

Centre of Research Excellence in End of Life Care **CRE-ELC**

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Highlights

The *Centre of Research Excellence in End of Life (CRE-ELC)* held a successful planning day, followed by a networking function, on 1 September. Timed to coincide with the arrival of delegates to the 13th Australian Palliative Care Conference in Melbourne, the networking function attracted about 50 people from diverse palliative care-related sectors.

Two CRE-ELC representatives spoke about the Centre's research program, knowledge translation activities and opportunities for collaboration: Ms Sue Boyce, a former member of the Australian Senate for Queensland, a passionate advocate for palliative care and disability matters, and now Chair of the Expert Advisory Committee; and Professor Patsy Yates, Director of the CRE-ELC, who has a long history in research and service improvement programs, focused on developing workforce capacity in palliative care.

Our website www.creendoflife.edu.au is now live, and contains information on the CRE-ELC, our research program, and knowledge translation. We encourage you to let others who may be interested in our work know that they can also subscribe to future editions of this newsletter online via the website. Our plan is to increase our online activity by providing resources and webinars. Watch this space: we are developing the first webinar, scheduled for early 2016, as this newsletter is being prepared.



Delegates enjoyed robust discussion during the CRE-ELC planning day in Melbourne



Ms Sue Boyce, Chair of the CRE-ELC Expert Advisory Committee, discussed the relevance of CRE-ELC research to Australia's increasingly elderly population



Professor Patsy Yates, Director of the CRE-ELC, at the networking session



CRE-ELC Expert Advisory Committee members, Chief Investigators, Research Fellows and Higher Degree Research Students

Research Update

RESEARCH PROGRAMS	PROJECTS	STATUS
Research Program 1 <i>(Service delivery stream)</i> will design and evaluate innovative service models and interventions to improve outcomes for people at end-of-life.	Achieving needs-based end-of-life services: a prospective, longitudinal study of the pathways for patients with Stage 3-5 chronic kidney disease. Aim: To determine how patients with Stage 3-5 chronic kidney disease interact with health services and how they perceive quality of life, supportive care needs, symptoms and their experience with health services.	In progress
	Patient outcomes in palliative care – a national perspective of malignant and non-malignant diseases. Aim: To describe the symptom burden of people referred to specialist palliative care services using data collected through the Palliative Care Outcomes Collaboration http://ahsri.uow.edu.au/pcoc/index.html .	Data analysis complete; publication in preparation
	Implementing principles of end-of-life care in acute care settings. Aim: To develop and evaluate new models of care based on the principles of 'The National Consensus Statement: essential elements for safe and high quality end-of-life care'.	Commenced in Oct 2015
	Evaluating the BASIC-NP Project (Better Assessment, Support and Interdisciplinary Care – Nurse Practitioner). Aim: To evaluate Nurse Practitioner led case conferences with the General Practitioner for people with advanced, life-limiting diseases in a regional community.	Completed and new project in progress
	Evaluating the role of innovative technologies to enable end-of-life care service provision. Aim: To identify barriers and enablers to technology use by staff in care facilities, and what potential applications could be used to improve outcomes in palliative care provision.	Due to commence 2016
Research Program 2 <i>(Consumers stream)</i> will improve consumer, health care professional and policy maker knowledge to make better informed choices.	Developing and validating a national approach to assess consumer and carer experience of end-of-life care. Aim: To trial interventions aimed at improving accessibility of palliative care services by evaluating specialist consultation and cost effectiveness of models delivered.	Due to commence 2016
	Enabling consumer participation in end-of-life treatment decisions.	Literature review in progress
Research Program 3 <i>(Regulatory stream)</i> will generate evidence to improve the regulatory environment to better support health systems, organisations and health professionals on end-of-life care.	Dying in pain: a pilot study. Aim: To examine whether concerns about legal and ethical risks affect the provision of pain relief to patients at the end of life.	In progress
	Designing regulatory systems that are responsive to evolving medical practice at the end of life. Aim: To establish baseline data to track trends in end-of-life decision making as the population ages.	Commenced in Dec 2015



CRE-ELC Research projects – snapshot

Evaluation of palliative care education for General Practitioners in Queensland.

This project evaluated a pilot model of care involving a patient's general practitioner (GP), a specialist, and nursing service provider through a case conference approach.

Baseline data collection comprised six patient-carer interviews where care was provided in home settings; follow-up interviews occurred a month later and, in some cases, case conferences between the patient's GP, their Nurse Practitioner, and other health care professionals. Some were interviewed together and others separately. Data were coded using NVivo™ software and analysed for recurring themes using the project's objectives as an analytical filter.

Findings indicated that case conferencing supported successful discharge home for several patients who would otherwise have had prolonged hospitalisations. This was evidenced through:

- Increased frequency of completed Advance Care Plans early in the palliative journey
- Decreased use of afterhours emergency services by those palliative care patients
- Increased confidence of palliative care patients and their carers about their decision to remain at home
- Increased of a multidisciplinary approach in addressing the health care needs of palliative patients returning home from hospitals or hospice facilities
- Clinicians in primary care settings with increased knowledge and confidence to manage palliative care patients On the basis of this pilot study a larger trial of a Nurse Practitioner led services is being developed.

Staff and Students

CRE-ELC RESEARCH FELLOWS



Dr Jennifer Fox PhD RN BNurs B.Com CPA

Jenny commenced as a Research Fellow with the CRE-ELC in June 2015 after completing a PhD at Queensland University of Technology in early 2015. Jenny's PhD thesis, 'The transition to palliative care: A critical exploration in the context of metastatic melanoma', provided a multiperspective view of issues around referrals to palliative care in acute care settings. Interviews with patients, carers and health professionals provided insight into the complexities inherent in the transition process. Jenny's current research interests include supportive care for those nearing the end of life, particularly in acute care settings. When Jenny is not at her desk she can be found clocking up kilometres on her bike on the river loop and enjoying the outdoor ambience that makes Brisbane an excellent city for cycling in Australia.



Alison Bowers BNurs MClinRes

Alison Bowers is a Registered Nurse, holds a Bachelor of Nursing (Child) and a Master of Clinical Research. She currently works as a Research Ethics and Governance Officer at the West Moreton Hospital and Health Service. Alison also worked as a paediatric nurse and hospital Quality Manager (acting) in the Northern Territory before relocating to Queensland. Prior to moving to Australia in 2013, she worked as a paediatric nurse and gained experience in a variety of settings to include bone marrow transplant, acute general paediatrics, community child and family health and paediatric clinical research. Alison is undertaking a PhD in the area of paediatric palliative care, with the aim of informing the models of palliative care and service needs for children and young people with life-limiting or life-threatening conditions in Australia.

For further information

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