Incorporating advance care plans into the new Personally Controlled Electronic Health Record

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Background
As life expectancy increases so do the number of older people living with advanced life-limiting chronic illness. Advances in medical technology have greatly extended medicine’s ability to prolong life through artificial or mechanical means. There is also an increasing awareness and debate around people having the right to choose what health care and in what environment, including the level of aggressiveness of treatment and care they receive when dying. Recent research indicates that for many, their individual preferences are at odds with the healthcare models available to them, resulting in people dying in greater distress, increased carer distress, increased bereavement problems and increased health provider stress (1-4). A proposed approach to communicating these wishes has been to include them in the Personally Controlled Electronic Health Record (PCEHR) (5, 6).

One approach to ensure that individual’s treatment wishes and preferences are respected is to help them to develop an Advance Care Plan. This document, which is completed by a person whilst legally competent to do so, communicates their preferences and choices for treatment or life sustaining interventions to be initiated, should their condition deteriorate such that death is imminent. It also provides details of enduring guardianship.

Aim
Whilst research continues into the development of electronic Advance Care Plans in the palliative care setting and residential aged care setting, there is a need to understand the relevance and practicality of developing an electronic Advance Care Plan (eACP) for use by older people living with life-limiting chronic illnesses in the community.

Methods
A systematic review was conducted into models of electronic Advance Care Planning for older people living in the community. An electronic database PICO search using MESH terms and key words was conducted. Key words included: advance, chronic illness, life-limiting, terminal, old, elderly, community-dwelling, primary care, advance care, directives, plan, enduring guardian, attorney, model, electronic record, plan, satisfaction, support, care. Databases searched were: Cochrane, Pubmed, CINAHL, ProQuest, Psychinfo, Embase, Google & Google Scholar.

Results
Seventy one papers resulted from the search strategy with seventeen papers selected for review. Of these 17 papers, only one paper provided evidence of models of electronic advance care planning for community dwelling older people. This paper by Yung, Walling, Min et al (2010) was a mixed method study involving 811 participants and their medical records. These participants were a community sample of older adults drawn from two previous studies titled ACOVE I and ACOVE II. Ninety five per cent of all participants had medical records retrieved. The aim of this study was to assess the flow of advance care planning information from patients to their medical record. Patient interview data was compared to medical record documentation from a range of settings such as health care provider offices, hospital care records, emergency department care records and outpatient care records to determine preference for end-of-life care being present in the medical record for patients who noted specific preferences at interview. Fifty four percent of participants reported giving their health provider a copy of their advance care directive. However, only 19% of participants had any preference documented in their medical record, and only 42% of these participants had any information about enduring guardianship recorded in their medical record. The authors concluded that translation of
patients’ end-of-life preferences and information on enduring guardianship into documentation is poor. The authors recommend that a structured approach to documenting patients’ preferences could reduce these problems (7).

**Conclusion**

As the PCEHR rolls out across Australia and is being generated by General Practitioners and others working in the primary care sector, the proposed inclusion of the electronic Advance Care Plan requires careful consideration.

**Recommendations**

Any model for advance care planning for community dwelling older adults particularly those with life-limiting chronic illnesses must incorporate structured electronic documentation that can be shared across the continuum of care. Health providers in all settings need to be educated and confident to conduct conversations to identify patients’ preferences and to assist in developing and modifying advance care plans. Further research is needed to identify effective models of advance care planning and how the documents generated are best communicated across the continuum of care ensuring relevant information is available at the point of care.

**References**


