Putting the needs of the person with dementia, and their carers, first: Research Driving Change

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The Australian Government’s National Health and Medical Research Council (NHMRC) Partnership Centres for Better Health initiative has brought together clinicians, consumers, researchers, aged-care providers and decision-makers to better implement research outcomes into health and health system improvement in Australia.

The Partnership Centre on Dealing with Cognitive and Related Functional Decline in Older People (Cognitive Decline Partnership Centre or CDPC) is a working example of a co-creation model in practice. Co-funded through government and industry, the CDPC has supported 32 research activities and a number of workshops to bridge a knowledge gap between evidence and practice, and to create implementable research outcomes. Putting the person with dementia, and their carers first, has meant involving them from the beginning: giving them the power to decide what research questions needed answering, and what evidence-based resources needed development. This focus is driving change through successful creation of resources, and implementation of evidence-based research outcomes into policy and practice, to improve the quality of life, care, and wellbeing of people living with dementia.

**NEED: MEANINGFUL GUIDELINES FOR CLINICIANS, AND USER-FRIENDLY VERSIONS FOR PEOPLE WITH DEMENTIA AND THEIR CARERS**

The CDPC funded the development of the Clinical Practice Guidelines and Principles of Care for People with Dementia in Australia and the Consumer Companion Guide, both of which involved consumers in the development process. And, consumers were included as authors on the academic publication. These Guidelines are influencing clinical practice, have directed government funding initiatives, and are informing health and aged-care services.

Due to the input of consumers, the Companion Guide provides a clear language version of the Guidelines for people with dementia and their carers, about the level of clinical care they expect in Australia.

**NEED: MEASURES OF COST AND WAYS TO IDENTIFY APPROPRIATE CARE OPTIONS AND PATHWAYS**

The CDPC has a number of projects aimed at improving care within services, providing details information in the areas of cost of care delivery for the person with dementia, and improved and new models of care.

**NEED: UNIFORM POLICIES AND PRACTICES ENABLING THE UPHOLDING OF THE WISHES OF OLDER PEOPLE WITH COGNITIVE DECLINE**

CDPC funded researchers have provided evidence-based information to aged-care providers, policy-makers, and the community on the role of regulation in the aged care system.


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http://sydney.edu.au/medicine/cdpc/resources/supported-decision-making.php


The Centre has informed older Australians about the importance of Powers of Attorney through a series of community seminars across the state of New South Wales in 2017 and 2018.

CDPC research is influencing policy at a state- and national-level, through collaborative submissions to Law Reform Commission Inquiries into Elder Abuse and Guardianship legislation, and through the 2018 release of an evidence-based Policy Development Guideline for Aged Care Providers in Australia.


The views of carers, users, who included people living with dementia in the community, as well as their carers or advocates, highlighted specific dimensions of the relationship between regulation and provision.


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The Organisation of Risk: How do dementia care providers collect, analyse and use data? 3rd year research project detailing the effects of regulation on residential care for people with dementia


The authors gratefully acknowledge funding and support provided by the NHMRC, Brightwater Care Group, Dementia Australia, Hammondcare, and Helping Hand Aged Care through the NHMRC Partnership Centre: Dealing with Cognitive and Related Functional Decline in Older People. The contents of the published materials are solely the responsibility of the individual authors identified, and do not reflect the views of the NHMRC and any other Funding Bodies or the Funding Partners.