

# Briefing Paper

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## Update on the new Electronic Health Record: *PCEHR*

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### Background

As of 1 July 2012, all Australians can create their own Personally Controlled Electronic Health Record (PCEHR), with individuals choosing whether to opt-in to the system.

The scheme has been in development for some time and there are great expectations about its potential. In particular, a comprehensive e-health system promises great benefits for people living with HIV, given that people living with HIV have complex health needs and are frequent users of the health system. However, some questions are yet to be addressed and concerns remain – including around the readiness of consumers, health providers and the system itself, to meet expectations.

The Australian Federation of AIDS Organisations (AFAO) has been heavily engaged with e-health consultation processes, with the aim of ensuring the needs of people living with HIV and those of affected communities such as gay men, are met. This briefing paper explains what we currently know about how e-health records should operate - including features that should give users greater control over their personal information - and what questions remain unanswered.

### *PCEHR - The Basics*

The PCEHR is designed to give individuals an electronically accessible medical history that both they and their approved health providers can access throughout Australia. The PCEHR is intended to complement practitioners' existing medical records with additional information<sup>1</sup>, while also giving consumers precise controls over what their PCEHR contains and who has access to the information.

The PCEHR should allow healthcare providers, as authorised by the consumer, to see an overview of:

- allergies/adverse reactions;
- medicines;
- pathology tests;
- medical history;
- immunisations;
- directives;
- recent health care events and pathology; and
- radiology reports

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<sup>1</sup> What is a PCEHR? [online] National E-Health Transition Authority. Retrieved from:  
<http://www.nehta.gov.au/ehealth-implementation/what-is-a-pcher>

Pathology and radiology reports are not included in the PCEHR in the first stage of the roll-out. According to the PCEHR design document– *The Concept of Operations: Relating to the introduction of a Personally Controlled Electronic Health Record System* ('the Concept of Operations'), the aim is to have these available from large private sector laboratories by 30 June 2013 and other providers by 30 June 2014.<sup>2</sup>

According to the National E-health Transition Authority (NEHTA), the PCEHR is designed<sup>3</sup>:

- to bring together key health information from a number of different systems, and present it in a single view;
- to allow information to be accessed by the individual and their authorised health care providers. Over time the individual will be able to contribute to their own information and add to the recorded information stored in their individual record;
- not to hold all the information held in the individual's health care professional's records but to complement those records by highlighting key information; and
- in the future as it becomes more widely available, to allow individuals to access their own health information from anywhere in Australia.

### Consumer controlled levels of access

At the core of the PCEHR system is a user controlled 'access list' which controls which organisations are permitted to access an individual's records. The PCEHR offers consumers the choice of two levels of control over the access list, *default* and *advanced* access controls<sup>4</sup>.

People living with or being tested for HIV generally wish to maintain confidentiality and privacy regarding testing and HIV status. Consumers can register and administer control settings via an online portal, accessible at the recently launched [www.ehealth.gov.au](http://www.ehealth.gov.au). This should enable people to confidentially vary settings to levels they feel are appropriate at any time. Consumers can ring the call centre on 1800 723471, or visit a service centre at a Medicare Office for assistance with registration and to manage access list settings, as well as<sup>5</sup>:

- general enquires about the PCEHR System
- about the registration process
- resolving issues around the PCEHR System
- resolution of complaints
- feedback around the PCEHR System.

The online portal also contains a public learning centre located at <http://publiclearning.ehealth.gov.au/consumer/>. Over time, individual consumers will also be able

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<sup>2</sup>Department of Health and Ageing, Concept of Operations: Relating to the introduction of a Personally Controlled Electronic Health Record System, Canberra, September 2011, 55. Retrieved from: [http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/CA2578620005CE1DCA2578F800194110/\\$File/PCEHR-Concept-of-Operations-1-0-5.pdf](http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/CA2578620005CE1DCA2578F800194110/$File/PCEHR-Concept-of-Operations-1-0-5.pdf)

<sup>3</sup>What is a PCEHR?, op. cit.

<sup>4</sup>Department of Health and Ageing, op. cit.

<sup>5</sup> ibid.

to contribute to the information stored in the PCEHR themselves<sup>6</sup>.

### ***Default access***

Under default access, *any* health care organisation involved in the care of the individual is automatically added to the access list of the PCEHR, unless the individual requests otherwise<sup>7</sup>. However, control over which documents are stored on the record remains with the individual; where they express a preference not to upload a particular document, the healthcare provider should not do so.<sup>8</sup>

### ***Advanced access***

Additional access control settings can also be administered by the individual which provide greater control over who has access to information stored in their PCEHR. These settings include the ability to<sup>9</sup>:

- **Set up a Provider Access Consent Code (PACC).** The PACC is effectively a PIN number which the individual is able to give out to healthcare providers at their discretion. If the individual chooses to set up a PACC, then organisations will not be able to add themselves to the access list unless they have the PACC.
- **Restrict organisations from being on the access list.**
- **Prevent a PCEHR from being found.** Individuals will be able to determine if they want their PCEHR to be 'findable' or not. If the individual chooses for their PCEHR to be 'not findable', a healthcare organisation not currently on the access list who looks the patients up on the PCEHR database will receive a 'not found' message.

Similarly, if the organisation is marked as 'revoked' on the access list then it will not be able to find the individual's PCEHR. By default, a PCEHR will be findable, unless the individual changes this setting; however, a PCEHR can still be found with emergency access if the individual has selected this option<sup>10</sup>.

### ***Managing document level access***

If an individual enables PACC pin access on their record they will be able to control which organisations can access individual documents stored on their record. They will also be able to describe what level of access each organisation on their access list is afforded to each document: either 'general access' or 'limited access'.<sup>11</sup>

'General access' means that the clinical document will be accessible by any healthcare organisation which has been granted PACC access. 'Limited access' means the clinical document is only available to a more limited group of healthcare organisations. The clinical document is still accessible to the

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<sup>6</sup> National E-Health Transition Authority website, op. cit.

<sup>7</sup> Department of Health and Ageing, op. cit.

<sup>8</sup> *ibid.*

<sup>9</sup> *ibid.*

<sup>10</sup> *ibid.*

<sup>11</sup> *ibid.*

healthcare organisation that supplied it. 'Limited access' can be overridden by a healthcare provider in an emergency situation.<sup>12</sup>

Once a document has been marked 'limited access', by default it will not be viewable by any healthcare providers. In order to allow a particular, trusted healthcare provider to view it, an individual must create another pin, called the PACCX. This can be given out at the consumer's discretion to particular providers that the consumer would like to access a particular document<sup>13</sup>.

### *Effective removal of clinical documents*

The PCEHR System will support a process called 'effective removal', in the event that a clinical document has been loaded into a PCEHR which should not be there. This includes events such as<sup>14</sup>:

- **Identification error:** the healthcare organisation has inadvertently misidentified the individual in the clinical document.
- **Clinical information error:** the healthcare organisation has supplied incorrect information and the clinical document needs to be removed.
- **Individual initiated removal:** the individual did not wish the clinical document to be included in their PCEHR.

Documents can be 'effectively removed' either through the call centre or the online consumer portal, According to the Concept of Operations, if the individual requests a clinical document be 'effectively removed' from their PCEHR, they will be required to indicate that they understand the implications of its removal (namely that the clinical document will no longer be accessible via their PCEHR and this may mean the individual may not receive the benefits of having this information available via their PCEHR in future episodes of care).<sup>15</sup>

## **Issues for consideration**

### *Criminal implications*

It is important to note that although documents that have been 'effectively removed' are locked preventing further access by an individual or their healthcare providers (including using emergency access)<sup>16</sup>, this does not appear to prevent access by people at the back-end. According to the Concept of Operations, an effectively removed document remains accessible to the PCEHR System Operator ... only be accessed for legal reasons.' This leaves open the door for authorities to access 'effectively removed' documents, where individuals are subject or party to legal proceedings, such as criminal investigations of alleged exposure or transmission of HIV for example.<sup>17</sup>

Clause 70 of the PCEHR Bill 2011 stipulates that the System Operator may disclose health information to law enforcement agencies for prescribed purposes set out in sub-clause 70(1); these include the 'prevention, detection, investigation, prosecution or punishment of criminal offence or

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<sup>12</sup> *ibid.*

<sup>13</sup> *ibid.*

<sup>14</sup> *ibid.*

<sup>15</sup> *ibid.*

<sup>16</sup> *ibid.*

<sup>17</sup> *ibid.*

breaches of certain other laws'.<sup>18</sup> AFAO believes that this discretion is too broad and that this may result in law enforcement authorities 'fishing' for evidence possibly contained in a person's PCEHR.

Criminal investigations into allegations of HIV sexual transmission or exposure by people with HIV, is a case in point. Providing access to health/medical information for the purpose of prosecuting criminal matters or resolving civil legal disputes should be subject to court-ordered subpoena rather than the System Operator's discretion, and should relate to particular information rather than to general information contained in a person's PCEHR.

Furthermore, as the Concept of Operations states, effectively removed clinical documents will be accessible for legal reasons. HIV-sector organisations are therefore in a quandary about how to guide our members/communities/constituents. Specifically, are we able to confidently advise people that by exercising the 'effective removal' mechanism, any record thus removed containing information regarding, HIV status, sexual history, or injecting drug-use, is safe from being accessed by authorities? If so, how do we communicate this? If the answer is 'no' - or the more, likely 'currently unknown' - should our advice err on the side of caution to not upload any such information in the first place, as there is reasonable chance that authorities may be able to search PCEHRs?

## Consumer Rights and Remedies

It is essential that consumers are able to control and monitor their record and if something appears to have gone wrong, pursue a remedy.

In some circumstances it might be clearly apparent that sensitive information has been inappropriately disclosed. For example, if in the course of treating their patient a health worker was to remark to them, 'I'm sorry to hear that you have HIV, how did it happen?' However, whether disclosure has occurred is not always so clear.

### *Hypothetical case study*

Angelique, an HIV-positive African woman, chooses to have HIV-related discussions only with her S100 subscriber, discussing all other health matters with the family GP. Because of the trusted nature of their relationship, she chooses to link her HIV-related health information to her PCEHR. Later, during a consultation with her GP about her children's health, she notices subtle but perceptible changes in the GP's behaviour and attitude. Here, the ability to view the audit trail of a record may help Angelique identify if the family GP did inappropriately access her PCEHR.

### *The Audit Trail – a crucial protection*

AFAO has advocated for both the provision of a thorough audit trail recording access to PCEHR, and, crucially, the right for consumers the ability to access this record. It is pleasing to see that the legislation provides robust provisions guaranteeing access to the audit trail.

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<sup>18</sup> Personally Controlled Electronic Health Records Bill 2011, Explanatory Memorandum, 54. Retrieved from: [http://parlinfo.aph.gov.au/parlInfo/download/legislation/ems/r4738\\_ems\\_f076ddf7-5345-448d-9115-c120e217a462/upload\\_pdf/362618.pdf;fileType=application%2Fpdf#search=legislation/ems/r4738\\_ems\\_f076ddf7-5345-448d-9115-c120e217a462](http://parlinfo.aph.gov.au/parlInfo/download/legislation/ems/r4738_ems_f076ddf7-5345-448d-9115-c120e217a462/upload_pdf/362618.pdf;fileType=application%2Fpdf#search=legislation/ems/r4738_ems_f076ddf7-5345-448d-9115-c120e217a462)

An individual's ability to see an audit trail of who has accessed and handled their PCEHR should provide them with greater confidence in the system. In a situation where someone believes they may be receiving inferior and/or discriminatory health care, such as Angelique's, they will be able to check if the healthcare provider has indeed found out personal information that they shouldn't have. If this has occurred, they could choose to raise it with the provider informally, or pursue a formal complaint.

### Complaints

The Information Commissioner can receive complaints in relation to any act or practice that breaches the PCEHR Bill.<sup>19</sup> It will treat any contravention as interference with privacy under the Privacy Act. Where something doesn't necessarily breach the PCEHR legislation, it may still be possible for a complaint to be made to the relevant professional body. If someone is disclosing sensitive information in a casual conversation, based on what they saw sitting on computer monitor, this may be subject to professional disciplinary proceedings.

### Other issues

Other issues requiring further attention include:

- Acceptance of PCEHR varies among physicians. The Australian Medical Association (AMA) in late August expressed support for the Government's announcement that "additional time spent by a GP on a shared health summary or an event summary during a consultation will count towards the total consultation time, and that the relevant time-based GP item can be billed accordingly". AMA President, Dr Steve Hambleton, said that the Government has listened to the AMA's concerns and delivered an outcome that will encourage doctors to become actively involved in the implementation of the PCEHR.<sup>20</sup> The January 2012 AMA survey about member views of the PCEHR indicated that between half and two-thirds would use the PCEHR to access some kinds of patient health information.

At the same time, only 30% indicated that they would commence use of it as of 1 July 2012. This lower rate of support may be explained, partially, by technical issues which were anticipated in the roll-out –and which eventuated, to some extent. It may also be explained by the concerns expressed by the AMA that the record where it may not be comprehensive. The AMA guide to the PCEHR<sup>21</sup> has advised GPs to reconsider engaging with the e-health record if their patients have restricted availability to some documents.

The recent announcement that hospitals are not going to use individual health identifier for patient identification is concerning. The chief executive of the Australian Healthcare & Hospitals Association, Prue Power, said the lynchpin of the e-health system – the Individual

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<sup>19</sup> *Privacy Act 1988*. Retrieved from: [http://www.austlii.edu.au/au/legis/cth/consol\\_act/pa1988108/](http://www.austlii.edu.au/au/legis/cth/consol_act/pa1988108/)

<sup>20</sup> Government delivers PCEHR incentives for doctors, AMA website, retrieved from: <http://ama.com.au/media/government-delivers-pcehr-incentives-doctors>

<sup>21</sup> Australian Medical Association (2012, April 12). Draft AMA Guide to Using the PCEHR, point 6.1.7, 18. Retrieved from: <http://ama.com.au/draft-ama-guide-using-pcehr>

Health Identifiers – had been poorly designed and executed and the hospital sector had more faith in its own patient identification systems<sup>22</sup>.

A lack of hospital participation in the PCEHR could seriously undermine the system's viability, potentially discouraging ambivalent/unsure consumers from creating their own PCEHR.

- Lack of e-health conformant infrastructure in hospitals, and for allied health professionals.
- Paucity of practical consumer information, beyond the very general. Detailing real-life use of the PCEHR will be essential to establishing trust of consumers generally, particularly those with stigmatising conditions, such as HIV.

## Conclusion

The PCEHR is now upon us, and there is much to welcome, including the fact that consumers will eventually be able to access a range of their own health information. However, expectations should be modest. Initially, only some types of information will be available, while at the same time only some healthcare providers will be willing and able to participate in the system. Most significantly, the HIV community organisations and clinicians must be able to confidently advise constituents and patients of the system's pros and cons, including the risk that any PCEHR information may be able to be accessed contrary to their will, for legal/investigative purposes.

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<sup>22</sup> Lack of e-faith: hospitals snub identifier system, retrieved from:  
<http://www.medicalobserver.com.au/news/lack-of-efaitH-hospitals-snub-identifier-system>