Breaking down advance care planning barriers to improve patient choice

Advance care planning encourages consumers to consider and document preferences for their future healthcare before such decisions need to be made. This can give them increased choice and control over their end-of-life decisions and prevent unwanted and potentially distressing medical treatment and hospitalisation. To improve their accessibility and use, Bendigo Health, Monash University and Murray Primary Health Network collaborated to identify and address barriers to the uptake and communication of Advance Care Plans in regional and rural Victoria.

## Background

Advance care planning is an important process where a consumer consults with their family and healthcare providers to communicate their values, beliefs and preferences in relation to their future medical treatment. These preferences, which can be documented in an Advance Care Plan (ACP), can then guide clinical decision-making if the consumer is unable to make or communicate their decisions themselves.

ACPs have been shown to improve end-of-life care, increase patient and family satisfaction with healthcare, and reduce anxiety, stress and depression in surviving relatives of patients who have died.

Yet only 14 per cent of Australians have an ACP in place, suggesting that much of the information needed to provide person-centred end-of-life care is not available.

Through their Better Care Victoria Innovation Fund project, Bendigo Health, Monash University and Murray Primary Health Network (the project team) aimed to identify and address barriers to the uptake and development of ACPs in primary healthcare services and enhance the communication of these plans to acute hospital settings.

By doing this, the project team sought to increase the number of ACP preferences fulfilled and improve the quality of care at the end of a patient’s life.

Advance Care Plans across the health system in rural Victoria

**Leads** Bendigo Health, Monash University, Murray Primary Health Network

**Partner** Bendigo Primary Care Centre

**Duration** September 2017 – January 2019

**Key outcomes**

* Identified system challenges, societal attitudes to death and dying, and the unique relationship between patients and their long-term rural healthcare providers as barriers to ACP development and communication
* Measurably improved healthcare professionals’ advance care planning knowledge through targeted education
* Developed a new advance care planning protocol and guidelines, and a secure and direct communications strategy based on feedback from health professionals and the community
* Within six months, saw a 52 per cent increase in the average number of ACPs received per month at Bendigo Health for patients aged 75 and over, which, while unconfirmed, is likely due to project activities

## Key activity

* Conducted three medical record audits of people aged 75 years and over who had died in hospital from January 2016 to December 2017 (the decedents) to determine:
  + how many had an advance care planning alert and/or document in their hospital record
  + how many who did not have an advance care planning alert in their hospital record had advance care planning documents in their general practice records that had not been communicated to the hospital
  + how many who had an ACP in their hospital record and who had lost their decision-making capacity upon hospital admission had their place of death preferences fulfilled. This information was used to analyse the costs of ACP development and unwanted hospitalisation.
* Interviewed key stakeholders to understand their views on advance care planning and any barriers to the communication of ACPs between primary healthcare services and Bendigo Health or other acute hospitals.
* Delivered targeted advance care planning education for health professionals throughout the project, including:
  + online training through Advance Care Planning Australia
  + a one-day workshop at Bendigo Health
  + individual or group mentoring and/or organisational support with form development and policy design.



## Outcomes

### Perceptions and barriers

Based on semi-structured, qualitative interviews with 12 participants, including hospital staff, private practice staff and consumer representatives, the project team identified three themes influencing ACP development and communication:

* **Necessity of plan creation –** For various reasons, many interviewees did not believe an ACP needed to be created. For example, one commented that due to the long-term relationships that rural/regional healthcare providers have with their patients, they are already aware of their patients’ needs – including their end-of-life preferences – so there is no need to document them in an ACP. Some interviewees also expressed an expectation that patients receiving certain types of care, such as palliative of hospice care, would already have a completed ACP.
* **Attitudes surrounding death and dying –** Healthcare professionals’ attitudes towards end-of-life care and cultural considerations were reported to be barriers to ACP development. For example, some cultural groups may consider it inappropriate for a healthcare professional to insist they provide written documentation of their end-of-life preferences.
* **System challenges to communication between health services –** Interviewees said the advance care planning process was unclear and the use of multiple information technology systems added to the complication. They also expressed logistical concerns, such as the lack of a clear pathway from advance care planning document creation through to medical record storage, and the transfer of documents across the multiple health services a patient may use.

### Enhanced communication

Using the audit and interview findings, the project team developed strategies to improve the uptake and communication of advance care planning:

* **Education –** The aforementioned targeted education program included seven one-day workshops with a total of 70 attendees, 80 per cent of whom were based in general practice. Pre- and post-workshops surveys showed an overall improvement in participants’ knowledge of advance care planning.
* **Guidelines and protocol –** The project team developed advance care planning guidelines for primary healthcare staff and, based on feedback, also created an accompanying one-page ACP protocol that could be used by both general practitioners and practice nurses.
* **Communication strategy –** After extensive consultation, the project team developed a new, secure system that allowed primary healthcare staff to directly and electronically send ACPs to Bendigo Health’s advance care planning office. This has resulted in the electronic storage of all advance care planning documents at Bendigo Health.
* **Feedback and knowledge share –** Participating general practices were given individualised feedback and education based on their clinics’ results to help facilitate better communication of ACPs. Project findings were also shared with Bendigo Health staff and aspects of the study were submitted for publication in peer-reviewed journals to enable broader dissemination of the project’s learnings.

The average number of ACPs Bendigo Health received per month for patients aged 75 and over increased by 52 per cent within six months of completing an initial 2016–17 baseline audit. The number of patients in this age demographic with a new advance care planning alert on their hospital record also increased by 31 per cent.

A causal relationship between the project and these outcomes could not be confirmed. However, it is likely the increased confidence and knowledge of advance care planning in primary healthcare services that resulted from the project team’s education and revised communication strategy contributed positively towards these results.

‘Advance care planning is now discussed with patients during [75 years and older] health assessments, GP management plan and team care arrangement appointments.’

**– Primary healthcare staff member**

### Cost savings

Auditing identified four decedents who had an ACP in their hospital record that listed ‘home’ as their preferred place of death. The four decedents spent a combined 52 days in hospital, and all had lost their decision-making capacity by the time of admission.

A cost analysis conservatively estimated that more than $38,000 in healthcare system costs could have been saved if the ACP preferences of these decedents had been followed and they had died in their home or residential aged care facility instead of being hospitalised.

## Key learnings

* While community conversations about death and dying are increasing, they are not yet mainstream.
* Research on ACP content and implementation is in its infancy, and healthcare professionals require further education and support to help them understand the value and application of ACPs.
* Clinical and health service leadership is critical to enabling innovation in advance care planning improvements.
* Health service providers seeking change need to understand their business environment and their partners’ financial, policy and practice drivers.
* Health services’ use of multiple information and communication technology systems can complicate the advance care planning process and be a barrier to communication of ACPs.