

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

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Highlights

Welcome to The Centre of Research Excellence in End of Life Care's (CRE-ELC) 3rd newsletter. Since our last newsletter one Research Program One pilot study (*Evaluating the BASIC-NP Project: Better Assessment, Support and Interdisciplinary Care – Nurse Practitioner*) has been completed, and several new projects are commencing (see table over for details).

Assistant Professor Kenneth Chambaere, an international scholar from Belgium, has recently spent 10 weeks at QUT's Australian Centre for Health Law Research. The main focus of Kenneth's visit was to develop the study design and methodology, and meet with key stakeholders for the CRE-ELC's project 'Enabling consumer participation in end-of-life treatment decisions making', led by Professors Lindy Willmott and Ben White. This project replicates a large study conducted by Kenneth in Belgium. Whilst at the Centre Kenneth conducted cognitive pre-testing of the survey he used in his Belgium study to ensure its validity for our Australian study, and gave a series of presentations on his end-of-life research.

Associate Professor Jennifer Tieman, one of the CRE-ELC's Chief Investigators, has developed an eLearning module using palliative care scenarios to explore knowledge translation principles. To learn more about this new module follow the link www.caresearch.com.au/caresearch/tabid/3973/Default.aspx. You can also visit our website www.creendoflife.edu.au and learn more about knowledge translation www.creendoflife.edu.au/translation/.

We are also developing strategies to communicate better with our stakeholders, and establishing collaborations with other research groups working in the palliative care space. In this context, we are collaborating with the NHMRC CRE in Chronic Kidney Disease (CKD.CRE) through the project 'Achieving needs-based end-of-life services: A prospective, longitudinal study of the pathways for patients with Stage 3-5 chronic kidney disease (CKD)'. Opportunities also exist for the CRE-ELC and the CKD.CRE to collaboratively explore and test the most effective and efficient ways to support later stage CKD patients and their carers, and to find ways to best educate and support the health professionals who care for this cohort.

The CRE-ELC also has recently awarded one additional higher degree scholarships to Catherine O'Leary.

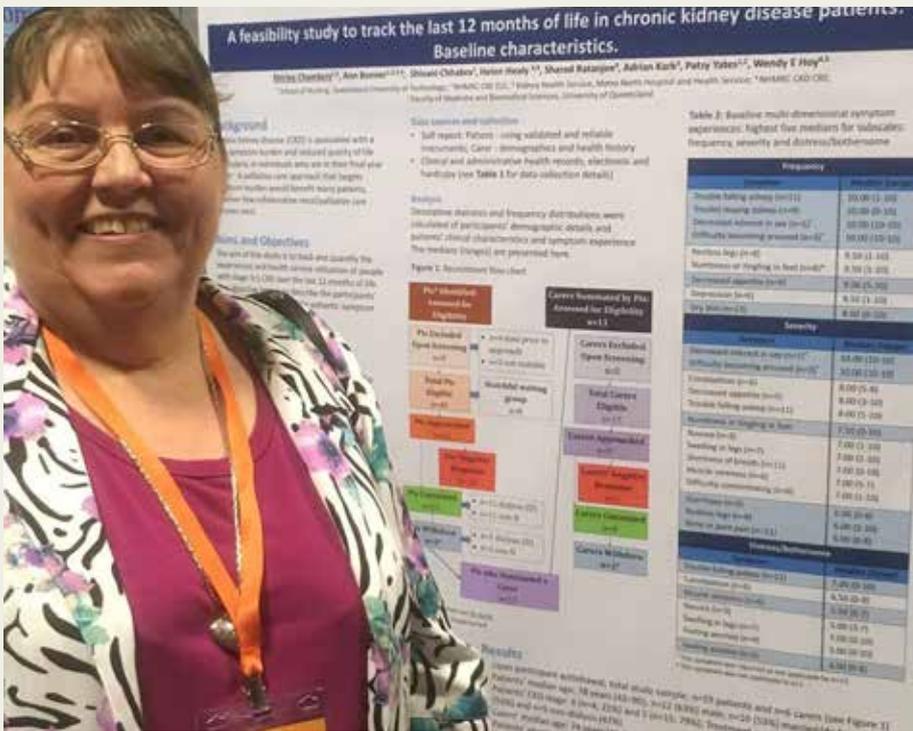


Students, Research Fellows and a Chief Investigator from the CRE-ELC and the CKD.CRE at the 2016 Renal Society of Australasia Annual Conference.

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.	Data collection in progress
	Patient outcomes in palliative care – a national perspective of malignant and non-malignant diseases.	Analyses completed and manuscripts preparation in progress
	Implementing principles of end-of-life care in acute care settings (PreEPAcS).	Sites selection in progress
	Evaluating the BASIC-NP Project (Better Assessment, Support and Interdisciplinary Care – Nurse Practitioner).	Completed
	Evaluating the role of innovative technologies to end-of-life care service provision.	Due to commence in 2017
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 assessing consumer and carer experience of end-of-life care.	Scoping review completed and study protocol developed
	Enabling consumer participation in end-of-life treatment decisions.	Systematic 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.	Do concerns about legal and ethical risk affect the provision of pain relief at end of life?	In progress*
	An Australia study: Incidence and characteristics of end-of-life decisions in Victoria.	In progress

*Project synopsis below



Research Fellow Dr Shirley Chambers and her 'top 10 poster' at the Renal Society of Australasia Annual Conference.

The CRE-ELC was well represented at the Renal Society of Australasia's annual conference, 20–22 June 2016, on the Gold Coast. Research Fellow Dr Shirley Chambers' poster *A feasibility study to track the last 12 months of life in chronic kidney disease patients: Baseline characteristics* was awarded in the top 10 posters at the conference. Dr John Rosenberg, a palliative care nurse and a Research Fellow in the CRE-ELC, gave a plenary presentation *The interface between palliative and renal care*, which was well received.

Work presented at the Renal Society of Australasia conference highlighted kidney disease is a growing problem both in Australia and globally, and that palliative and end-of-life care is an emerging component of care for patients with chronic kidney disease.

CRE-ELC Research projects – snapshot

Do concerns about legal and ethical risk affect the provision of pain relief at end of life?

Despite increasing recognition of the importance of palliative care, we know that pain continues to be undertreated at the end of life. What we don't know is whether health professionals provide inadequate pain relief, at least in part, because of concern that providing such relief may cause or hasten the patient's death. There is anecdotal evidence that some health professionals take a conservative approach to pain relief because of potential legal or professional risks of administering palliative care. This is despite evidence that properly administered palliative care does not shorten life (and may in fact extend life), and that the law supports such care provided it is administered in accordance with good medical practice and with the intent to relieve pain rather than to cause death.

Professors Lindy Willmott and Ben White are leading a project to better understand the nature and extent of legal (and ethical) concerns about administering palliative care at the end of life and how this influences practice. The study has two phases:

Phase 1

- To identify and compare the regulatory regimes across Australia that govern decisions about administering pain and other symptom relief at the end of life

Phase 2

- To describe and analyse health professionals' knowledge and perceptions regarding the laws in Queensland and New South Wales on prescribing and administering adequate pain and other symptom relief at the end of life
- Examine the impact of health professionals' knowledge and perceptions of the law on their practice in relation to prescribing and administering pain and other symptom relief to end-of-life patients.

Governance

A meeting of the Expert Advisory Group was held on 17 June. The Advisory group provided valuable insights into the focus of existing projects and future directions, as well as strategies to promote knowledge translation.

Staff and Students

CRE-ELC RESEARCH FELLOWS



Dr Shirley Chambers

Dr Shirley Chambers (formerly Connell) is a Research Fellow in the Palliative and Supportive Care Research Group at QUT's Institute of Health and Biomedical Innovation (IHBI) and the NHMRC Centre for Research Excellence in End-of-Life Care. Shirley's PhD thesis was Experiences of young Australian women with breast cancer. After finishing her doctoral studies in 2005 she began working in the field of palliative care research and education, particularly relating to health service delivery. Shirley's current research is focused on the experiences and/or health service utilisation of patients who have a life limiting illness and their carers. Dr Chambers has led two longitudinal studies tracking advanced cancer patients use of health services toward the end of life, collecting data from various health administrative datasets and via patient held diaries, while also capturing patients' and carers' experiences. Shirley is currently leading a similar study with a cohort of non-malignant patients—those with Stage 3-5 chronic kidney disease (CKD). In addition, Shirley has managed two projects to scope and map the quantum of palliative care service delivery within Queensland.

For further information

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