

April 2015

# Dementia roundtable

## 27 March 2015

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## INTRODUCTION

Knowledge Translation (KT) has emerged as a major focus of activity in recent years, as powerfully borne out by the establishment of the NHMRC Research Translation Faculty and the appointment of Professor John McCallum as the Head of the Research Translation Group. The emphasis now being placed on KT is occurring during a period of increasing need for services for people with dementia and at a time when there is no unifying strategy for the development or delivery of these services.

### THE DEMENTIA TRAINING STUDY CENTRES (DTSCS)

There are five Dementia Training Study Centres across Australia (New South Wales/Australian Capital Territory, Queensland, South Australia & Northern Territory, Victoria & Tasmania and Western Australia). The Centres work as a national organisation with each centre having its own specialities. The strategic plan which guides their activities begins with the following description of who they are:

*The Dementia Training Study Centres work closely with tertiary education institutions, health and related service providers, and individual health professionals to upskill the current and future dementia care workforce. This is achieved through the transfer of contemporary knowledge about dementia into practical, effective approaches to helping people living with dementia and their families.*

Each DTSC has a set of National Priority Areas. One priority area for the NSW/ACT DTSC is Knowledge Translation. While the DTSCs are not research organisations, the contracts with the Department of Social Services (DSS) defining the deliverables for each DTSC also stipulate that KT research is an exception to this rule and the DTSCs are mandated to undertake KT research.

### THE DTSC AND DCRC PARTNERSHIP IN KNOWLEDGE TRANSLATION

The discussions that have taken place within the DTSCs have resulted in the tentative conclusion that knowledge translation, in one form or another, is the common goal of all services directed at helping people live with dementia. The DTSCs are not alone in their commitment to KT. The Dementia Collaborative Research Centres (DCRCs), established at the same time as the DTSCs, have a core mandate for *Translating Dementia Research into Practice*.

The DTSC Directors therefore resolved to foster a discussion on the possibility that a shared understanding of knowledge translation in dementia care could inform the

development, articulation and delivery of services to people with dementia. A preliminary meeting between the DTSC and DCRC Directors took place on January 16 2015 to test the acceptability of this proposal, resulting in an agreement to work together on it.

### ROUNDTABLE: 27 MARCH 2015

A roundtable discussion was initiated on 27 March 2015 as the first action to be taken as a result of this partnership. The participant list was not intended to be exhaustive in its representation but included people from the DTSCs, DCRCs, DBMAS, NHMRC, the Cognitive Decline Partnership Centre, large aged care providers, health care agencies, government, peak bodies, and researchers who have contributed to large scale KT projects (see Appendix 1 for a list of the roundtable participants).

The purpose of the meeting was, broadly, to agree on ways to improve knowledge translation in dementia care and to agree on next steps to progress the issue. More specifically, the meeting considered:

1. What do we mean by KT in dementia care?
2. How is KT practised in our organisations?
3. How can a shared understanding of the KT process improve dementia care?
4. How can we promote a shared KT strategy across organisations and stakeholders?

Professor John McCallum, Director of NHMRC Dementia Research, put these questions into context by presenting an overview of the current and prospective funding of dementia research in Australia, illustrating the commitment to significantly improving the impact of research on practice.

### THIS REPORT

This report on the roundtable has been prepared by Greg Masters of Nexus, who facilitated the meeting. The report does not purport to be a comprehensive account of the discussion; rather it aims to capture the major themes emerging as a basis for future action. The report is structured as follows:

- **section 1** considers some conceptual issues about KT in dementia care
- **section 2** discusses how to promote a shared KT strategy across organisations and stakeholders
- **section 3** sets out some proposed next steps.

## 1. KT IN DEMENTIA CARE

The Director of the NSW/ACT DTSC, Professor Richard Fleming, acknowledged the work of Professor Brian Draper and Professor Kaaren Anstey in laying a firm foundation for the discussion of Knowledge Translation in the field of dementia care and went on to present a four step model of knowledge translation developed by Pathman et al<sup>1</sup> for consideration at the roundtable:



The following table summarises the goals and activities for each of the four steps.

STEP	GOALS	ACTIVITIES
<b>AWARENESS</b>	<ul style="list-style-type: none"> <li>• Be aware of relevant evidence</li> <li>• 'knowing what you don't know'</li> </ul>	<ul style="list-style-type: none"> <li>• Education (knowledge transfer)</li> <li>• Information updates</li> <li>• Continuing professional education</li> </ul>
<b>AGREEMENT</b>	<ul style="list-style-type: none"> <li>• Be persuaded evidence is relevant</li> <li>• Agree that evidence can be translated into (local) practice or policy</li> </ul>	<ul style="list-style-type: none"> <li>• Tailored/local; e.g. inservice</li> <li>• Advocacy</li> <li>• Whole of organisation targets, e.g. change readiness</li> </ul>
<b>ADOPTION</b>	<ul style="list-style-type: none"> <li>• Implement evidence-informed change</li> <li>• Implement/begin policy review</li> </ul>	<ul style="list-style-type: none"> <li>• Implementation research</li> <li>• Change management</li> <li>• Policy development</li> </ul>
<b>ADHERENCE</b>	<ul style="list-style-type: none"> <li>• Sustain a change</li> <li>• Policy and legislation implementation</li> </ul>	<ul style="list-style-type: none"> <li>• Impact measurement</li> <li>• Train the trainer</li> <li>• Continuous Quality Improvement</li> </ul>

There was general support for the model and an agreement that most organisational effort in dementia research and care was concentrated at the awareness end of the spectrum. Moreover, it was acknowledged that mere awareness of the evidence base is insufficient to effect and sustain change and that moving to the adoption and adherence end of the spectrum requires systematic change management strategies.

While there was general support for it as a good starting point for developing a KT framework in Australia, the roundtable also raised some issues with the Pathman

<sup>1</sup> Pathman, D. E., T. R. Konrad, et al. (1996). "The awareness-to-adherence model of the steps to clinical guideline compliance. The case of pediatric vaccine recommendations." *Medical Care* 34(9): 873-889

model. Firstly, there was a concern that the model implies that evidence is something that simply 'feeds into' a system when in fact dementia care involves complex human and organisational elements. That is, the model was seen as too linear and did not take sufficient account of the evidence accumulated by the learned experience of providing care and implementing practice change.

Secondly, it was suggested that the model could be improved by adding a fifth 'A' for Assessment to recognise the need for evaluating the impact of the changes in practice and feeding the results back to the researchers and change agents.

Other issues raised in the discussion of KT in dementia care included:

- the patchiness of the evidence base in relation to dementia care
- the need for KT to apply across all steps of the continuum; that is, in relation to achieving agreement, adoption and adherence
- the need for a common, readily understandable definition of KT.

## 2. PROMOTING KNOWLEDGE TRANSLATION

The roundtable considered how to promote a shared KT strategy across organisations. There was general agreement that this required a systematic change management approach, with resourcing and leadership. Some key themes emerged concerning the need for:

- a clear vision
- consumer, family and carer engagement
- clear communication of the evidence
- involving the full breath of dementia care services
- leadership and culture change
- partnerships and leveraging.

Firstly, there was agreement on the need for **a clear vision**, not only about knowledge translation but, more importantly, about dementia care itself and, in particular, what constitutes good dementia care. This vision includes agreed metrics for assessing progress that incorporate measures of quality of life and client satisfaction.

Secondly, **consumers, families and carers** need to be actively engaged in setting this vision, in contributing to the evidence base, in advocating for good dementia care and in the governance of services and other organisations. The possible use of new technologies for consumer ratings of services (cf Trip Advisor) was seen as a possible development in this regard.

Thirdly, there was seen to be a need to synthesise and better **communicate the research evidence** by filtering it and translating it into information that is user-friendly and understandable to consumers and services alike. In this context, a distinction was drawn between true KT on the one hand, which is about effecting change, versus communication to build a research profile (e.g. through the use of social media), on the other hand. Models of 'good practice' or exemplars were suggested as ways of communicating the evidence and promoting high quality dementia care. The need to draw on international evidence and knowledge translation in other sectors was also advocated.

Fourthly, the roundtable stressed the importance of considering the full **breath of dementia care services**, not just the residential care component.

Fifthly, progressing from awareness to agreement, adoption and adherence requires **leadership and culture change** at multiple levels. There was seen to be a need for an agency to provide leadership at the national or system level and for individual organisations boards (including consumer representatives) were seen as pivotal in driving the culture and practice change.

Finally, the culture change could be facilitated by establishing **partnerships** between organisations (e.g. research and care providers) and by **leveraging** off other quality improvement initiatives (e.g. by aligning with quality management, accreditation and regulatory systems). Similarly, the KT agenda can be promoted by linking the adoption of evidence-based care to providers' commercial imperatives to be attractive to clients and to attract and retain staff in order to be successful in an increasingly competitive environment.

### 3. NEXT STEPS

The roundtable was not the appropriate vehicle for laying out a detailed plan for implementing a knowledge translation reform agenda. Nevertheless, the meeting did set out some key principles to inform the next steps:

- assigning a group or entity with the carriage of the KT agenda
- generating and articulating a vision via a highly participatory process involving the larger community, consumers, families and carers that aims to present a personal face to the disease
- articulating a clear KT strategy that flows from this vision and draws on the international experience, particularly the Canadian experience
- establishing a structure for filtering the evidence and establishing broad research priorities, including research into implementation and effective change management strategies
- establishing an accepted measurement framework to monitor progress.

Critically, the group saw a need for the momentum gained from the roundtable to be maintained and the DCRC/DTSC Dementia Forum taking place in September 2015 was identified as an opportunity to continue the conversation.

## APPENDIX 1: ROUNDTABLE PARTICIPANTS

- Ms Marie Alford  
Hammond / DementiaCare
- Ms Hannah Baral  
Dementia Training Study Centres (DTSC-National)
- Prof Elizabeth Beattie  
Dementia Training Study Centres (DTSC-Qld) – Director  
Dementia Collaborative Research Centres (DCRC - Carers and Consumers, QuT)  
- Director
- Prof Henry Brodaty  
Dementia Collaborative Research Centres (DCRC - Assessment and Better Care, UNSW) – Director  
Centre for Healthy Brain Ageing (CHeBA, UNSW) - Co-Director
- Prof Lynn Chenoweth  
Faculty of Nursing, Midwifery and Health, University of Technology  
Dementia Collaborative Research Centres (DCRC - Assessment and Better Care, UNSW) – Nursing Node Leader
- Dr Sam Davis  
Head of Discipline (Applied Gerontology) – Flinders University, SA
- Mr Jason de Bakker  
Alzheimers Australia Qld - Corporate Services Manager
- Dr Maree Farrow  
Alzheimer's Australia Vic – Research Fellow  
Dementia Collaborative Research Centres (DCRC - Early Diagnosis and Prevention, ANU) - KT Fellow
- Dr Deirdre Fetherstonhaugh  
Australian Centre for Evidence Based Aged Care (ACEBAC), La Trobe - Director
- Prof Richard Fleming  
Dementia Training Study Centres (DTSC-NSW/ACT) - Director
- A/Prof Belinda Goodenough  
Dementia Training Study Centres (DTSC-NSW/ACT) - Manager, KT Program  
Dementia Collaborative Research Centres (DCRC) – KT Fellow

- Dr Sue Hunt  
Department of Social Services (DSS) - Senior Nurse Advisor, Dementia Policy Section, Ageing and Sector Support Branch
- Ms Linda Justin  
Uniting Care Ageing NSW.ACT - Director, Continuous Service Improvement
- Prof Sue Kurrle  
NHMRC Cognitive Decline Partnership Centre (CDPC) - Director
- Ms Karen Martin  
Aged Care Channel - Strategic Development and Partnerships Manager
- Prof John McCallum  
NHMRC Dementia Research - Director | National Institute for Dementia Research (NNIDR)
- Mr Collin McDonnell  
Uniting Care Ageing - Care Manager (NSW – Starrett Lodge)
- Ms Anne Moehead  
NSW Health Dementia Care and Competency Training Network - Leader (Directorate)
- Ms Susie Pairman  
DBMAS-NSW / Hammondcare - Manager
- Dr Lyn Phillipson  
Centre for Health Initiatives, University of Wollongong - Lecturer
- Ms Kristene Rice  
Anglican Retirement Villages - General Manager Care Services
- Prof Andrew Robinson  
Wicking Dementia Research and Education Centre, Hobart - Co-Director
- Dr Andrew Stafford  
Dementia Training Study Centres (DTSC-WA) - Director
- Dr Margaret Winbolt  
Dementia Training Study Centres (DTSC-Vic/Tas) – Director

## APOLOGIES:

- Prof Kaaren Anstey  
Dementia Collaborative Research Centre (DCRC-EDP) – Director
- Ms Carol Bennett  
Alzheimer's Australia – CEO
- Ms Kathryn Cunningham  
Dementia Training Study Centres (DTSC-SA/NT)
- Prof Brian Draper  
Prince of Wales Hospital, Aged Care Psychiatry
- Prof Alison Hutchinson  
Deakin University
- A/Prof Lee-Fay Low  
University of Sydney
- Dr Ellen Skladzien  
Alzheimer's Australia, Consumer Dementia Research Network - Manager
- Dr Glenys Webby  
Blue Care (Qld)