

National Palliative Care Grant Recipients' Forum

7-8 April 2016 | Vibe Hotel, Canberra Airport

Project Information Form

Project: Respecting Patient Choices

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| Key objectives | <p>To improve access to advance care planning (ACP) for people with dementia, from non-English speaking backgrounds and through innovative technologies through three sub-projects:</p> <ol style="list-style-type: none">1. “ACCESS” - The objective of the “National Access to Advance Care Planning Through Innovative Use of Technologies” project is to provide national advance care planning support, networking and resources for consumers and health workers, and a hub for development of evidence-based practice through research, information sharing and promotion of advance care planning through education forums.2. “DEMENTIA” – The objective of the “Dementia in the Community – The Capacity for the Conversation” project is to educate and train health care workers to conduct ACP with persons with dementia and /or their family members who are still living in the community. A further objective of the activity, therefore, is to increase the uptake of ACP among persons at the early stages of dementia (while they still have capacity to do so).3. “CALD” - The objective of the National Approach to Consumer Needs – Knowing What Matters Activity is to develop resources aimed at assisting Australians from non-English speaking backgrounds (NESB) to more successfully engage in ACP to ensure end-of-life treatment wishes are known and respected. |
| Key outcomes <i>(e.g. resource development, education and training)</i> | <p>ACCESS</p> <ul style="list-style-type: none">• Development and use of online technologies including downloadable forms• A national electronic forum• A national hub for resources through the current ACPA website to improve education and training• Delivery of two annual national conferences• Telephone advisory service• Engagement with selected organisations to deliver input to national curriculum strategies <p>DEMENTIA</p> <ul style="list-style-type: none">• A report examining the knowledge and uptake of ACP amongst consumers with dementia• Educational materials for patients with dementia to improve awareness of ACP• ACP training package, including e-learning and workshop, for health care workers in the community with dementia clients• An ACP helpline for health professionals undertaking ACP with dementia clients, persons with dementia and their carers <p>CALD</p> <ul style="list-style-type: none">• Bi-lingual Advance Care Planning resources in Greek, Italian, Chinese and Vietnamese.• Community information sessions for elderly members of the Greek, Italian, Chinese and Vietnamese communities.• Advance Care Planning resources for health professionals working with CALD patients including online learning modules• An Advance Care Planning telephone advisory service for consumers and health care professionals from/working with Non English Speaking Background. |

Level 1, 21 Napier Close, Deakin, ACT 2600
PO Box 24 Deakin West, ACT 2600
ABN: 85 363 187 904
t: +61 2 6232 4433 | f: +61 2 6232 4434
w: www.palliativecare.org.au | e: pcainc@palliativecare.org.au

Target audience

(e.g. who is the target audience/s for your project activities?)

ACCESS

- All healthcare workers and relevant professionals
- Aged care workers
- Medical and nursing schools and professional colleges
- Consumers

DEMENTIA

- Consumers living with dementia (Resources)
- Patients with dementia
- Alzheimer's Australia Trainers (ACP Train the Trainer)
- Home and Community Care workers (ACP Training)
- Other community health workers (ACP Training)

CALD

- Consumers from Italian, Greek, Vietnamese, Cantonese, Mandarin backgrounds. (Resource Development)
- Health Care Professionals working with Italian, Greek, Chinese and Vietnamese communities. (Educational Material/Resources)

Outcomes to date

ACCESS

- Website promotion and upgrades have increased the number of unique visitors to the existing website to 185,000 to in the 12 months to 31st January 2016.
- Internal issues paper and draft specification for website redesign and upgrade prepared for consultations with web designers
- Successful hosting of the 2015 Advance Care Planning and End of Life Care National Conference in Melbourne in November 2015 with 276 registered attendees from around Australia with over 30 speakers. Attendees from a cross section of the health workforce were represented with doctors, nurses, executives, academics, managers, policy makers, project staff, researchers, trainers and volunteers from every state and territory. Feedback was overwhelmingly positive with 78% respondents rating the conference and associated elements positive or above.
- Project planning for the 2016 Conference is well advanced with initial Save the Date milestones already achieved.
- Initial environmental scan of medical schools, learned colleges and nursing schools undertaken to determine the extent of advance care planning in current curricula.

DEMENTIA

- A Consumer resource outlining why ACP is important to people with dementia has been through an Alzheimer's Australia Consumer Review group for feedback and is in the final stages of development.
- Surveys of People with Dementia and carers have been developed approved by consumer groups and Ethics and will be open shortly.
- E-Learning modules have been developed for health professionals working with people with dementia and will be hosted on the CareSearch website along with our current Decision Assist modules.
- Pilot education sessions with Alzheimer's Australia Victoria trainers have been scheduled. Subsequent education sessions for community workers have been scheduled.
- Education sessions for all Alzheimer's Australia trainers have been tentatively scheduled for sessions in Western Australia and Victoria.

CALD

- Knowledge, Attitude and Needs report based on the findings from the literature review and the initial stakeholder engagement has been completed and was submitted to the Department on the 30th November 2015.
- Fifteen bilingual researchers (3 Mandarin, 2 Cantonese, 3 Vietnamese, 3 Greek and 4 Italian) have been employed on a casual basis to conduct semi-structured interviews within the community, to run focus groups and to translate material.
- Elderly CALD Consumers are currently being interviewed regarding their understanding of ACP and what they would like relevant ACP resources and services to provide. Interviews completed to date are as follows: 40 in total – Vietnamese (14); Mandarin (16); Cantonese (6); Italian (4). Initial findings indicate a very low level of understanding or exposure to ACP. Contrary to perception they are more open to the idea of discussing the topic although they are reluctant to bring up the topics, a lack of information is the main limitation and they would ideally like the information given in community settings i.e. community groups.
- Survey of "health professionals" from a CALD background has been distributed to the Chinese Doctors Society of Victoria. Initial analysis of the survey will be conducted to ensure the survey is meeting the objectives prior to widespread distribution.
- Survey distribution channels have been established.
- Basic bilingual resources have been developed and are currently being uploaded to the hospital document repository. These will be refined before national distribution.

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Challenges & lessons learnt

(e.g. were there any difficulties which may assist others?)

There has been significant turnover of staff in the Advance Care Planning Department of Austin Health that has affected all projects and proved challenging to the continuity of projects.

ACCESS

- A manual system was used for handling registrations and payments for the 2015 National Conference. This was very time-consuming and an online registration system is being investigated for the 2016 National Conference.
- Maximising planning lead times to ensure comprehensive communication and marketing is essential
- Ensuring target audience, subject scope of a national conference are clear in the ACP market
- Implementing change into diverse university curricula requires extensive consultation and long lead times.

DEMENTIA

- One of the identified challenges has been the changing service delivery environment in aged care, and how this is impacting on frontline service delivery. This includes an increasingly full training agenda for AA trainers and negotiating with AA to ensure that the ACP training to be provided is prioritised. To address these challenges we have collaborated further with AA and designed the training to meet their needs in terms of time required for training and location of delivery.
- The achievement of the AA trainers then going on to train 600 Alzheimers Australia front line staff (patient facing) is questionable in terms of its value as we have learned from a recent project completed in the Home Care Packages area. An article (being drafted due for submission in March but already circulated to Department in confidence) suggests that training personnel in an agency where they are able to have ACP conversations with their clients do not necessarily lead to more ACPs being completed, and those that are completed may be of such poor quality so as not to be useable.

CALD

- A number of challenges have been identified relating to consumer engagement and access to participants in this project. Consequently there has been a strong focus on consultation with community groups, peak bodies and project co-ordinators from analogous CALD consumer projects. This consultation process, while time-consuming and contributing to front end delays to the project, it has however, resulted in good consumer engagement and access.
- The reluctance of many elderly CALD consumers to provide signed consent to be interviewed has reduced the number of participants. This has been addressed by providing additional in-language information to elderly groups prior to interviews to allow the consumers to consult their family prior to their participation. We are working with Austin Health's ethics department to allow verbal consent to interviews where appropriate and expect this issue to be resolved soon.
- Knowledge of ACP within elderly migrant populations is extremely low. Given the low knowledge it is extremely difficult to ascertain useful information on what they require to participate in ACP.

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Plans for 2016 and 2017

ACCESS

- The 2016 Advance Care Planning National Conference is scheduled for 15-16 November in Melbourne
- Build of new website capable of running e-forums and housing resources.
- Further investigations into national curricula strategies.

CALD

- Interviews of elderly members of the Greek, Italian, Chinese and Vietnamese will be finalised in Melbourne and Sydney. Findings will be used develop and refine resources tailored for each cultural perspective.
- The national survey of health professionals Knowledge Attitudes and Needs will be used to develop online content to assist health professionals in performing ACP with people from CALD backgrounds.
- Bilingual resources that are currently being developed will be refined through a process of consumer focus groups and distributed nationally
- Evaluation of the consumer satisfaction of bilingual researchers will be completed.

DEMENTIA

- Consumer resource has been completed and is ready for distribution. This will be made available through the AA training sessions and will be made available on line when website design is completed.
- Online content specific to ACP with people with dementia will be made available on the website once completed.
- Training of Alzheimer's Australia- Victoria trainers (Train the trainer) will commence in May with the subsequent training of Home and Community Care workers (and others) scheduled to commence in the second half of this year.
- Training sessions for other Alzheimer's Australia trainers nationally will occur in August.
- Survey of people living with dementia and carers will be opened in May. This survey is aimed at assessing the Knowledge and attitudes towards Advance Care Planning. It is envisaged that we would be after 500 respondents

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