

Research translation: engage decision-makers at the beginning, middle, or end?

Jennifer Thompson,
NHMRC Partnership Centre Dealing with Cognitive and Related Functional Decline in Older People (CDPC)
University of Sydney (@Jenntrix)

co-authors:
Professor Susan Kurrle, CDPC, University of Sydney
Sally Grosvenor, CDPC, University of Sydney

ENGAGEMENT

The interaction between researchers and research end-users outside of academia for the mutually beneficial transfer of knowledge, technologies, methods, or resources.

(Australian Research Council (ARC), 2017)

IMPACT

The demonstrable contribution that research makes to the economy, society, environment and culture beyond the contribution to academic research.

(Australian Research Council (ARC), 2017)



CDPC staff and partners in research at the 2017 Dementia Australia Conference. Photo Credit: Cognitive Decline Partnership Centre

COGNITIVE DECLINE PARTNERSHIP CENTRE (CDPC)

(NHMRC Partnership Centre Dealing with Cognitive and Related Functional Decline in Older People)



<http://sydney.edu.au/medicine/cdpc/>

	Collaborative New Research
	Synthesis and Dissemination
	Capacity Building
	Implementation of Research Informed Change

Service Model Options		
CDPC 1301	Long Term Care Configurations	In Conduct
CDPC 1302	Confused Hospitalised Older Persons Study (CHOPS)	Completed
CDPC 1315	Modelling for Estimation of Cost Effectiveness of Aged Care	Completed
CDPC 1326	Dementia Delirium Care with Volunteers	Completed
CDPC 1333	Validating and evaluating a quality of life instrument for people with dementia.	In Conduct
CDPC 1337	Development of Dementia Reablement Guidelines and Programs	In Conduct

Attitude and Culture		
CDPC 1307	Regulation of Aged Care Services - Effects	Completed
CDPC 1308	Living with Dementia in the Community	Completed
CDPC 1318	Dementia in the Public Domain	In Conduct

Planning for Later Life		
CDPC 1305	National Advance Care Planning	Completed
CDPC 1306	Financial Institution Policies / Practices	Completed
CDPC 1324	Supported Decision Making in Dementia Care	In Conduct

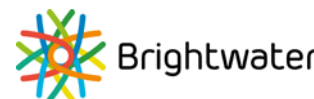
Medication Management		
CDPC 1311	Quality Use of Medicines	In Conduct
CDPC 1312	Implementation of Vit-D Supplements in Residential Aged Care Facilities	Completed
CDPC 1320	Telehealth Enabled Prescribing in Dementia	In Conduct

Workforce Development and Education		
CDPC 1309	Evaluation of Inter-Professional Education (IPE) in Residential Aged Care	Completed
CDPC 1310	Supporting and Caring for Residential Care Staff	Completed
CDPC 1316	Healthy Ageing in Australian Physicians	Completed
CDPC 1322	Improving residential dementia care through staff	In Conduct
CDPC 1328	Implementing and embedding interprofessional learning, education and practice across the aged care sector	Completed
CDPC 1338	Intervene Stage 2 – Pain management - best practice in residential aged care	In Conduct
CDPC Events	Workshops and Information Sessions: Change Management Implementation and Sustainability, Health Economics, Powers of Attorney, Technology & Telehealth, CDPC/COTA Powers of Attorney Seminar Series, and NHMRC Partnership Centres joint events: Policy Engagement, Measuring Impact	Completed

Clinical Guidelines		
CDPC 1313	National Australian Dementia Guidelines	Completed
CDPC 1314	Primary Care Consensus Guide	Completed
CDPC 1327	National Australia Dementia Guidelines Implementation: use of audit and feedback to improve care	In Conduct

Functional Decline		
CDPC 1319	Understanding risk and preventing falls and functional decline in older people	In Conduct
CDPC 1321	Implementing Care of Older Persons with Dementia (COPE) in Australia	In Conduct
CDPC 1329	Implementation Evaluation - Exercise Prescription (EP) in Aged Care Project	In Conduct
CDPC 1330	Innovation Research - understanding human-robot interaction	Completed

Pathways and Navigation		
CDPC 1303	Key Worker Role	Completed
CDPC 1304	Alternative Respite Models	Completed
CDPC 1317	Psychosocial Impact of Having a Parent with Dementia	Completed
CDPC 1325	Consumer Journey Modeling – Ideal State Project	Completed

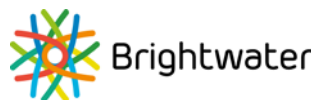


RESEARCH OUTCOME AND RESOURCE THEMES

<http://sydney.edu.au/medicine/cdpc/>



- Positive Care Environments and Quality of Life
- Clinical Practice Guidelines
- Perceptions, and Attitudes to Dementia
- Planning, Decision-Making, and Risk
- Medication Management
- Maintaining Functional Independence
- Building a Sustainable Workforce
- Care Service Pathways



CASE STUDY 1

PLAN IN THE MIDDLE OR AT THE END

Implementation of Goal-Directed Medication Review Electronic Decision Support System (G-MEDSS)
(Prof Sarah Hilmer, University of Sydney)



G-MEDSS[®]
The Goal-Directed Medication Review Electronic Decision Support System

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This website has been created with funding from the NHMRC Cognitive Decline Partnership Centre and The University of Sydney

IDENTIFIED NEED: TOOLS AND IMPLEMENTATION STRATEGIES FOR IMPROVING MEDICATION MANAGEMENT PRACTICES

COMMUNICATIONS PLAN: Not required by the CDPC

AIMING TO ENABLE CHANGE WITHIN A POLICY CONTEXT? Yes

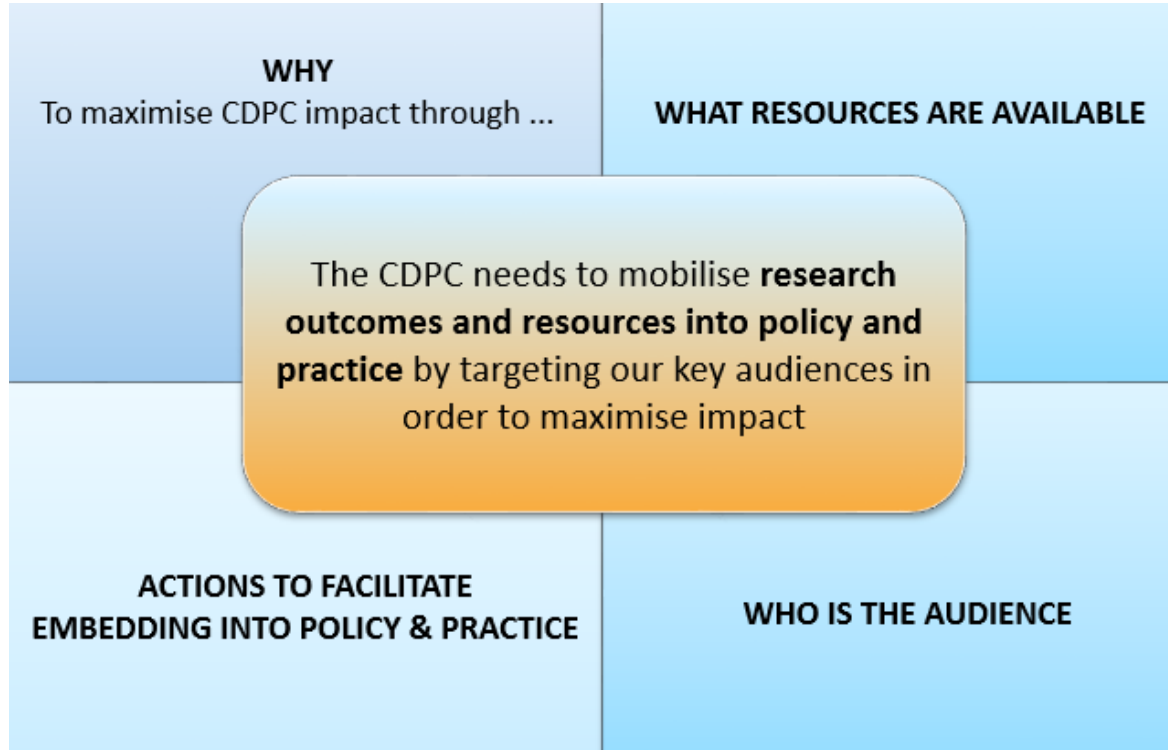
The G-MEDSS online deprescribing tool will be evaluated and plans developed for further rollouts of the Quality Use of Medication tool(s) and policy for older people with cognitive decline.

ENGAGEMENT STRATEGY TO CREATE IMPACT:

1. Meet with key professional and policy groups to determine strategy for widespread implementation if G-MEDSS intervention is effective.

NOTE: RECRUITMENT FOR G-MEDSS STUDY NOT ENVISAGED TO COMPLETE UNTIL DECEMBER 2018.

FRAMEWORKS FOR KNOWLEDGE MOBILISATION



PLANNING FOR KNOWLEDGE MOBILISATION

Planned Resources

- 1) National Stakeholders Meeting to Optimise Quality use of Medicines for Older Australians.
- 2) Policy Brief to policy-makers recommending implementation of a Strategic Action Plan to Optimise Quality use of Medicines for Older Australians to be released to professionals, academic and policy groups for implementation.
- 3) G-MEDSS: web-based tool developed and online ready to be trialed and evaluated.
- 4) Pharmaco-epidemiologic data generated on effects of medicines in people with cognitive and related functional decline.
- 5) DeprescriBe questionnaire for older people, caregivers and people with dementia.
- 6) Deprescribing Guidelines - Evidence-based Clinical Practice Guideline for Deprescribing Cholinesterase Inhibitors and Memantine
<http://sydney.edu.au/medicine/cdpc/resources/deprescribing-guidelines.php>
- 7) Peer-reviewed publications

Who will benefit from knowing about this?

Policy and decision-makers for medication use in Australia.
Clinicians working in community care, acute care, and residential aged care.

SPECIFIC AUDIENCES

Policy document: Australian government minister of health and department of health and key stakeholders involved in development of document (clinical, academic, policy)

Guideline: clinicians and consumers, NPS Medicinewise

Revised patient attitudes to deprescribing questionnaire (older adult, person living with dementia and carer versions): consumer and clinician professional groups involved in medication review.

G-MEDSS software: health professionals involved in medication review for older people with cognitive and functional decline

What does the evidence tell us?

This project's outcomes will answer the question:

- How can health and aged care providers reduce the drug burden on older people with cognitive decline in hospital, community and residential aged care settings?

This is important because people with cognitive and associated physical decline have increased rates of hospitalisation, falls and frailty linked to use of medications for which the current risk outweighs benefit.

While de-prescribing activities can be conducted safely, it can be challenging to implement them in routine clinical practice, especially for target populations with cognitive decline.

RECOGNISE IMPACT



“At IAGG 2017... our research, through the CDPC, on patients’ attitudes to deprescribing and development of the G-MEDSS software was very well received, with requests for international access for research and clinical practice.”

Lead Researchers, September 2017

After the trial was advertised through e-newsletters / social media of professional pharmacy organizations (Australian Association of Consultant Pharmacy, PSA, the Australian Deprescribing Network) ... over 30 expressions of interest and enrolment of 19 accredited pharmacists who met the selection criteria in the study.

Research Activity Report to CDPC, September 2017

CASE STUDY 2

PLAN FROM THE BEGINNING



Supported Decision Making in Dementia Care (Dr Craig Sinclair, University of Western Australia)



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

COMMUNICATIONS PLAN: Yes. Developed within first 6-months of study conduct.

AIMING TO ENABLE CHANGE WITHIN A POLICY CONTEXT? Yes.

Raise awareness of supported decision-making and generate policy action by providing evidence-based recommendations to policy developers.

ENGAGEMENT STRATEGY TO CREATE IMPACT:

1. Create physical information resources to encourage supported decision-making as an alternate to substitute decision-making.
2. Create State based Supported Decision-Making Interest Groups.
3. Create policy briefs to Ministers, Members of Parliament (state & federal), Parliamentary Advisers and Policy makers within Health, Justice and Social Services Depts, and disseminate them to the policy-makers in person.

- 1) **building and maintaining constructive networks with research stakeholders, to enable collaborative knowledge sharing across disciplines and between different stakeholder groups**
 - Regular (at least monthly) communication with Investigator Team regarding project updates, scheduling of key research tasks/milestones, investigator team meetings (teleconference/video-conference or face-to-face), circulation of meeting agenda/minutes/decisions
 - Contact with external research stakeholders involved in supported decision-making working groups, appropriate to their level of engagement with the project and preferred method of engagement (e.g. working group participants via phone/email ~bi-monthly)
 - Regular (monthly) blogging about topics related to this research on relevant platforms (e.g. Palliverse)
 - Frequent (daily-weekly) social media and twitter activity to build a network of relevant followers
- 2) **disseminating research findings to key stakeholder groups, to:**
 - a) **raise awareness about the issues relevant to implementation of supported decision-making policy frameworks among practitioners and policy developers**
 - Peer-reviewed journal articles (open access) and conference presentations (Activity 24 workplan sets a goal of publishing 3 relevant articles and giving at least 3 relevant and high-profile conference presentations prior to the completion of the project).
 - Articles in health practitioner newsletters (e.g. Dementia Centre and Dementia Training Study Centre publications)
 - Articles and interviews in lay press and media (newspaper, radio)
 - *Where possible, these publications will be supported through participation of Activity 24 Team Members in local presentations, seminars, workshops and panel discussions
 - b) **generate policy action by providing evidence-based recommendations to policy developers**
 - Provide policy briefs to relevant Ministers, Members of Parliament (state & federal), Parliamentary Advisers and policy makers within Government Health, Justice and Social Services Departments (3 key policy briefs during 2018, aligned with relevant focus weeks e.g. National Palliative Care Week, International Disability Awareness Day)
 - Submissions to relevant reviews of State and Commonwealth legislation, and relevant regulatory and accreditation standards (e.g. NSQHC and AACQA standards)

INITIAL COMMUNICATION PLAN

Key Messages

- 1) People living with dementia describe the importance of being involved in making decisions about their own lives
- 2) Our research has identified that people with dementia and their carers employ the following strategies to support continued involvement in decision-making (specific strategies are expected to be revealed and collated within this research)
- 3) Australia has obligations under international law to develop programs and systems for supporting people in decision-making, rather than resorting to substitute decision-making
- 4) Current best practice approaches to capacity assessment (time- and decision-specific, functional capacity assessment, with relevant supports for the person being assessed) can be more fully implemented even under existing legislation

PLANNING FOR KNOWLEDGE MOBILISATION

Planned Resources

- 1) Supported Decision-Making Policy Guidelines
<http://sydney.edu.au/medicine/cdpc/documents/resources/SDM-Policy-Guidelines.pdf>
- 2) Consumer Guidebook on Supported Decision-Making
http://sydney.edu.au/medicine/cdpc/documents/resources/SDM_Handbook_Online_Consumers-ReducedSize.pdf
- 3) Webinar series: 3 videos
<http://sydney.edu.au/medicine/cdpc/resources/supported-decision-making.php>
- 4) Training module: 4 introductory sessions for aged care staff and dementia support workers (available from the investigational team via sms.cdpc@sydney.edu.au)

Who will benefit from knowing about this?

LASA, ACSA and aged care providers across Australia, particularly senior clinical and management staff, care coordinators and middle management.

Support staff around Australia who are working with people with dementia (outside of aged care e.g. NDIS support workers).

Aged Rights Advocacy services around Australia ACAT teams and others involved in assessment and care planning.

Health professionals (doctors, nurses, allied health practitioners, and health professionals in training) who provide care to people living with dementia.

People with dementia and care partners reached through Dementia Australia and Carers Australia and similar

What does the evidence tell us?

Supported decision-making is a progressive, rights-based approach to decision-making and this approach is aligned with the 'social model of disability', which identifies the root cause of disability as the failure of society to support and accommodate those with impairments. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) mandates that supported decision-making is a key ethical component of a human rights-based approach to dementia care (United Nations Enable, 2008).

When this project was initiated Australian legislation and policy approaches to healthcare decision-making and advance care planning did not adequately accommodate supported decision-making. The researchers used an evidence informed process to develop evidence-based recommendations and practical resources for use in the Australian context to implement supported-decision making frameworks across residential aged care.

RECOGNISE IMPACT



“I commend the work... in developing the SUPPORTED DECISION-MAKING IN AGED CARE: A Policy Development Guideline for Aged Care Providers in Australia. These important guidelines address the day to day question that we see playing out in aged care settings all over Australia.”

Nick Ryan, CEO, Australian Aged Care Quality Agency (in the foreword to the guidelines)

“...investigators, interest group members and consumers directly involved in the project are starting to tell me how the findings are influencing their own practice and actions in their own lives.”

Craig Sinclair, Lead Researcher, June 2018

“Developing the Comms Plan was a good way to have a structured discussion with the investigator team about further options for disseminating findings and it has kept me forward-looking in terms of knowing there is lead time involved in achieving some of the comms outcomes.”

Craig Sinclair, Lead Researcher, June 2018

BEGINNING, END, OR MIDDLE?



Both teams can be equally successful in promoting change in policy and practice however:

1. Would one team find it easier?
2. What further action/s could one or both of these research teams take to maximise their policy and practice impact?

Policy-formulation is therefore approached through means-end analysis: First the ends are isolated, then the means to achieve them are sought.

Lindblom. (1959). The science of “muddling” through

Whether or not the best and most relevant research reaches the person with the problem depends on the efficiency of the communications links. Therefore . . . the usual prescription for improving the use of research is to improve the means of communication to policy makers.

Weis. (1979). The Many Meanings of Research Utilization

REFERENCES



CDPC RESEARCHERS REFERENCED

- Prof. Sarah Hilmer, University of Sydney (Medication Management)
- Emily Reeve, University of Sydney @Reeve_Research (Medication Management)
- Dr Craig Sinclair, University of Western Australia @csinclair28 (Supported Decision-Making)

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