the US, aims to support and empower people with dementia and their carers by working with occupational therapists and nurses to help identify challenges and implement strategies to manage everyday difficulties.

Read the latest COPE Newsletter Here

For more information on our COPE project visit our COPE page (http://sydney.edu.au/medicine/cdpc/resources/cope.php)
The CDPC Evaluation team is looking forward to the next round of data collection, which will begin in May 2017. Here is a snapshot of what it will mean for you, as a CDPC network member.

Why are we doing this?

The CDPC internal Evaluation is an important component of the overall CDPC structure. The purpose of the Evaluation is to determine the extent to which the CDPC is meeting its objectives and achieving its stated goals. The data collected for the Evaluation provides valuable information and an opportunity for ongoing improvement of the CDPC.

What does it mean for you?

Data is being collected in three different streams – through a network survey, qualitative interviews, and existing CDPC quarterly monitoring data. All active CDPC members (who joined prior to 2017) will be invited to participate in the Network Survey. We will also be conducting qualitative interviews with key CDPC stakeholders including lead investigators, Enabling Subunits (including consumers), Governance Authority, Executive Committee, as well as some external service providers. Additionally, it is important to note that being in this study is completely voluntary and network members do not have to take part if they do not wish to do so.

Time Commitment

The Network Survey will take approximately 30 minutes to complete and will be sent out by email in May 2017. The qualitative interviews will be conducted either face-to-face or by teleconference. These interviews will run for no more than an hour and will be scheduled at a time that is convenient to you.

Further details

Data collection also occurred in 2015 (as some CDPC members may remember). For those of you who are new to the network and are interested in reading more about the findings in the Baseline Evaluation Report, you can click here.

Look for an email in the next few weeks with further details from the Evaluation team about the next steps. This email will include a Participant Information Sheet with more details regarding the research study and what to expect. In the meantime, if you have any questions, please contact either Alexandra Kitching (alexandra.kitching@sydney.edu.au) or Dr Shannon McDermott (shannon.mcdermott@sydney.edu.au)

We look forward to hearing from you over the coming months!

Shannon McDermott, CDPC Research Fellow, and Alexandra Kitching, CDPC Project Administrator
CDPC Directorate/Operations Update

The CDPC Directorate team have been very busy in the first few months of 2017. One of our priorities at this time each year is pulling together the data required for completion of our Annual Report to the NHMRC. For this report we have to provide specific data to show that we are meeting our expected NHRMC objectives in facilitating Implementation of Research-Informed Change, Synthesis and Dissemination of Existing Research, Collaborative New Research, and Capacity Building.

I am pleased to advise that for the 2016 year we have been able to inform the NHMRC that we have performed well against our objectives and I provide some of that data here for your information.

Research-Informed Change: Since the first year of research specific activity at the CDPC (2014) the number of organisations implementing research-informed change has risen from 12 to 307 by 31 December 2016.

Synthesis and Dissemination: The CDPC’s first outputs (outcomes, reports, presentations and other forms of dissemination) were recorded right back in 2012 and from 2012, when there were 3 outputs, there has been regular growth in number of outputs recorded and you can see from the Figure provided here there were 320 outputs recorded in the 2016 year.

Collaborative New Research: The CDPC has a number of Activities that are categorised as Collaborative New Research. In 2016 there were 17 Activities falling into this category and within those there were a total of 91 investigators/researchers working. Of those researchers 41 were academic researchers; 30 were researchers based in residential aged care, community, acute, or primary care; and 20 were consumers involved in CDPC research.

Capacity Building: In 2016 there were 86 CDPC training presentations facilitated by CDPC researchers and the Directorate team and it is estimated that 11,450 people were exposed to information on the CDPC. Of those, the majority were given to an audience outside of academia which gives evidence that CDPC research has a broad reach into health systems, the community, and academia in Australia and internationally.

Jennifer Thompson, Operations Manager
(sms.cdpc@sydney.edu.au)
Jane Thompson

What is your role in the CDPC?
I have a voluntary role as a consumer. I have been involved since the CDPC’s inception as a member of the subgroup of consumers supporting Joan Jackman in her role. I have been involved in Activities 3, 13 and 21 and 27.

What did you do prior to joining the CDPC?
I was a member of Alzheimer’s Australia’s former Consumer Dementia Research Network which I joined when it was established in 2010. My husband was diagnosed with Alzheimer’s disease in early 2004 and he died in late 2007. During those years I was his primary carer and tried to keep up part-time work in women’s health research.

What has surprised you most about working for the CDPC?
The extent to which I have felt able, as a consumer, to influence the content and direction of the CDPC’s activities.

What do you like to do when you are not at work?
I am retired from the paid workforce now and I so have plenty of time to enjoy playing golf, swimming year round in my local pool, walking holidays and meeting my walking group on Saturday mornings to walk around Lake Burley Griffin (and chat over coffee and cake on the deck of the National Library of Australia afterwards).

Tell us one thing about yourself that we might not know?
I have a PhD in Zoology (thesis topic: Embryo-maternal relationships in a viviparous lizard)

Describe yourself in three words:
Calm, persistent, resilient.

What is the best advice you were ever given?
When my husband was diagnosed with Alzheimer’s Disease one of my friends advised me : “Access as much help and support as you possibly can, you are going to need it!”. How true she was.

What is your best achievement?
Without a doubt, giving birth to and raising my three beautiful sons. They have now grown into fine caring men and two of them wonderful fathers. I take some credit for that!
Upcoming Events

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

7th International Carers Conference (Adelaide 4 -6 October)

17th Alzheimer’s Australia Biennial Dementia Conference (Melbourne 17-20 October)

CDPC Annual Meeting 2017 (Melbourne 17 October 2017)

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