

# Proposed changes to the personally controlled electronic health system (PCEHR) and the Healthcare Identifiers (HI) Service – APNA submission

### **24 JUNE 2015**

The Australian Primary Health Care Nurses Association (APNA) welcomes the opportunity to contribute to the Australian Government's consultation on proposed changes to the personally controlled electronic health record system (PCEHR) and the Healthcare Identifiers (HI) Service. We are providing this submission on behalf of our membership, Australian primary health care nurses.

# **APNA Submission**

As an overall comment on the proposed legislative changes, APNA supports any changes aimed at increasing participation in, and use of, the national eHealth record system.

APNA has long supported the development of a national eHealth record as part of a safe and effective healthcare system, and believes it is imperative for primary health care nurses to be actively involved with the widespread adoption, use and integration of eHealth into contemporary primary health care. The engagement of all nurses, in particular nurses working in general practice, is critical to the success of the eHealth system.

With the ageing Australian population and increasing numbers of people with chronic and complex health conditions, the need for an effective and efficient eHealth system is vitally important. Primary health care nurses can work with patients and multidisciplinary teams to ensure the success of this system, thereby ensuring the delivery of safe, high quality and seamless care to the Australian public.

With the proposed implementation of an opt-out participation system, primary health care nurses are also well placed to support patients to set up and maintain their own electronic health records and support their active and meaningful use.

APNA's comments on the specific legislative proposals set out in the Government's Legislation Discussion Paper are outlined below.

### *Proposal #1 – Rename the PCEHR to My Health Record (MyHR)*

APNA supports the proposal to rename the PCEHR to My Health Record (MyHR).

A simplified name that is recognisable to clinicians and consumers, while reflecting a partnership between the clinician and the patient, will generate clinical confidence, improved utility and greater uptake of the PCEHR.

# *Proposal #2 – Effect legislative changes to align definitions across related acts*

APNA supports proposals aimed at aligning definitional terms between the PCEHR Act, the HI Act and the Privacy Act.

APNA supports proposals to clarify whether provisions apply to healthcare provider organisations and/or individual healthcare providers, and that information about healthcare provider organisations, including their healthcare identifier, is no longer treated as personal information.

APNA supports the proposal that the definition of 'identifying information' in relation to an individual includes the power to make regulations prescribing additional identifying information for individuals. APNA agrees this would provide the necessary flexibility to the PCEHR System Operator and the HI System Operator to collect additional information if necessary (for example, if it was necessary to send a message to an individual by mobile phone or via email).

### Proposal #3 - Governance

APNA supports the transition to, and the establishment of, the Australian Commission for Electronic Health (ACeH). However, APNA remains concerned that the dissolution of the National E-Health Transition Authority (NeHTA) without adequate transition to the ACeH may result in loss of critical NeHTA staff, both technical and operational, and raises issues of loss of time, costs of re-training and the significant risk of loss of intellectual capital. APNA suggests that NeHTA, which has always been a transitional authority, be absorbed into the ACeH, thus retaining all key operational or technical staff and intellectual capital.

APNA believes primary health care nurses should be closely involved with the operation of the implementation taskforce. APNA also believes it is imperative that the primary health care nursing profession is adequately represented on the ACeH Board, as well as on any supporting advisory committees.

APNA supports the proposal to allow regulations to be made to prescribe a different entity to be the HI Service Operator and agrees this will allow future flexibility.

### *Proposal #3 – Participation*

APNA supports an opt-out participation model for the PCEHR for individuals, which is consistent with international models. APNA believes this is likely to result in increased uptake of the PCEHR system and increase its value to, and encourage its use by, healthcare providers.

APNA supports the use of trials, including opt-out trials, as part of assessing the effectiveness of the opt-out participation model. APNA believes it is important that individuals retain the right to cancel (deactivate) their PCEHR at any time in the trial regions.

Of all members of the primary health care team, nurses are likely to be the ones most directly affected by the implementation of both the opt-in and opt-out participation models. In light of this, APNA believes it is

imperative primary health care nurses and APNA are closely involved, supported and consulted in the development and implementation of the participation trials, as well as ongoing governance, operations and evaluation.

In relation to individual consent, APNA believes adequate consideration needs to be given to how the mechanisms proposed to address privacy concerns are appropriately communicated to individuals.

### *Proposal #4 – Obligations of parties*

APNA supports the proposal to remove the need for healthcare provider organisations, contracted service providers, repository operators and portal operators to enter into participation agreements.

APNA believes it is critical that, with the proposed abolition of participation agreements, the obligation to report data breaches is imposed on healthcare provider organisations and contracted service providers. It is also important appropriate clarity be provided on when the data breach notification must occur.

APNA supports the proposal to include a requirement for registered healthcare provider organisations to have policies that address how the organisation will ensure data quality. APNA believes it is critically important to ensure the quality of population data so this data can have increased impact and meaningful use.

In terms of the obligations to use the PCEHR system, APNA believes it is important there are suitable exceptions to the general requirement that payment for Medicare items relating to health assessments, comprehensive assessments, mental health care plans, medication management reviews and chronic disease planning items depend on the uploading of specific documents to the PCEHR system. It is also important there are clear processes in place for individuals to direct a healthcare provider not to upload a document and for that decision to be recorded and retained.

APNA suggests that healthcare providers not be required to upload a health assessment, comprehensive assessment, mental health plan, medication review report or chronic disease plan where the risk of any injury, harm or ill effect would outweigh the benefits of incorporating this data to an individual's PCEHR.

In terms of obligations for the System Operator to retain records, APNA agrees with the proposal to retain records for the longer of 30 years after date of death or if date of death is not known, 130 years from the individual's date of birth.

APNA supports the proposal to provide the PCEHR System Operator with a function to develop and implement a test environment so they have an opportunity to test how systems operate and interact before they are fully implemented. APNA suggests that in its testing processes the PCEHR System Operator seeks appropriate feedback from stakeholder and user groups.

### *Proposal #5 – Privacy*

APNA supports the proposal to require the System Operator to add an optional access control that alerts individuals (who have provided due consent) by SMS or email each time their PCEHR is opened.

APNA also supports proposals to allow suspension of access to a PCEHR by representatives if there is a risk to the individual, and by participants in the PCEHR system in certain circumstances.

In terms of the collection, use and disclosure of information, APNA agrees that the current prescriptive approach to specifying particular entities that may collect, use or disclose information for and for what

purposes is confusing. APNA would support any measure taken to simplify this, such as the proposed adoption of a principles-based approach.

APNA also supports clarification of the fact that healthcare providers may include relevant third party information in a record uploaded to the PCEHR system, and the System Operator is authorised to collect this information for inclusion in the individual's PCEHR.

In terms of the handling of healthcare identifiers by prescribed entities, APNA supports the proposal to allow regulations to be made prescribing additional uses of healthcare identifiers in closely restricted areas.

APNA does not have a particular view on the appropriateness of applying criminal or civil penalties to cases of a breach of PCEHR information. APNA also does not have a view on whether civil penalties should be introduced for less serious misuses of healthcare identifiers. However, in order for the public to have suitable trust in the security and safety of the PCEHR system (which impacts on participation and engagement with that system) there needs to be robust and proportionate sanctions if private information is disclosed or misused in any way.

# **About APNA**

The Australian Primary Health Care Nurses Association (APNA) is the peak professional body for nurses working in primary health care including general practice. APNA provides primary health care nurses with a voice, access to quality continuing professional development, educational resources, support and networking opportunities. APNA strives to increase awareness of the role of the primary health care nurse, and to be a dynamic and vibrant organisation for its members.

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