



Australian
College of
Nursing

Voice of influence

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To whom it may concern

Re: Inclusion of Advance Care information in the Personally Controlled Electronic Health Record (PCEHR)

Thank you for contacting Australian College of Nursing (ACN) seeking our feedback on the proposed inclusion of Advance Care information within the PCEHR. As a key professional nursing organisation, Australian College of Nursing (ACN) welcomes the opportunity to provide feedback.

ACN supports the inclusion of Advance Care documents on the PCEHR. In particular, it is ACN's view that the uploading of an Advance Care Directive on the PCEHR has great potential to improve quality of end-of-life care for many individuals. However, ACN believes that the PCEHR should include verification that the Advance Care documents reflect individuals' wishes for end-of-life care and are current. This information would increase health care professionals' confidence and support for the inclusion of the documents.

Please see the attached document for ACN's responses to the questions posed in the consultation paper.

Please do not hesitate to contact me for further information or discussion on this matter.

Yours sincerely

Adjunct Professor Debra Thoms FACN (DLF)
Chief Executive Officer

6 December 2013

**Feedback on the inclusion of Advance Care information within the PCEHR
Australian College of Nursing (ACN)
December 2013**

We welcome the opportunity to respond to the Department of Health's Advance Care project and consulted with our members regarding the six questions included in the Department's consultation document.

ACN would like to make following observations in response to the Department's questions:

1. From your perspective, would having a copy of an Advance Care Directive stored on the PCEHR be beneficial?

ACN supports having a copy of the Advance Care Directive stored on the PCEHR. Whether a person who is cognitively impaired and/or unable to communicate wishes to receive life-saving treatment is often difficult to determine for health care professionals, particularly in an emergency. Having access to documents that clearly state individuals' preferences would resolve uncertainty about treatment goals and thus improve the quality of care given to individuals.

The effectiveness of storing an Advanced Care Directive on the PCEHR would be greatly enhanced if the jurisdictions introduced legislation governing Advanced Care Directives that makes such directives operable nationally.

2. What would be your greatest challenge in using an Advance Care document uploaded to a PCEHR or in uploading an Advance Care document to a PCEHR?

For health care professionals using Advance Care documents stored on the PCEHR, a great challenge would be confirming that the uploaded documents are the most recent version. This issue is of great importance if the individual requiring treatment is unable to communicate at the time of the medical emergency. Instituting an annual review of the Advance Care documents that are recorded on the PCEHR may alleviate health care professionals' uncertainty as to the currency of the documents.

For individuals unable to communicate, a further challenge for health professionals may be gaining certainty that the uploaded Advance Care Directive actually represents the individual's wishes. A statement by a witness outlining the discussion that took place prior to signing the Directive may dispel health care providers' concerns. The paper-based documents currently in use pose the same challenges for health care providers.

Individuals may encounter a number of technical barriers to uploading an Advance Care document on their PCEHR such as: lack of access to a scanner to produce a PDF, lack of access to a computer or to the internet and lack of computer skills. Individuals with severe physical disabilities or cognitive impairment will also experience difficulties with uploading Advance Care documents.

3. Consumers can currently nominate representatives to help manage their eHealth Record such as a son, neighbour, or trusted friend. If the consumer allows these representatives to record information on their eHealth Record, should these representatives also be able to upload an Advance Care Directive on behalf of the consumer?

In ACN's view, the most important aspect of an Advance Care Directive is that it accurately represents the wishes and interests of the individual to whom it applies. In order to safeguard the individual's interests, ACN would prefer that any person helping with the uploading of an Advance Care Directive also hold an Enduring Power of Attorney that empowers the attorney to make health related decisions.

4. Is there additional information relating to a consumer's Advance Care wishes that should be stored within the PCEHR system?

Additional information that could be stored within the PCEHR may include documentation such as Enduring Power of Attorney, Guardianship documents, and Refusal of Medical Treatment Certificate (valid in Victoria only). Further, the Advance Care data base on the PCEHR should identify any

circumstances under which the Advance Care Directive should be temporarily suspended and the conditions under which the directive should be reinstated. Additionally, the individual's full medical records should be available with the Advance Care information on the PCEHR.

5. From your perspective, what supporting communications information (e.g. Fact Sheets) may need to be developed to guide consumers and/or providers with the PCEHR Advance Care planning process? Is there any material that you are aware of that could be leveraged in support of this initiative?

Health care providers should not be assumed to have a good understanding of Advance Care planning and accompanying documentation. As providers will be a key source of information about Advance Care to the public, providers should be targeted with education campaigns about the formulation, access to and use of Advance Care documents.

Information on Advance Care planning targeting the general public should be easy to find, easy to use and easy to understand. Resources informing the formulation and use of Advance Care documents should also meet the communication needs of individuals who are illiterate, who are vision impaired, do not have access to the internet and are not fluent in English. This information should point out the importance of including next of kin or other significant others in the process of Advance Care planning. How an Advance Care Directive affects significant others' ability to influence medical decision-making about the patient's care in an emergency should also be discussed.

Many resources addressing Advance Care planning have been developed. Inserted below is a list of resources identified by ACN members that support Advanced Care planning:

1. Office of the Public Advocate for the following states
 - o VIC – www.publicadvocate.vic.gov.au
 - o QLD - <http://www.justice.qld.gov.au/justice-services/guardianship/public-advocate>
 - o SA - www.opa.sa.gov.au
 - o WA – www.publicadvocate.wa.gov.au
 - o ACT – www.publicadvocate.act.gov.au
2. RACGP Advance Care Planning - www.racgp.org.au/your-practice
3. Advance Care Planning Australia - <http://advancecareplanning.org.au/>
4. Advance Care Planning (VIC) - <http://www.health.vic.gov.au/acp/>
5. Alzheimer's Australia - <http://www.fightdementia.org.au/>
 - o Publications
 - o Help sheets
6. Austin Health – Respecting Patient Choices Program - <http://www.austin.org.au/page/449>
7. ACT Health – Respecting patient choices & Advance care planning - <http://health.act.gov.au/consumer-information/respecting-patient-choices>
8. Caresearch - <http://www.caresearch.com.au/caresearch/Default.aspx>

6. Are there any specific demographic groups or geographic areas that should be targeted for early adoption?

A specific demographic group that could be targeted for early adoption is the population residing in aged care facilities. Geographic areas that may be targeted are those with a relatively high proportion of people of older age, such as coastal areas popular with retirees.

ACN suggests that individuals with specific conditions may also constitute groups suitable for early adoption. For example, individuals with mild cognitive impairment and dementia in early stages with full decision-making capacity may benefit from early adoption. Further, people living with chronic and complex conditions who are moving to the terminal phase of their illness trajectory may also be suitable early adopters.