

**FACTSHEET for Individuals**

**Electronic Health Records and Healthcare Identifiers: Legislation Discussion Paper**

The Australian Government is proposing changes to the personally controlled electronic health record (PCEHR) system and the Healthcare Identifiers (HI) Service primarily as a result of reviews undertaken on their operations and legislation.

The PCEHR review found that there was overwhelming support for continuing the path of implementing a consistent eHealth record system for all Australians, but that a change in approach was needed to correct early implementation issues. The HI Service review found that the core functionality of the HI Service is operating and working effectively, but since it is now impacting on clinical workflow, there are some risks and issues emerging that may require enhancement and adjustment of processes and the legislative framework.

The proposed changes are aimed at bringing forward the benefits including better health outcomes and a more efficient system, by increasing the number of individuals and healthcare providers participating in the PCEHR system and making the system more user-friendly. The changes will result in a system that better aligns with existing clinical workflows in healthcare practices and ensure additional information, such as current medication lists and known adverse drug interactions are easily identified.

The *Electronic Health Records and Healthcare Identifiers: Legislation Discussion Paper* is intended to promote discussion within the community about the proposed changes.

The discussion paper proposes changes to address important aspects of the PCEHR system including:

* participation;
* governance; and
* privacy and security.

**Participation**

The primary change being considered is to the participation arrangements for individuals. Currently the PCEHR system operates on an opt-in basis where individuals who want a PCEHR register for one. From 2016, trials of different participation arrangements for individuals will occur in order to inform Government about future approaches to increasing individual participation in the system. The trials will include an opt-out approach where individuals in certain trial regions will be automatically registered for a PCEHR record unless they advise that they do not want one.

While the trials are being undertaken the system will continue to operate on an opt-in basis across the rest of Australia.

**Governance**

The PCEHR review identified concerns with the current eHealth governance arrangements. In response to these it is proposed to establish the Commonwealth statutory authority, the Australian Commission for Electronic Health (ACeH).

The establishment of ACeH will strengthen the governance and accountability arrangements across all national eHealth development and implementation and improve key stakeholder involvement. This will involve the transition of the work and functions of the National E-Health Transition Authority (NEHTA), a company owned by the Commonwealth and states and territories, as well as the PCEHR governance and operations of the Department of Health to ACeH.

ACeH would be a separate legal entity to the Commonwealth and would report to health ministers. It will be governed by a skills-based board with an independent chair and supported by a number of advisory committees.

ACeH would assume responsibility for the governance and operation of all national eHealth development and operations in Australia.

**Privacy and security**

The PCEHR system provides access control mechanisms that enable registered individuals to set controls for their PCEHR if they wish to do so. Individuals can grant access to their PCEHR to healthcare provider organisations as well as to other persons such as family members and carers. If an individual chooses not to set any controls the default settings in the system apply.

The technical settings in the PCEHR system ensures that a healthcare provider or other authorised user can only access an individual’s PCEHR if the individual has granted them access, except in emergency circumstances. Individuals cannot prohibit emergency access to their PCEHR by healthcare providers.

Individuals can elect to be notified (by email or by SMS) when certain activities occur in relation to their PCEHR, including when a healthcare provider accesses their PCEHR by asserting an emergency exists or when their nominated healthcare provider uploads a new shared health summary.

The PCEHR review recommended a new notification be provided that would allow individuals to be notified whenever their PCEHR is opened or used. It is proposed to amend the legislation to require the System Operator to add an optional access control that alerts individuals by SMS or email each time their PCEHR is opened. This access control would only be available to individuals who request the alert and who have provided their mobile number or email address to the System Operator. The legislation would be amended to allow this information to be collected, used and disclosed, as necessary, to give effect to this access control.

It is also proposed to allow the System Operator to suspend access to an individual’s PCEHR in circumstances where there is a threat to the security of their record or the PCEHR system or there is an issue or suspected issue with an individual’s (or their representative’s) identity or other technical or operation issue. This change will not affect the registration of an individual or their access to their PCEHR but will provide an increased level of security for the record or the PCEHR system as a whole.

The privacy framework of the PCEHR system and the HI Service is prescriptive in specifying who may collect, use or disclose information and for what purposes. It is proposed to change from this prescriptive approach to a principles-based approach by listing the information that is protected, who may collect, use and disclose the information and for what purposes. This will not relax the privacy framework or change the nature of the authorisations but simply provides clarification and assists the HI Service Operator and the PCEHR System Operator to meet their obligations.

The HI Act and PCEHR Act, together with the Privacy Act, currently provide penalties for misuse of information and healthcare identifiers. The discussion paper highlights that consideration is being given to increasing the range of enforcement and penalty options available for breach of the PCEHR Act. This includes consideration of introducing criminal penalties for more serious misuses of PCEHR information while retaining the ability to impose civil penalties. This would establish a more graduated framework and enable better response to inappropriate behaviour in a way that is proportional to the severity of the breach.

**Feedback**

Readers are invited to make a submission on the discussion paper. This can be in the form of contributing ideas or responding to the issues and questions raised in the paper.

Submissions must be in writing and identify the names of the parties and/or organisations they represent, as well as respective contact details.

The period for making submissions closes 5:00 p.m. (Australian Eastern Standard Time) Wednesday 24 June 2015.

Submissions can be made by any of the following ways:

1. mail it to PCEHR/HI Discussion Paper Feedback

Department of Health

MDP 1003

GPO Box 9848

CANBERRA ACT 2601

1. email it to ehealth.legislation@health.gov.au
2. upload it at [the eHealth website](https://consultations.health.gov.au/ehealth/ehr-and-hi-legislation-discussion-paper-1)
3. fax it to (02) 6289 5673