

January 2016

Companion to report

# Future planning and advance care planning

Why it needs to be different for people with  
dementia and other forms of cognitive decline



COGNITIVE  
DECLINE  
PARTNERSHIP  
CENTRE



HammondCare  
An independent Christian charity



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Generous support and contributions of time were made by the Stakeholder Advisory Committee who ensured this project was well informed by stakeholders. Members included individuals from a wide range of backgrounds and expertise – including consumer, primary care, aged care, hospital, policy and government to ensure the variety of settings and perspectives relevant to dementia specific advance care planning were taken into account. As the legislative base and health system differs across Australian jurisdictions members were drawn from a number of states. The Stakeholder Advisory Committee comprised:

**Chair and Lead Investigator:**

**A/Prof Meera Agar**

Director of Palliative Care,  
Braeside Hospital, HammondCare  
Conjoint Associate Professor  
UNSW

**Members:**

**A/Prof Josephine Clayton**

Staff Specialist Physician  
in Palliative Medicine,  
HammondCare, Greenwich and  
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Associate Professor of Palliative  
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# Stakeholder Advisory Committee

**Sue Field**

Adjunct Fellow in Elder Law  
School of Law  
University of Western Sydney

**Dr Patrick Kinsella**

General Practitioner  
Gippsland Lakes Community  
Health, Victoria

**Dr Catriona Lorang (and  
previously Rebecca Forbes)**

Designated System Based  
Investigator, HammondCare

**Dr Joel Rhee**

General Practitioner,  
HammondCare Centre for Positive  
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Senior Lecturer, School of Public  
Health & Community Medicine, UNSW

**Dr Chris Shanley**

Manager, Aged Care Research  
Unit, Liverpool Hospital  
Conjoint Senior Lecturer,  
University of New South Wales

**Dr Craig Sinclair**

Research Fellow  
The Rural Clinical School of  
Western Australia

**Jan Van Emden**

Designated System Based  
Investigator, Helping Hand

**Kathy Williams**

Consumer representative  
(former carer)  
Consumer Dementia Research  
Network  
Alzheimer's Australia

**Staff:**

Adele Kelly and Gail Yapp  
Project Officers

Natalie Ohrynowsky  
Administration Assistant

# Methodology

## Literature review

The aim of the literature review was to gather evidence on the effectiveness of strategies to inform models of Advance Care Planning (ACP) that address the specific needs of people with dementia and other chronic cognitive impairment and that would be optimally delivered and communicated across the different service settings typically encountered. Particular focus also included the barriers to the implementation of ACP for people with dementia and their carers and health professionals, and what facilitates ACP. In gathering the evidence a wide range of material was examined: an extensive search of the academic literature including dementia specific and more generally on ACP; a review of the grey literature including reports and policy documents by federal, state and territory governments; and review of resources and websites available to consumers and health professionals to facilitate ACP.

## Stakeholder interviews

### Research aim

The aim of the consultation component of the project was

to seek key stakeholders views and experiences to inform consideration of how ACP could be improved for people with dementia and other forms of cognitive decline across multiple health settings.

### Research questions

In relation to both advance care planning generally, and specifically in relation to focusing on those with cognitive decline:

1. What are the different models for implementing ACP in a range of different health and aged care settings?
2. What are the participants views on the outcomes which each model can achieve and how well have these been evaluated?
3. What do participants identify as the enablers and barriers to implementation of various models of ACP?
4. What are the participants views on how the uptake of ACP be improved in a range of different settings?

### Participants

The stakeholders approached were from organisations across Australia. They were selected because of experience and/

or interest in providing care for older people, including those with dementia; or their experience with ACP. Purposive sampling was used to ensure a wide range of views and experiences were explored. Participants were drawn from different health sectors including non-government organizations providing residential and/or community care, public hospital providers, carers' organisations, Medicare locals, community health centres, and community groups. In addition invitations were sent to individuals who have been identified as having undertaken research or had a special interest in ACP.

### Study design

The study design used a qualitative approach, using semi-structured interviews and thematic content analysis.

### Analysis

A coding framework using a template analysis method was used as it enabled the considerable knowledge gained from the literature to form a basis for the coding and this was then developed in light of the responses. (Symons and Cassell 1998). The interview questions were initially used as the basis

for initial coding and category development. Individual points were identified in the transcripts and organised into themes. The coding framework was further developed as new themes were identified. A process of independent review and peer consensus was used to validate the findings.

The extraction of interview data was completed using QSR NVivo (a qualitative data software programme) to organise the data.

# Demographics of interview participants

In consultation with the management of change enabling subunit and the stakeholder advisory group, potential stakeholders were identified and then rated according to their urgency, legitimacy and power against two criteria. Evaluating against two criteria the salience of the information they are able to provide, and the ability to influence the project spread we were able to prioritize stakeholder to ensure we focused stakeholder interviews on the groups most important to the project outcomes.

A total of 67 interview and focus groups were conducted, with 82 participants. Details of the participants are outlined opposite.

## State

Participants were spread throughout Australia, with smaller states/territories over-represented in comparison with population share. Higher participant number in South Australia (SA) compared with relative population was due to the high level of interest in ACP in SA due to recent legislation changes and active interest by participants in this area.

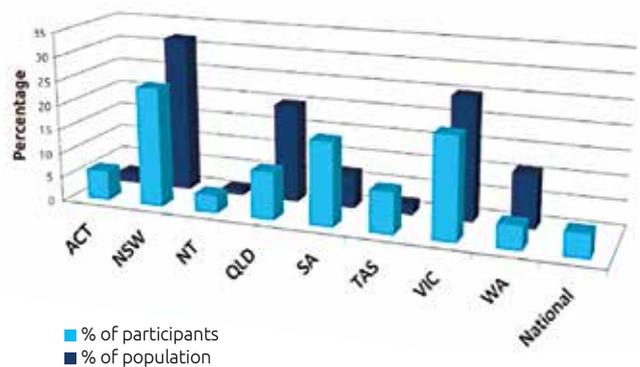


Figure 1. Percentage of participants in each state overlaid on percentage of population

## Setting

Participants were targeted that worked in the full range of settings where ACP typically occurs. Many participants worked across multiple settings with many academics also having clinical roles in acute or palliative care.

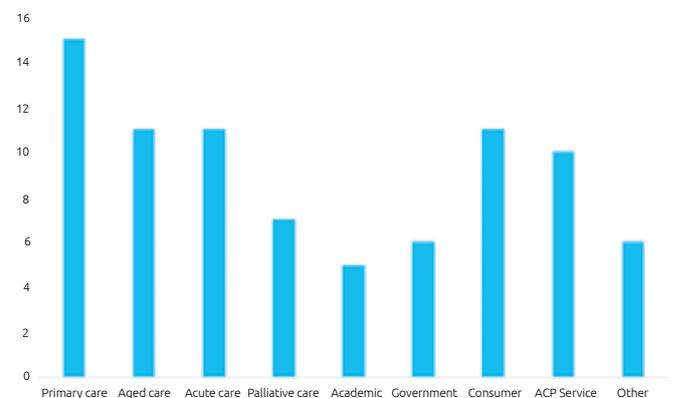


Figure 2. Setting in which participants work

## Participant's professional background

Profession data was not requested from participants and was gathered based on specific reference by participants. The relative high proportion of nurses in our sample is related to the high proportion of nurses in health related settings, many who are no longer in clinical nurse roles. Nurses interviewed worked in a variety of settings including as practice nurses, in ACP services, in Medicare locals as well as residential aged care facilities and acute care.

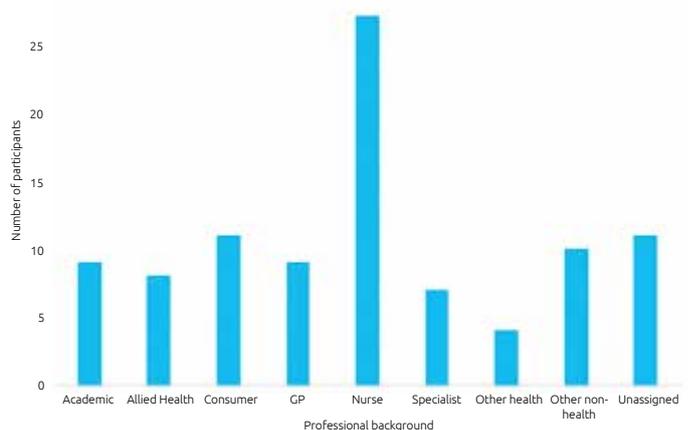


Figure 3. Participants professional background



## CONTACTS

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