



23<sup>rd</sup> June 2015

PCEHR / HI Discussion Paper Feedback  
Department of Health

Email: [ehealth.legislation@health.gov.au](mailto:ehealth.legislation@health.gov.au)

Thank you for the opportunity to respond to the *Electronic Health Records and Healthcare Identifiers: Legislation Discussion Paper*.

Palliative Care Australia (PCA) is the peak national body for palliative care, representing all those who work towards high quality palliative care for all Australians. Working closely with consumers, our Member Organisations, and the palliative care workforce, we aim to improve access to, and promote the need for, palliative care.

PCA welcome the continued focus on the delivery of an electronic health record for all Australians and support the proposed changes to the Personally Controlled Electronic Health Record (PCEHR) system and Health Identifiers (HI) Service, as described in the discussion paper. PCA is supportive of a consistent E- Health record system for all Australians and believe that these changes ought to lead to greater clinician use of the system in order to support meaningful decision making.

In relation to **participation** PCA support the trials of different participation arrangements. Ultimately an opt-out arrangement for the 'My Health Record' will help to ensure access to relevant and accurate information in a timely manner.

PCA also support the clarification of the term 'healthcare' in the PCEHR Act and HI Service Act to explicitly include palliative care services. This qualification is in line with the Privacy Commissioner's views and ensures that services, such as palliative care services provided in the community, can fall within the definition of a 'healthcare provider organisation'.

PCA also strongly support the establishment of the Australian Commission for Electronic Health (ACeH) which will ensure the appropriate skills contribute to the governance and accountability arrangements.

PCA also support the development of advisory committees to the ACeH and as a matter of urgency PCA call for the immediate convening of an advisory committee to discern a way forward that allows the uploading of Advance Care Directives and Advance Care Plans to the 'My Health Record'. This

remains an unresolved area of contention within the health sector and needs to be resolved in order to ensure that the 'My Health Record' can provide timely access to relevant information that will assist in the delivery of care. It is vital that these documents can be uploaded and accessed quickly.

Advance care planning is a process which can help you plan your medical care in advance so if you become too unwell to make decisions for yourself, your wishes can still be respected by your healthcare team, your family and carers. It is not only important for people receiving palliative care to have completed an advance care plan or identified a substitute decision maker to make decisions on their behalf, it is increasingly important for everyone to think about their own healthcare needs and discuss them with others. There is an increasing awareness of the value in advance care planning and identification of substitute decision makers and it is PCAs view that the 'My Health Record' system must be able to identify and store these types of documents in order to ensure all Australians receive the care that they would want.

Under NEHTA there was little progress made in developing consensus with the expected users of the system as to what form(s) advance care documents could take. It is recommended that an ACeH Advance Care Planning advisory committee also address this issue regarding what current forms of advance care plans and directives exist, and identify what elements of these documents (for example goals of care) are most critical to be accessed by those delivering care, particularly in an emergency situation.

There are other issues in relation to the 'My Health Record' that PCA would like addressed (such as after-hours support for community based palliative care recipients then subsequent documentation in the 'My Health Record'), however they are not relevant to the call for comment on the *Electronic Health Records and Healthcare Identifiers: Legislation Discussion Paper*.

Thank you again for the opportunity to provide comment. PCA would be happy to elaborate on any of these points made, and would be willing to assist the Department of Health in further understanding the importance of advance care planning as well as the current diversity in approaches to advance care planning across the country. I am contactable via email: [liz@palliativecare.org.au](mailto:liz@palliativecare.org.au) or phone: 6232 4433.

Yours Sincerely



**Liz Callaghan**

CEO

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