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**CONFERENCE ABSTRACT****Improving Palliative and End of Life Care on the Central Coast, Australia:  
Results from Two Clinically-Led Mixed-Methods Research Projects**

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Zoi Triandafilidis<sup>1</sup>, Sally Carr<sup>2</sup>, Daneill Davis<sup>2</sup>, Sarah Jeong<sup>3</sup>, Suzanne Lewis<sup>2</sup>, Thomas Osborne<sup>2</sup>, Nick Goodwin<sup>1</sup>

1: Central Coast Research Institute for Integrated Care, Gosford, New South Wales, Australia

2: Central Coast Local Health District, Gosford, New South Wales, Australia

3: University of Sydney, Sydney, New South Wales, Australia

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In 2019, New South Wales Regional Health Partners commissioned the Central Coast Local Health District to undertake clinician-driven research that would lead to the implementation of new service models designed to improve palliative and end-of-life care to the Central Coast community.

During 2020, a series of five stakeholder workshops with clinicians, healthcare managers, consumers and other local stakeholders involved in palliative and end of life care led to the development of two translational research projects: palliative and end of life care for people with advanced dementia; and the experiences of people who access emergency care towards the end of life. The subsequent clinically-led research programs were undertaken between January 2021 and September 2022. In this presentation, we discuss the results of these two mixed-methods research projects.

To understand the patient journey, both projects undertook audits. For people who died with dementia, a retrospective case notes audit of 705 people who died between January 2015 and December 2019 found half died in public hospitals, and the other half in other settings. Less than one in five patients dying in public hospitals had an advanced care directive recorded, and fewer than one in 13 had an advanced care plan. The second audit of 1730 Central Coast residents who died between August 2020 and July 2021 found nearly half had 1 (45%) emergency department presentation in the 90 days before their death, and more than one in four had 2 presentations. There was a significant difference in the number of emergency department presentations and hospital admissions when comparing patient age and place of death.

Across both projects, a total of 303 bereaved carers completed a postal survey. Respondents reported high levels of satisfaction with end of life care across settings. Most people receiving care were always treated with respect and dignity. Pain was managed best in hospital, compared to residential aged care and home settings. Less than half of carers said the person cared for had enough choice about where they died, but on balance, more than four in five said the person died in the right place.

Thematic analysis of 19 in-depth interviews with bereaved carers found three themes were common across projects: 1) There is a lack of acknowledgement of end of life, and discussions about death usually happen in the final days; 2) Services and supports are complex and fragmented,

knowledge is needed to navigate them and experiences vary; and 3) End of life caring is challenging and there is limited support for carers to care.

Drawing on previous evidence that was presented during ICIC22, we examine the lessons learned from these research projects on the importance of clinically-led research and how this is translating into the implementation of an integrated model of end of life care on the Central Coast. Key lessons for international colleagues from this research are considered.