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## Public Advisory Statement

### The 'Personally-Controlled' Electronic Health Record

#### Frequently Asked Questions by Clinicians

Version of 11 August 2013

#### Background

The PCEHR has been devised by the government as a central element within the eHealth system, and involves almost the entire sector. If a person agrees to have a PCEHR, it will contain personal data that is important, and that is at least somewhat sensitive.

A PCEHR is specifically intended to enable shared access not just to the data it contains, but also to further data that may be even more important and even more sensitive. This shared access is enabled by a unique Individual Healthcare Identifier (IHI), that has been assigned to every Australian, specifically to link the PCEHR and other government health systems to you as an individual.

Details of this can be found at the Department of Human Services. Healthcare Identifiers Service:  
<http://www.humanservices.gov.au/customer/services/medicare/healthcare-identifiers-service>

The system commenced operation in July 2012. Yet the information provided by the government about the scheme is inadequate and misleading. It is therefore vital that representative and advocacy groups identify, and attempt to answer, the range of questions emerging from the community.

#### Purpose

This FAQ provides clinicians with information about the PCEHR and its implications, in order to balance published or broadcast across media outlets by government agencies. The FAQ follows through the fine print in the government's publications and legislation.

Generally-relevant documents include:

1. The National E-Health Transition Authority's Web site – <http://www.nehta.gov.au/>
2. Department of Health and Ageing  
<http://www.ehealth.gov.au/internet/ehealth/publishing.nsf/content/home>
3. Federal Government launches advertising campaign 'Medicare For All'.  
<http://www.nehta.gov.au/media-centre/news/412-federal-government-launches-advertising-campaign-medicare-for-all>.
4. Office of the Australian Privacy Commissioner. Privacy Fact Sheets.  
<http://www.oaic.gov.au/privacy/privacy-resources/privacy-fact-sheets/>
5. Australian Medical Association. 'Getting ready for the PIP eHealth incentive and PCEHR.'  
<http://www.ama.com.au/getting-ready-pip-ehealth-incentive-and-PCEHR>
6. YouTube. Search term "PCEHR". [www.youtube.com](http://www.youtube.com)

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## **APF Public Advisory Statement**

### **The ‘Personally-Controlled’ Electronic Health Record**

#### **Frequently Asked Questions by Clinicians**

The first two pages provide very brief responses to a set of key questions.

More detailed responses to these questions are provided on the pages following.

**1. When I sign the Participation Agreement, do I completely assign my intellectual property rights to the Department of Health and Ageing for all patient data uploaded to the PCEHR?**

Yes.

**2. May I terminate the Participation Agreement and retract my IP rights if I change my mind about registering for the PCEHR?**

Yes and No.

**3. Am I correct in assuming the Department will not reassign my IP rights?**

No.

**4. Am I correct in assuming the patient data will be used only for healthcare?**

No.

**5. How will the PECHR system work?**

The PCEHR, an eHealth record system, provides access to key health information drawn from a patient's PCEHR. The PCEHR includes a Shared Health Summary, which consists of 1) Medical History (conditions) 2) Current Medications 3) Allergies 4) Immunisations.

**6. Is Information stored in the PCEHR a complete patient record?**

No.

**7. Is the information I upload to a patient's PCEHR confidential between that patient and their clinician/s?**

No.

**8. What happens if my patient and I disagree about information I believe is important to upload into their PCEHR?**

Patients must consent to information uploaded to the system.

**9. I can choose what is uploaded to the PCEHR Shared Health Summary?**

Yes and No.

**10. Are there concerns about consumer registration assistant training?**

Yes.

**11 Can rights to access the PCEHR be conferred to other participants?**

Yes.

**12. What occurs in the instance of an uncoded diagnosis?**

Conditions can be delineated within the software and labelled at the clinician's choice.

**13. What occurs when information is accidentally uploaded to the PCEHR system?**

Uploading a new Shared Health Summary will supersede those preceding: both records will be stored but only the latest record is published on the system.

**14. How long is the PCEHR kept?**

The PCEHR is kept for 30 years after the death of the patient, or 130 years from commencement.

**15. If a patient changes his / her mind may he / she cancel the PCEHR and have it deleted?**

Yes and No.

**16. If patients cancel their PCEHR, can they be sure information stored there will never be revealed?**

No.

**17. Are the purposes and uses of the electronic health record clearly defined and limited by legislation?**

No.

**18. Is it difficult for someone to gain unauthorised access to my patients' records?**

No.

**19. Is the NASH system a robust method to protect from unauthorised access to PCEHR records?**

Yes and No.

**20. What happens to practitioner information stored on the PCEHR system if I "opt out" after registration?**

Rights to the information can never be revoked even on termination of the agreement

**21. Are all hospitals using software that enables Shared Health Summary records?**

No.

**22. Are potential PCEHR medico-legal liability issues well understood?**

No.

**23. What about children?**

Parents or Guardians generally make all system decisions and have full access to their children's PCEHR record from the age of 0-14 years; arrangements vary from this point.

# APF Public Advisory Statement

## The 'Personally-Controlled' Electronic Health Record

### Frequently Asked Questions by Clinicians

#### **1. When I sign the Participation Agreement, do I completely assign my intellectual property rights to the Department of Health and Ageing for all patient data uploaded to the PCEHR?**

Yes.

You grant the department a perpetual, irrevocable, royalty-free and licence-fee free, worldwide, non-exclusive licence.

This includes:

- a right to sub-license, and
- to use, reproduce, copy, modify, adapt, publish and communicate (including to other healthcare provider organisations and to organisations that store health information) material you have uploaded to the PCEHR system for the purposes of the PCEHR system.<sup>[1]</sup>

#### **2. May I terminate the Participation Agreement and retract my IP rights if I change my mind about registering for the PCEHR?**

Yes and No.

You may terminate the Agreement, but you may not retract your IP rights.

The following clauses survive termination of the agreement:

- (a) clause 7 (intellectual property)
- (b) clause 8 (assistance in relation to inquiries, etc), but only for the term of this agreement and for a period of seven years following termination
- (c) clause 9 (costs); (ca) clause 10A (resolving disputes), but only to the extent a dispute arises between the parties in connection with a clause that survives termination under this clause 12.5;
- (d) clause 11 (liability)
- (e) clauses 12.5 (survival) and 12.6 (accrued rights);and
- (f) clauses 13.1 (jurisdiction), 13.2 (entire agreement), 13.6 (giving effect to this agreement) and 13.7 (severability: a contract that can be divided and apportioned into two or more parts that are not necessarily dependent upon each other), and any definitions or other provisions necessary to give effect to these clauses.<sup>[2]</sup>

In other words, even if GP practices and other organisations cancel the contract, half of the agreement stays in place: 7 of the 14 clauses in the agreement survive termination.

#### **3. Am I correct in assuming the Department will not reassign my IP rights?**

No.

The department grants all other participants to the Agreement perpetual, irrevocable, royalty-free and licence-fee free, worldwide, non-exclusive licence (including a right to sub-license) to use, reproduce, copy, modify, adapt, publish and communicate material you have accessed via or downloaded from the PCEHR system for:

- (a) the purpose of providing healthcare; and
- (b) other purposes of the PCEHR system.<sup>[3]</sup>

This means any other participant to the Agreement may download your patient data into their own practice database.

#### **4. Am I correct in assuming the patient data will be used only for healthcare?**

No.

PCEHR data may be used for:

- (a) law enforcement purposes<sup>[4]</sup>
- (b) medical insurance<sup>[5]</sup>
- (c) medical research
- (d) other purposes authorised by law.<sup>[6]</sup>

## **5. How will the PECHR system work?**

The PCEHR, an eHealth record system, provides access to key health information drawn from a patient's PCEHR. All "Participation Agreement" signatories are given intellectual property rights to all participants' healthcare data uploaded to the PCEHR. This is so, regardless of patient consent, and is a fundamental shift in the matter of privacy of patient data. The PCEHR includes a Shared Health Summary, which consists of 1) Medical History (conditions) 2) Current Medications 3) Allergies 4) Immunisations. The system is already being used by general medical practices.

## **6. Is Information stored in the PCEHR a complete patient record?**

No.

The PCEHR system does not replace practice records. Clinicians will need to populate both the PCEHR system as well as practice records.

Also, if clinicians add a new medication they must upload another Shared Health Summary to the PCEHR record to be accurate. Often this may not occur and so information stored in the PCEHR might not be up to date or reliable for diagnosis and treatment. The PCEHR system has proven:

Time consuming and incumbent on the GP to maintain

Legal to access under certain circumstances – e.g. a Medicare audit of practice records.

## **7. Is the information I upload to a patient's PCEHR confidential between that patient and their clinician/s?**

No

The information may be lawfully accessed for law enforcement and medical insurance purposes.

The PCEHR Provider Agreement hands intellectual property and copyright of patient notes to Government

The System Operator, consumers, clinicians, health care organisations, repository operators, portal operators and contracted service operators have access to information included in the PCEHR of consumers

The Department of Health and Ageing dispute assertions that the PCEHR is a 'Government Store' of information about clinicians and their patients. However [my.gov.au](http://my.gov.au) currently manages access to PCEHR system information and other Department of Human Services bodies, which are under the auspices of Health and Ageing.<sup>(17-18)</sup> The Department of Health and Ageing and their agents have the lawful right to copy, adapt and communicate PCEHR contents to others (See 3 above).

## **8. What happens if my patient and I disagree about information I believe is important to upload into their PCEHR?**

Patients must consent to information that is uploaded to the PCEHR system. It is a condition of registration that the provider does not upload consumer information if the consumer has advised it should not be uploaded. (p36) Unauthorised collection, use or disclosure attracts civil penalties of 120 units (\$20,400). (p48)

## **9. I can choose what is uploaded to the PCEHR Shared Health Summary?**

Yes and No

The default setting in clinical software is to upload all information to Shared Health Summary. However the interface does allow selection and de-selection of all data deemed to be a part of the Shared Health Summary.

A new Shared Health Summary supersedes the previous Summary- former versions of the document are retained.

According to documentation currently available to APF, consumers cannot limit access to the Shared Health Summary.

## **10. Are there concerns about consumer registration assistant training?**

Yes.

The training provided to consumer registration assistants "signing up" individuals in the community and provision of balanced information to consumers about the PCEHR system by registration assistants have been questioned by professional groups and consumer groups, especially the APF. Several individuals have reported approaches targeting Centrelink clients and those in rehabilitation, the chronically ill and parents of newborns while the mother is in labour.

MediCare Locals have convened sessions with general practice staff to encourage them to approach patients in waiting rooms with "assisted registration".

Almost 500,000 Australians have registered into the system but only 3,818 have populated Shared Health Summaries.<sup>(20)</sup> From this evidence, we infer a variety of people have been 'incentivised' to register with the system.

**11 Can rights to access the PCEHR be conferred to other participants?**

Yes.

Access rights are conferred under the Participation Agreement.<sup>(15-16)</sup>

**12. What occurs in the instance of an uncoded diagnosis?**

Not all diagnoses have been coded for the PCEHR system as the clinical terminology supporting the system is presently immature. Conditions may be delineated within the software and labelled at the clinician's choice.

**13. What occurs when information is accidentally uploaded to the PCEHR system?**

There is no indication that information accidentally uploaded to the PCEHR system can subsequently be withdrawn or deleted. However, new Shared Health Records should supersede preceding records. The software allows un-checking of items in the Past History of an individual's PCEHR so, although stored on the system, they may not be included in future, published iterations of the Shared Health Summary.

**14. How long is the PCEHR kept?**

The PCEHR is kept for 30 years after the death of the patient, or 130 years from commencement, if date of death is not known.<sup>[7]</sup>

**15. If a patient changes his / her mind may he / she cancel the PCEHR and have it deleted?**

Yes and No.

Patients may cancel their PCEHR, but it is never deleted.<sup>[8]</sup>

**16. If patients cancel their PCEHR, can they be sure information stored there will never be revealed?**

No.

After cancellation, the PCEHR may be accessed by healthcare providers and for other purposes authorised by law.<sup>[9-10]</sup>

**17. Are the purposes and uses of the electronic health record clearly defined and limited by legislation?**

No.

Under the PCEHR Act 2012, the Minister may make PCEHR Rules, which allows change without legislation.

The PCEHR Rules may specify ongoing or changed requirements relating to the PCEHR system that apply to consumers or participants in the PCEHR system.<sup>[11]</sup>

**18. Is it difficult for someone to gain unauthorised access to my patients' records?**

No.

A computer hacker who gains access to any other healthcare provider's National Authentication Service for Health (NASH) certificate, either by social engineering or internet penetration is able to masquerade as a legitimate healthcare provider in order to obtain full system access.<sup>[12] [13]</sup> Masking their internet protocol (IP) address may mean the hacker escapes detection.<sup>[14]</sup>

PCEHR records can be downloaded to a clinician's practice records and the consolidated view on the Shared Health Summary can be printed, which means "downstream" use of the record cannot be controlled by any authority.

**19. Is the NASH system a robust method to protect from unauthorised access to PCEHR records?**

No.

The National E-Health Transition Authority believes it will be three years before the National Authentication Service for Health (NASH) system is complete.

**20. What happens to practitioner information stored on the PCEHR system if I “opt out” after registration?**

The PCEHR system is not "opt out" because healthcare providers have signed an agreement giving the Department of Health and Ageing the right to copy, adapt and communicate your PCEHR data to others:

- these rights can never be revoked even on termination of the agreement
- these rights are then conferred by the Department on all other participants in the agreement.

**21. Are all hospitals using software that enables Shared Health Summary records?**

Not to the best of our knowledge. The means the PCEHR of patients treated at these hospitals is necessarily incomplete.

**22. Are potential PCEHR medical liability issues well understood?**

No.

The key risks, identified by the current advice from the MDA National Limited (MDA), a national medical defence organisation are:

- Privacy breaches.
- Negligence for failing to detect critical patient information contained within the PCEHR.
- Loss or corruption of electronic documents or data.
- Intellectual property disputes.
- Fines and penalties.<sup>(21)</sup>

Some indemnity insurances do not cover fines and civil penalties related to the PCEHR.

**23. What about children?**

Parents or authorised guardians will usually have control of their children's PCEHR from 0 to 14 years, including decisions as to whether the child participates or removes their record, and their access controls.

After a child turns 14, they will be able to choose whether to manage their own PCEHR in the same way they can apply for their own Medicare card.

If between 14 and 17, a patient does not take control of their record, their parents will maintain control. At the age of 18, the PCEHR system will no longer allow a parent or guardian to access an individual's PCEHR unless that parent or guardian has been authorised to access information on their child's behalf.<sup>(22)</sup>

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- [6] Personally Controlled Electronic Health Records Act 2012, Clause 61, 62, 63, 64, 65, 66, 67, 68, 69, 70. <http://www.comlaw.gov.au/Details/C2012A00063>
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