



PCEHR/HI Discussion Paper Feedback
Department of Health
MDP 1003
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**Re: Carers Australia Submission to the Electronic Health Records and Healthcare Identifiers:
Legislation Discussion Paper**

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with disability, chronic condition, mental illness or disorder, drug or alcohol problem, terminal illness or who are frail aged.

Carers Australia welcomes the opportunity to provide input to the Electronic Health Records and Healthcare Identifiers: Legislation Discussion Paper (June 2015). While our recommendations are not directly related to the legislation discussion paper, we would like to use the opportunity to identify improvements to the Personally Controlled Electronic Health Record (PCEHR) that would improve responsiveness to patient needs and, which we believe, will improve the functionality of the records.

Background

There are 2.7 million family and friend carers in Australia, 770,000 of which provide the most substantial amount of care to one or more people with disability, chronic condition, mental illness or disorder, drug or alcohol problem, terminal illness or who are frail aged.

Carers can be the partners, parents, children, grandparent, grandchildren, siblings or other relations of the person being cared for. Many are also friends and neighbours.

Nineteen percent of primary carers provide between 20 and 39 hours of care a week and 40 percent provide 40 or more hours of care per week.

The 2012 survey of Disability, Ageing and Carers identified 280,000 of co-resident primary carers who said that they could not leave a person over the age of 15 who they cared for for more than a day without difficulty.

Recommendation 1: Recognise participants' caring responsibilities and any dependents

It is important for participants of the PCEHR to be able to state on their record if they have caring responsibilities for someone who is dependent on them to provide regular assistance.

Carers Australia suggests that whether a participant is a carer should be included in the Your Personal Details sections of the PCEHR. Participants could select if they are a carer or have dependents and, if they select 'yes', they should then be prompted to provide the name and contact details of care recipient/s. Where appropriate, contact details of a person or entity who can take responsibility for the caring role should also be included.

In recognition that many carers do not identify with the term 'carer', and may interpret it to mean a paid formal carer, a description explaining who family and friend carers are should be included so that participants can accurately identify if they are a 'carer'. For example:

Carers are people who provide unpaid care and support to family members and friends. Carers may help and support the person they care for with daily activities, emotional, social and financial support.

Recommendation 2: Changes to the Emergency Contact Details section to better identify that the participant has a carer and their relationship with the participant

Although it is currently possible for the person being cared for to identify the contact details of their carer in their Emergency Contact Details, it would be useful to define what is meant by carer (see possible definition above). It should also be possible to identify the relationship of the carer to the individual (ie. partner, parent, child, brother or sister, grandparent, grandchild or friend). It is just as important for carers to know what has happened in an emergency as it is for another family member who is not providing care.

Recommendation 3: Ability to upload Advance Care Plans

Carers Australia strongly supports the uptake of Advanced Care Directives and/or Plans to allow people to identify their wishes in relation to medical and personal care if they find themselves in a position where they are unable to communicate these wishes. Advanced Care Directives both provide a degree of assurance that the person's wishes about their future care are respected and takes the burden off family and other nominees to make such complex and often very upsetting decisions.

Carers Australia believes there would be value in allowing participants to upload their Advance Care Plans to their PCEHR. This would alert health care professionals to the existence of the directive or plan and allow easy access if other holders of the Plan are not able to produce it – especially in an emergency.