

Australian Capital Territory and South New South Wales Local Health District End of Life and Palliative Care Research Collaborative

Strategic Plan 2019 - 2023



ACT
Government

**Canberra Health
Services**



Australian
National
University

MEDICAL SCHOOL



Calvary



UNIVERSITY OF
CANBERRA



ACU
AUSTRALIAN CATHOLIC UNIVERSITY

**Capital
Health
Network**
Partnering for better health



phn
SOUTH EASTERN NSW
An Australian Government Initiative

Background

End of life and palliative care research is young in Australia and an area of increasing focus at both a state/territory and national level. Similarly, there is great interest in this area in the Australian Capital Territory (ACT) and South New South Wales Local District Health Board area (SNSW LHD). The interest and appetite for such research has also come out of current opportunities to provide quality evidence on which to develop innovative models of care and service delivery in the ACT and SNSW.

This document was developed following a co-design workshop held on 21st February 2019 to ascertain the role of an end of life and palliative care research collaborative in the ACT and SNSW LHD. The workshop had representatives from clinical, research, quality improvement and management, covering the public, private and NGO sector.

The content of the document outlines the strategic priorities that have been identified for the ACT/SNSW End of Life and Palliative Care Research Collaborative (the Collaborative), and highlights the infrastructure needed to build a world class research base in the ACT and SNSW.

Strategic Principle: Create exceptional end of life and palliative care research

The strategic principle for the Collaborative is to create exceptional end of life and palliative care research that can be used both in the ACT and SNSW, with the ability where possible to translate to wider audiences. The Collaborative is keenly interested in applied research and the translation of research to make a difference in clinical practice and improvements in patient and service outcomes.

Supporting Principles

The supporting principles that underpin the work of the Collaborative in leading excellence in this field are:

Collaboration

The Collaborative was developed from a co-designed approach and will encourage and support collaborative research between members as individuals as well as organisations in the ACT and SNSW to undertake research activities that are also co-designed. The Collaborative will also pursue partnerships with other research collaboratives focussed on end of life and palliative care to enable capacity to deliver outcomes of both local and national relevance.

Membership of the Collaborative is inclusive and open to all in the ACT and SNSW who are interested in end of life and palliative care research. This includes researchers, consumers, clinicians, students, academic institutions, primary health care providers, non- government organisations, private institutions, linguists, digital health workforce, finance analysts, and policy makers.

The Collaborative will seek the meaningful engagement of consumers in all aspects of the research process including the promotion of co-design research that is inclusive of consumers and cultural experts.

Leadership

The Collaborative views itself as having a leadership role in the development of research capacity in the ACT and NSW using best practice research methodologies including international benchmarking. It also sees itself as promoting leadership thinking through the sharing of knowledge including conference presentations and publications in major local, national and international forums.

The Collaborative will also lead in the development of a culture that aligns end of life and palliative care research to the maximising wellbeing at end of life.

Access

To achieve excellence, it is necessary for those interested in research to have access to resources including expertise, possible co-researchers, data sources, funding, and updated information on other research activities in the region to avoid duplication. Capacity building activities are also vital to grow research capability.

Translation to practice

The Collaborative will focus on the promotion of applied research and the following translation of research into practice. Research undertaken will be encouraged to align with quality improvement and quality assurance activities of end of life and palliative care services, but also have a focus on the generation of new knowledge and improving outcomes for patients, families and health care practitioners. The Collaborative will encourage all research to consider patient outcomes and incorporate consumers in the design of studies. It will also support researchers to build on current research to test validity and avoid duplication.

Building a strong collaborative

The Collaborative will focus on three key areas over the next 5 years in order to provide a sustainable and effective impact: Building Capability, Developing a Supportive Research Culture and Consumer engagement.

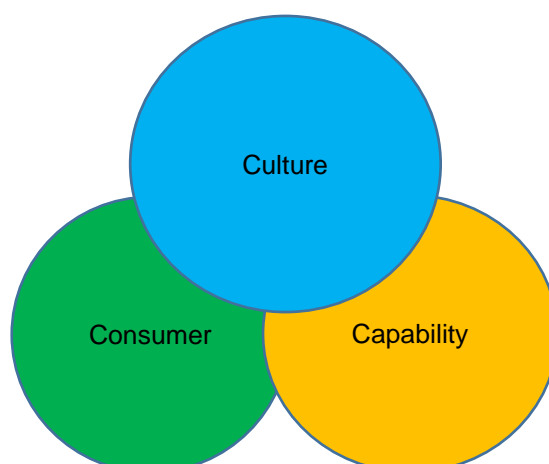


Figure 1: Three key focus areas for the End of Life and Palliative Care Research Collaborative over the next 5 years.

Developing a Research Culture

Our strategic vision articulates the need for a culture that promotes multi-disciplinary collaboration in patient and practice focused research. In order to achieve the culture change and sustainability required to foster a research - intensive culture and embed routine evidence-based practice (EBP), the development of a model which supports clinicians and consumers to understand their contribution to creating and sustaining this environment is necessary.

Involving clinicians and consumers from all areas of health care in the development of this approach will help to foster ownership and engagement. At the basic level everyone will be engaged in the application of research so that research becomes part of the culture and 'just what we do'. The model should indicate increasing levels of research awareness, capability and participation fostered across the workforce so that we have staff engaged and developed up to leadership positions.

Consumer

Based on the principles of co-production as an underpinning of the strategic plan, consumers and carers within the end of life and palliative care field will be active encouraged to be engaged in research development. Traditionally, research has typically been done 'on' consumers and carers, with assumptions that those receiving palliative or end-of-life care would lack capacity to be partners in the research process. However, it has been well-established in other health fields that research co-produced with or led by consumers' benefits from greater relevance, increased reputation, and safer outcomes. A recent systematic review of existing literature about consumer leadership in palliative care research, education, and services found that co-produced and consumer-led approaches are not yet widespread. Thus the collaborative has identified non-tokenistic collaborations with consumers and carers as a strategy to produce impactful, world-leading research.

To ensure that our work in the collaborative is truly co-produced, there are several factors that will need to be considered, including:

- **Early collaboration.** For true co-production to occur, partnerships need to begin as early as possible in the development of research. That is, consumer researchers should be part of the goal-setting of both broader research agendas and specific research projects.
- **Resources.** There are currently no dedicated consumer academic positions within palliative and end-of-life care in universities in Australia. As other researchers and research partners are usually in paid positions, this means that collaborations between consumer researchers and other researchers begin with inequity. The collaborative therefore recognises the importance of seeking research funding and resource supports to ensure that research can be genuinely co-produced with or led by consumer researchers.
- **Collaborative dissemination.** Whenever research has been co-produced with or led by consumer researchers, it is important that the dissemination of that research also involves all research partners. Whilst it may be that consumer research partners

choose not be publically recognised in resultant research it is important that they are given the opportunity for their contributions to be fully acknowledged as would be the case with any other research team member.

Capability

Within the ACT and SNSW LHD opportunities exist to support the development of novice researchers in end of life and palliative care research. The Collaborative, with a membership who have expertise in end of life and palliative care, in conjunction with local universities, health services and consumers can provide support for both new and developing researchers to undertake research based on the priorities areas identified. Clinical academics likewise, can act as role models for evidence-based healthcare whilst being an expert resource for clinical colleagues across the region.

The development of research capability and capacity in medical, nursing and allied health professionals is critical to the success of the Collaborative's ambition. Developing a research culture requires taking steps to cultivate people with research potential while supporting research projects within development framework. The establishment of a workshop and network based structure will assist to build research capacity and capability in the region and is critical to inspire individuals to become research active.