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**Summary report:**

**Results of pilot of end-of-life  
care audit and survey tools**

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## Introduction

The kind of health care that people receive in the last years, months and weeks of their lives can help minimise the distress and grief associated with death and dying for the individual, and their family, friends and carers. The majority of Australians would prefer to die at home,<sup>1</sup> yet more than half of those who die each year do so in acute hospitals.<sup>2</sup>

However, acute hospitals are often focused on diagnosis and treatment with a view to cure and discharge of the patient.<sup>3</sup> Because of this focus, recognition that a patient may be approaching the end of their life and in need of interventions – such as conversations about their goals of care, limitations on acute treatment, a palliative approach to care, or provision of terminal care – can be delayed. This delay can result in a level of care and communication that contributes to less than optimal end-of-life care.

As a means of improving care at the end of life, in 2015 the Australian Commission on Safety and Quality in Health Care (the Commission) developed a *National consensus statement: essential elements for safe and high-quality end-of-life care* (Consensus Statement).<sup>4</sup> The Consensus Statement sets out suggested practice for end-of-life care in settings where acute care is provided and focuses on core processes of care and organisational prerequisites for delivering high-quality end-of-life care. One of the elements within the Consensus Statement relates to evaluation, audit and feedback.

## Using data to understand how end-of-life care is delivered

The collection and use of data as a means of understanding how care is delivered within a hospital, and where improvements can be made, is essential for the delivery of high-quality end-of-life care. Current data on how end-of-life care is delivered in Australia is lacking, and there are few tools available to measure practice in this area for either research or local quality improvement purposes. There is some historical data reviewing end-of-life care both nationally<sup>5</sup> and internationally, but data collection tools are inconsistent,<sup>6</sup> and tools for local review and improvement are limited.<sup>7</sup>

The Commission, in partnership with Australian National University and the Canberra Hospital, modified and further developed an audit tool<sup>8</sup> to help hospitals examine the quality of their end-of-life care, and a survey of clinicians to help better understand the perceptions of clinicians about end-of-life care.

This short report summarises the process the Australian National University and the Canberra Hospital undertook in partnership with the Commission to pilot these tools.

## The audit tool

The audit tool was developed to give hospitals the ability to compile data in a manageable and uniform way. Having the capacity to collect and analyse this data allows hospitals to review how care is being delivered and identify opportunities for better alignment with the Consensus Statement, and improvement in general.

The audit tool supports collection of data to provide a picture of current end-of-life processes within a hospital, and includes demographic data, details on admission, location of care and death, prior admission patterns, documented preferences for end-of-life care, identified decision makers, evidence of resuscitation or escalation of care, and evidence of palliative care.

Data is manually extracted from individual records of patients who have died in the hospital, and entered into the audit tool. For the pilot study, the patients were selected chronologically during the study period, and the data was anonymised before being entered into the tool. The audit tool was developed to be used online, and data entered into the tool is aggregated into a single spreadsheet for analysis and review.

## The survey of clinicians

One of the challenges in implementing safe and high-quality end-of-life care is supporting and equipping clinicians to confidently deliver care that meets the needs and preferences of the patient at the end of life.

Clinicians are at the forefront of decision making, so understanding their views and perspectives is critical in informing the education, support and strategies required to improve end-of-life care.

The survey was designed to capture the views of clinicians about the quality of end-of-life care within their hospital. The survey was intended to be used in conjunction with the audit tool, and the data from both can be used comparatively to evaluate whether perceptions of care differ from the level of actual care provided.

The survey can be delivered both online and in hard copy to participants. Data is entered into an online data collection tool which produces a single spreadsheet for analysis.

## The pilot study

The primary objective of the pilot study was to undertake initial testing of the audit tool and survey to determine usability and reliability. A secondary objective of the pilot study was to provide data on the patterns of care for patients at the end of life within the Canberra Hospital, and perceptions of clinicians of that care.

A single investigator reviewed the records of 200 adult patients who died between 15 August and 31 December 2014 at the Canberra Hospital, and extracted and entered the relevant anonymised data into the audit tool. Patients who died in the emergency department or who were under 18 years old were excluded. In addition, 528 clinicians participated in the survey, including 54 consultants, 117 junior medical officers and 287 nurses.

## Study findings: Usability and reliability of the tools

### Survey

Prior to the distribution of the survey of clinicians, three consultants, four junior medical officers and five nurses critiqued the relevant survey tool. Feedback was provided to the survey designer and adjustments were made until there was a unanimous acceptance of the survey.

The survey was distributed and promoted from 7 October 2015 to 30 November 2015 via multiple open meetings, email distribution lists, personalised emails, and relevant committee meetings. Survey response rates were relatively low amongst consultants, junior medical officers and nurses (11%, 22% and 12% respectively). However, the data received from the survey provides good context on current perceptions of end-of-life care.

The reliability of the survey for each group of clinicians was assessed individually, and then assessed together to ensure the internal consistency of the tool and participant responses. This assessment indicated an acceptable level of reliability for each survey.

### Audit tool

The investigator who undertook the review, extraction and entry of audit data reported that the audit tool enabled easy collation of key data in an effective manner. The investigator found that once entered, the data was then easily exported into a spreadsheet for analysis.

Some of the issues the investigator reported with this process included the length of time required to manually enter the data, the clarification of specifications for some fields and the ordering of some of the fields.

The study investigators were able to use the audit tool and survey with ease, and the data produced from both provided a robust picture of the current end-of-life care provided by the Canberra Hospital that would be compared with the perceptions of the clinicians providing the care.

## Study findings: End-of-life care in the Canberra Hospital

### Audit findings

The median age of the 200 patients included in the audit was 77 years, with 44% being 80 years or over. Almost all of the patients who died had one or more co-morbidities (91%), with the most common co-morbidities being congestive cardiac failure (33%), chronic pulmonary disease (24%) or malignancy (22%). The average length of stay for patients was eight days.

Most patients were admitted from their home (82%), with the remaining 18% being admitted from a residential aged-care facility. Nearly half of the patients (45%) had an acute hospitalisation within the three months prior to their final admission, with the reason for the final admission being an acute exacerbation of a medical condition in 77% of patients. Table 1 outlines the key demographics for patients included in the audit.

**Table 1: Patient demographic and admission details**

	<b>Number (%)</b>
<b>Total patients</b>	200
<b>Sex (male)</b>	114 (57%)
<b>Age, years, median</b>	77 (65-85)
<b>Age group (years)</b>	
<b>18-59</b>	29 (15%)
<b>60-69</b>	36 (18%)
<b>70-79</b>	47 (24%)
<b>80-89</b>	64 (32%)
<b>≥ 90</b>	24 (12%)
<b>Admission source</b>	
<b>Home</b>	164 (82%)
<b>Residential aged care facility</b>	36 (18%)
<b>Admission type</b>	
<b>Medical unit</b>	<b>157 (79%)</b>
<b>Elective</b>	4 (2%)
<b>Emergency</b>	153 (77%)
<b>Surgical unit</b>	<b>43 (22%)</b>
<b>Elective</b>	6 (3%)
<b>Emergency</b>	37 (19%)

Table 2 outlines the total number of clinicians working at the Canberra Hospital and the number who completed the survey by profession. The highest response was from junior medical officers (22%), with senior medical officers and nurses at a lower rate of 11-12%.

**Table 2: Health care professional survey participants by profession**

	Senior medical officers	Junior medical officers	Nurses
<b>Number</b>	54	117	287
<b>Total</b>	473*	596*	2766*
<b>Response rate</b>	11%	22%	12%

\* Clinicians who worked predominantly in the emergency department or paediatrics were excluded.

## Recognising dying

A fundamental first step in providing safe and high-quality end-of-life care is to recognise those patients who would be likely to benefit from such care. The Consensus Statement specifies that recognition systems in acute health services should aim to identify patients at two critical points:

- when they are likely to die in the medium term (i.e. within the next 12 months) but episodes of acute clinical deterioration may be reversible
- when they are likely to die in the short term (i.e. within days or weeks, or during the current admission) and clinical deterioration is likely to be irreversible.

The audit showed the presence of documentation indicating communication with the family or substitute decision maker that the patient was dying in 98% of cases; however, only around 50% of cases indicated communication about dying with the patient. In addition, 26% of all of these documented discussions occurred on the day of death.

The majority of clinicians agreed or strongly agreed they were confident at recognising dying (consultants 96%, junior medical officers 81% and nurses 86%). When evaluating junior medical officers, only 46% of consultants and 47% of nurses agreed or strongly agreed that they were skilled in recognising dying. A similar number of consultants (46%) agreed or strongly agreed regarding the abilities of nurses.

## Advance care and resuscitation plans

The Consensus Statement outlines the importance of having processes in place to support proactive, anticipatory and individualised planning for end-of-life care. Patients who are likely to die within the short or medium term should be informed about the process and purpose of advance care planning, and be asked if they would like to instigate or revisit their advance care plan.

The study data indicated that 11% of the patients reviewed had a pre-admission written advance care plan in their medical record.

During the hospital admission a 'not for resuscitation' (NFR) order was documented for 95% patients, on average five days prior to death. Of these NFR orders 18% were



documented on the day of death. According to the patient records all NFR orders were communicated to either the patient, family or substitute decision maker.

In 43% of cases a doctor from either the intensive care unit or rapid response team documented and communicated the NFR order, rather than the treating clinician. The survey data showed that clinicians disagreed in their perceptions about who documented the majority of NFR orders. Consultants and nurses reported it was the advanced trainee (49% and 29% respectively), while junior medical officers reported it was the junior registrar (53%).

## Palliative care plans

The existence of a palliative care plan suggests that clinicians have recognised that a patient is nearing the end of life, and implies consideration is being given to the type of care the patient wishes to receive at that time.

Eighty per cent of patients audited had a documented palliative care plan. However, 65% of these plans were documented in the 48 hours prior to the patient's death.

The majority of junior medical officers (74%) and nurses (66%) agreed or strongly agreed that they would like to call palliative care earlier when caring for dying patients. However, 67% of consultants agreed or strongly agreed that the palliative care team was consulted appropriately.

## Life-sustaining medical treatments

Unnecessary burdens and medical interventions can cause further distress to the patient and their families. The Consensus Statement specifies that non-beneficial or unwanted observations or investigations should be avoided for dying patients.

The audit showed that over a third (40%) of patients were admitted to intensive care before they died, and 25% of patients were still receiving active treatment at the time of death. Patients were exposed to a range of acute interventions during their final 48 hours of life, including blood tests (57%), medical imaging (44%) and treatment with antimicrobials (42%).

The survey indicated that clinicians differed in their perception of the timeliness of withdrawal of acute treatments. Seventy per cent of consultants thought this occurred 'usually' or 'always', while only half of junior medical officers and nurses agreed.

## Overall view of end-of-life care

Seventy-two per cent of consultants agreed that they would feel confident that good-quality care would be delivered by their ward if they had a dying relative in hospital. However, when asked the same question, only 63% of nurses and 53% of junior medical officers agreed.

## Study conclusion

The data from the audit and clinician survey demonstrated that a significant proportion of dying patients in the Canberra Hospital did not appear to have end-of-life care that was consistent with the Consensus Statement. In addition, the survey data indicated a lack of confidence amongst some clinicians about how end-of-life care was being delivered.

This pilot study demonstrated the usability and reliability of the audit tool and survey in a single site. The audit tool was easy to use, and the data provided from it contributed to the Canberra Hospital's understanding of where to target improvement activity to support high-quality end of life care. For example, the Canberra Hospital was able to use the data from the audit tool and survey to inform implementation of a robust resuscitation form.

The survey provided useful insight into the perceptions and concerns of clinicians. While uptake on the survey was relatively low among clinicians, the introduction of implementation strategies could help hospitals to increase response rates and improve the robustness of their survey data.

The audit tool and survey were easy to understand and use, and can be used by hospitals to help them to better understand how end-of-life care is delivered in their service, the perceptions of clinicians about end-of-life care delivery, and how to better align care with the Consensus Statement.

There are a number of factors that need to be considered when interpreting the findings of this pilot study:

- The study was undertaken in one large tertiary teaching hospital using a small number of records for patients that had died in the hospital; therefore, the generalisability of the findings is not clear.
- There was a low participation rate for the survey, which may affect the findings.
- Transferring data from hospital records to the audit tool involves a level of subjective interpretation.
- Perspectives of patients and families were not included in the study.
- Paediatric patients and those dying in the emergency department were excluded.

## Next steps

Building on the findings of this pilot, in 2016–17 the Commission will undertake a validation process for the audit tool and survey. This validation process will involve testing the tools with nine hospitals including public and private facilities located in metropolitan and regional areas across five states and territories. This will ensure the tools are relevant, usable and reliable for a range of different types of hospitals.

This validation process will inform any final revisions and refinement to the audit tool and survey. The tools will then be released publicly, and form the basis of a suite of resources to be used across Australia for quality improvement in end-of-life care.

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