Tasmanian research captures national policy attention

Tasmanian research surrounding a potential model for people to electronically store their personal preferences for treatment and care has captured national policy attention.

UTAS Rural Clinical School (Burnie) researchers Professor Isabelle Ellis (chief investigator), Linda Jaffray and Cathy Smith have spent the past 18 months looking at what is known about electronic advance care planning in the community, especially for older people with chronic, life-limiting illness.

The researchers’ focus has been to start putting the patient and their values at the centre of the decision making process, with an aim to engage them in the advance care planning process long before they become seriously ill or face transition to an acute care or residential aged care facility.

Their work has gained national attention.

Following multiple conference presentations, the most recent being Linda’s presentation at the 12th Australian Palliative Care Conference, the research team was then invited to help inform the National Development of Advance Care Directives on the Personally Controlled Electronic Health Record (PCEHR).

“Currently there are multiple barriers to people engaging in this type of health care planning,” co-researcher Linda Jaffray said.

“We plan for our funerals, our wills, our finances, but we don’t plan for our end-of-life.”

The Australian Government launched the personally controlled electronic health (eHealth) record system last year.

“Aspects such as what care we would like, preferences for treatment, what we want to happen and what not to happen are not addressed, especially in an electronic format.

“Patients might have had conversations about their wishes, or written down some aspects of their future care – but nothing really formally exists in an electronic format.”
Mrs Jaffray presented her research abstract at the Conference, which also earned her the Ian Maddocks Guest Lecture award.

“We have looked at the literature and met with stakeholders which have led us to develop the Dignity of Life Inventory Model,” Mrs Jaffray said.

“The model addresses the electronic advanced care planning needs of older, community dwelling people with life-limiting illnesses.

“This type of engagement does not happen in a vacuum: it has to happen in discussion and communication with a range of individuals who are central to a person’s future health care needs, or wishes, as this case may be.”

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