

Project Title	A quantitative study of health care professionals' views and experiences of Paediatric advance care planning
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Lead discipline (please select one)

Nursing and Midwifery

Allied Health

Medicine

Pre-clinical

Health Policy

Health Economics

Biostatistics

Value-based Healthcare

Epidemiology

Other

Outline of the project 250 words max

The National Consensus Statement: Essential Elements for Safe and High-Quality Paediatric End-of-life Care (2016) states that Advance Care Planning in the Paediatric setting is a key component of family centered communication and decision-making. This ongoing process ideally allows children, parents, and interdisciplinary teams across health care settings to work together to reach decisions and provide care in the child's best interests, based on, evidence available, the realities of the child's condition and treatment options, and the child and their parents' choices, values and preferences.

Current evidence suggests emotional challenges, hesitancy and avoidance from families and clinicians alike, can delay important conversations and preparation for future, including end of life, care. Paediatric Advance Care Planning (pACP) conversations can aid parents' understanding and preparation for their child's death and improve access to palliative care options and available supports. Families moving between providers and services or attending for urgent care benefit from a plan that empowers them and avoids the need for them to retell their story.

pACP is different from adult ACP where future health care choices are determined by the person in the event of loss of decision-making capacity. Parents are the decision makers and decisions are dependent on clinicians' guidance and support. These conversations are a recognised component of care, however currently no identified framework, or formal structure to share and build on them, exists.

The significant role of clinicians in pACP is well recognised. The data obtained will inform the development and implementation of a pACP framework.

Proposed research methods

This study will use a quantitative methodology to survey health care professionals involved in caring for children aged 0–18 with life limiting illness on their perceptions and barriers to ACP. This study is based on a recently published study undertaken in NSW by Basu and Swil and will utilise the 25 question online survey that was developed by Basu and Swil, however tailored to the ACT context.



Paediatric Advance
Care Planning - JPCH

Outcome Measures:

The survey is designed to identify current challenges and opportunities for pACP

Research Question:

- To demonstrate perception of, and barriers to initiating and recording pACP conversations among clinicians, parents of children with life-limiting illnesses and if appropriate, the child themselves, to reflect and record wishes about their future health care.
- How these conversations are currently documented and shared across all health care settings.
- would the implementation of a framework to support these conversations improve clinical practice and end of life care?

Preferred study discipline being undertaken by the student

Any discipline

Benefits to the student and to the department

Student:

- Develop research and analysis skills
- Gain an understanding of paediatric advance care planning and palliative care
- Participate in analysis and report writing
- Develop knowledge for further application in clinical settings

Canberra Health Services

- Data collection and analysis of data on advance care planning and the impact it can have on quality of death for paediatric patients and their families
- Recommendations to inform the implementation of an pACP framework

Alignment with Government Research Priorities 100w max

The National Palliative Care Strategy along with the National Palliative Care Standards (PCA) and the Comprehensive Care Standard (NSQHS) are key areas for standards of care, demonstrating government priority for delivering timely, appropriate and compassionate end of life care to paediatric patients across healthcare settings in Australia.

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Department within ACT Health Directorate / Canberra Health Services where the student will be based

Advance Care Planning Service (Cancer and Ambulatory Services)