

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

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IN THIS ISSUE

- About us
 - Research Update
 - Governance
 - Staff and Students
-

About us

Each year in Australia approximately 70,000 people will die an expected death¹. As more and more members of our community live for many years with one or more chronic life limiting condition, such as cancer, dementia, and cardiovascular and respiratory disease, our health and social care systems need to adapt to ensure quality end of life care is available to all. The quality of end of life care in Australia is amongst the best in the world, however research is required to address a number of pressing questions for health systems and the Australia community, including:

- What is the most effective and efficient way of delivering health services for people with chronic life limiting conditions?
- How do we ensure person centred care at end of life?
- What regulatory and governance systems are required to support quality care at the end of life?

The Centre of Research Excellence in End of Life Care² (CRE-ELC) was established to generate new knowledge about health service interventions and to deliver strategies that will promote high quality and sustainable health care services for all Australians at the end of life. This newsletter is intended to keep you up-to-date on the Centre's research and knowledge translation activities. We welcome feedback and look forward to hearing from individuals or groups who would like to learn more about the CRE-ELC and its work.

Funded by the National Health and Medical Research Council, the CRE-ELC brings together Australia's leading researchers and industry partners to investigate health services at end of life. The overarching objectives of the CRE-ELC are to:

- generate and translate new knowledge to ensure service delivery models and health care interventions achieve optimal outcomes for all people at end of life
- support consumers, health services providers, regulatory bodies and funders to ensure optimal decision making about care and use of health resources at end of life.

The CRE-ELC also seeks to build capacity in the sector by developing a multidisciplinary research workforce in end of life services through collaboration, training of new researchers and developing research leaders in end of life services research.

1 Palliative Care Australia. A Guide to Palliative Care Service Development: A Population Based Approach. Deakin West: Palliative Care Australia; 2005

2 In the Centre of Research Excellence in End of Life Care, the term End of Life refers to that period of a life where a person is living with, and impaired by, a progressive, life-limiting illness, even if the prognosis is ambiguous or unknown.

Figure 1. CRE-ELC Research Programs



| 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 (CKD). | In progress* |
| | Patient outcomes in palliative care – a national perspective of malignant and non-malignant diseases. | In progress |
| | Implementing principles of end of life care in acute care settings | In development |
| | The BASIC-NP Project (Better Assessment, Support and Interdisciplinary Care – Nurse Practitioner). | In progress |
| | Evaluating the role of innovative technologies to enable end of life care service provision. | Due to commence 2016 |
| Research Program 2 <i>(Consumers stream)</i> will improve knowledge for consumers, health care professionals and policy makers on making better informed choices. | Development and validation of a national approach to assess consumer and carer experience of end of life care. | Due to commence 2016 |
| | Enabling consumer participation in end of life treatment decisions. | 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 examining whether concerns about legal and ethical risk 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. | Due to commence 2016 |

*Project synopsis over



CRE-ELC Research projects – snapshot

Tracking pathways of patients with Stage 3-5 CKD through health care services

This project aims to determine how patients with Stage 3-5 Chronic Kidney Disease (CKD) interact with health services, particularly those associated with meeting health and supportive care needs at end of life and to ascertain how patients perceive their symptoms, experiences with health services, quality of life (QOL), and supportive care needs. This prospective, longitudinal observational study will collect data at regular intervals from multiple sources for a 12 month period or until death. Recruitment is underway. Presently all baseline interviews have been conducted with 11 consenting patients and seven carers, with 3 months follow up interviews having been conducted with six patients. The objectives for the study are to:

- Describe patients demographic and clinical characteristics, experiences with health services, QOL, supportive care needs, utilisation of primary health care (General Practitioners and community), renal (including general medical), palliative and emergency services over time
- identify triggers and barriers to referrals and access to Specialist Palliative Care Services
- identify triggers to the use of emergency services
- identify associations between patient-reported perceptions of their experiences with health services, QOL and supportive care needs to their utilisation of health services.

Governance

The CRE-ELC is governed by an Expert Advisory Committee (EAC) and a Centre Management Committee. The EAC provides input from stakeholder representatives to ensure that the activities of the CRE-ELC deliver outcomes that are relevant to health service and policy improvement. The EAC comprises senior representatives of the CRE-ELC's primary stakeholder groups – consumers, health professionals and policy makers from diverse organisations. Members of the EAC are listed in the table opposite.

| EXPERT ADVISORY COMMITTEE MEMBERS | |
|-----------------------------------|--|
| Sue Boyce | Chair |
| William Silvester | Respecting Patient Choices |
| Mark Tucker-Evans | COTA Queensland |
| Tim Shaw | University of Sydney |
| Nicola Dunbar | Australian Commission on Safety and Quality in Health Care |
| Justice Ann Lyons | Queensland Supreme Court |
| Liz Callaghan | Palliative Care Australia |
| Venessa Curnow | National Congress of Australia's First Peoples Board |

CRE-ELC High Degree Research Students



Elina Close

Elina Close is a CRE-ELC PhD candidate for the project titled 'Legal implications of bedside rationing at end of life' and graduated with first class Honours in Psychology from the University of Calgary, and won a Rhodes Scholarship to study law at Oxford University. Before coming to study at QUT, she worked as a management consultant at Google, as a Judge's Associate at the Court of Appeal of Alberta, and as a Crown Prosecutor. Elina's research is focused on the legal implications of bedside rationing at end of life. She is interested in how the law may (or may not) shape doctors' behavior and the challenges of providing optimal patient care at end of life, despite an increasing climate of scarce resources.



Elise Button

Elise Button is a nurse at the Royal Brisbane and Women's Hospital and a CRE-ELC PhD Candidate. She has over six years' experience as a haematology and bone marrow transplant nurse and has also worked in a specialist palliative care service. Elise's interest in palliative care stemmed from her experiences as a clinician, and witnessing first-hand the positive impact palliative care has on patients and their families. To further her knowledge of palliative care, Elise completed a Graduate Certificate in Palliative Care followed by a Masters of Advanced Practice with Honours. Her PhD is focused on identifying patients with a haematological malignancy at high risk of deteriorating and dying and who are likely to benefit from integration of palliative care.

For further information

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