



**Australian
Privacy
Foundation**

<http://www.privacy.org.au>

Secretary@privacy.org.au

<http://www.privacy.org.au/About/Contacts.html>

Public Advisory Statement

The 'Personally-Controlled' Electronic Health Record

Frequently Asked Questions by Consumers

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 people 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.

Specifically-relevant documents are shown after most answers.

Generally-relevant documents include:

1. The National E-Health Transition Authority's Web site – <http://www.nehta.gov.au>
2. 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>.
3. Office of the Australian Privacy Commissioner. Privacy Fact Sheets.
<http://www.oaic.gov.au/privacy/privacy-resources/privacy-fact-sheets/>
4. YouTube. Search term "PCEHR". www.youtube.com
5. Kruys, E. PCEHR: Who is the customer? (slideshow) Doctor's bag blog
<http://doctorsbag.wordpress.com/2013/07/29/pcehr-who-is-the-customer/>

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APF Public Advisory Statement

The 'Personally-Controlled' Electronic Health Record

Frequently Asked Questions by Consumers

1. Is the PCEHR the same as e-health?

No.

A large number of e-health systems apply across the health sector. The PCEHR is the national Australian e-health platform. The record does not replace e-health practice records, which will list your health conditions, referrals and illnesses, more comprehensively. The PCEHR requires clinicians to maintain 2 sets of records about you; one is uploaded to the PCEHR system and the other, more comprehensive record, remains with the practice concerned.

2. Is the PCEHR system "opt in" and "opt out"?

Yes and No.

The PCEHR system is "opt in" but it is hard to "opt out" of the registration. If you ever opt in, and even if opt out again afterwards, the information stored in your PCEHR is never deleted and actively retained for 130 years. It can be accessed by healthcare providers and insurers for medical indemnity and law enforcement purposes.

Personally Controlled Electronic Health Records Act 2012, Clause 17.

<http://www.comlaw.gov.au/Details/C2012A00063>

3. How do I obtain a PCEHR?

You can obtain a PCEHR by registering with a consumer registration assistant or via my.gov.au, which currently manages access to PCEHR system information and other Department of Human Services bodies, which are under the auspices of Health and Ageing. The Department of Health and Ageing and their agents have the lawful right to copy, adapt and communicate PCEHR contents to others (See 7, 10 below).

Department of Health and Ageing. Concept of Operations: Relating to the introduction of a Personally Controlled Electronic Health Record System.

http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/PCEHRS-Intro-toc~ch4~4_3~4_3_1#.Ufndml0gd8F

Australian Government. myGov; Terms of Use. <https://my.gov.au/mygov/content/html/terms.html>

4. How long is the PCEHR held by Government authorities?

Information stored in your PCEHR is generally held for up to 130 years.

Healthcare providers sign an agreement giving the Department of Health and Ageing and their agents the right to copy, adapt and communicate your PCEHR to others.

These rights can never be revoked even on termination of the agreement.

Department of Health and Ageing. Participant Agreements.

http://www.ehealth.gov.au/internet/ehealth/publishing.nsf/content/providerregistration_participationagreement

5. Will my PCEHR will be used purely for the purpose of my healthcare?

No

PCEHR data may be used for:

- law enforcement purposes
- medical insurance
- medical research
- other purposes authorised by law

Department of Health and Ageing. Participant Agreements.

http://www.ehealth.gov.au/internet/ehealth/publishing.nsf/content/providerregistration_participationagreement

Personally Controlled Electronic Health Records Act 2012, Clause 70.

<http://www.comlaw.gov.au/Details/C2012A00063>

Personally Controlled Electronic Health Records Act 2012, Clause 68.

<http://www.comlaw.gov.au/Details/C2012A00063>

The Department grants all participants to the Agreement perpetual, irrevocable, royalty-free and licence-fee free, worldwide, non-exclusive licence (including a right to sub-licence) to use, reproduce, copy, modify, adapt, publish and communicate material you store on the PCEHR system for:

- the purpose of providing healthcare; and
- other purposes of the PCEHR system

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

6. Will my PCEHR be deleted on cancellation of my registration?

No.

On cancellation of your registration, the PCEHR is deactivated, that is, not published, but remains stored on the system.

Department of Health and Ageing. Personally Controlled Electronic Health Record (PCEHR) - Privacy Impact Assessment Report. Chapter 6 - PCEHR suspension, deactivation and reactivation.

<http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/pcehr-legals-pia-toc~chapter-6>

Department of Health and Ageing. Participant Agreements.

http://www.ehealth.gov.au/internet/ehealth/publishing.nsf/content/providerregistration_participation_agreement

7. Can the contents of my PCEHR ever be lawfully revealed?

Yes.

PCEHR can be revealed for law enforcement purposes.

The PCEHR can be revealed for medical insurance and other purposes.

Healthcare providers sign an agreement giving the Department of Health and Ageing the right to copy, adapt and communicate your PCEHR information to others.

Even after “cancellation”, your PCEHR may be accessed by healthcare providers and medical insurers and for “other purposes authorised by law”.

These rights cannot be revoked even on termination of the agreement.

The same rights are then conferred by the Department of Health and Ageing to all other participants in the participation agreement.

Department of Health and Ageing. Participant Agreements.

http://www.ehealth.gov.au/internet/ehealth/publishing.nsf/content/providerregistration_participation_agreement

Australian Government. Terms of Use.

<https://my.gov.au/mygov/content/html/terms.html>

Department of Health and Ageing. Frequently Asked Questions: healthcare Professionals.

[http://www.ehealth.gov.au/internet/ehealth/publishing.nsf/Content/74323BD48C928B37CA257A5E0016CE44/\\$File/HCP-FAQs-for-ehealth.gov.au-130626.pdf](http://www.ehealth.gov.au/internet/ehealth/publishing.nsf/Content/74323BD48C928B37CA257A5E0016CE44/$File/HCP-FAQs-for-ehealth.gov.au-130626.pdf)

8. What happens if my clinician 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 health provider does not upload consumer information if the consumer has advised it should not be uploaded. Unauthorised collection, use or disclosure attracts civil penalties of 120 units and a fine. Contravening a civil penalty provision is not a legal offence.

Personally Controlled Electronic Health Records Act.

http://www.austlii.edu.au/au/legis/cth/consol_act/pcehra2012473/

9. Can the information stored in my PCEHR be used unlawfully?

Yes and No

System security can never be guaranteed, all experts can do is address known PCEHR threats. For example, clinicians with immature e-health systems can download screen pictures of your PCEHR in a consolidated view and these may be passed downstream to other clinicians, who are governed by the Federal Privacy Act, 1988, not the Personally Controlled Electronic Health Records Act.

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. Masking their internet protocol (IP) address may mean the hacker escapes detection.

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

National Authentication Service for Health (NASH). <http://www.nehta.gov.au/our-work/nash>

Public Key Infrastructure. <http://www.medicareaustralia.gov.au/provider/vendors/pki/index.jsp>

Hide IP (machine address on the Internet). <http://www.hide-my-ip.com>

Department of Health and Ageing. Participant Agreements.

http://www.ehealth.gov.au/internet/ehealth/publishing.nsf/content/providerregistration_participation_agreement

10. Will my GP be penalised if they do not “volunteer” to sign up for PCEHR participation?

Yes and No

General practitioners who do not sign the participation agreement will become ineligible for incentive payments up to \$50,000 per annum per practice.

Australian Medical Association. Getting ready for the PIP eHealth incentive and PCEHR.

<https://ama.com.au/getting-ready-pip-ehealth-incentive-and-pcehr>

11. Is the system authorising clinician access to the PCEHR secure?

Yes and No.

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

The PCEHR legislation does not take human factors into account. For further information, see 8 above.

National Authentication Service for Health (NASH). <http://www.nehta.gov.au/our-work/nash>

12. Will my PCEHR allow clinicians to share reliable health information to support my care: the right patient at the right time at the right place with access to the right information?

Yes and No

Community contact with the APF from all over Australia strongly suggests PCEHRs storing inaccurate patient information are beginning to emerge. Patients registered on the system evidently spend a great deal of their time arguing about record contents with treating clinicians. Inaccurate information is not a safe foundation for clinicians to diagnose and manage illness.

There is evidence suggesting inaccurate information is affecting prescription data.

Audit legislation supporting the security and privacy of information stored in your PCEHR excludes human error and grants an amnesty for unintended breaches.

Department of Human Services. Healthcare Identifiers Service.

<http://www.humanservices.gov.au/customer/services/medicare/healthcare-identifiers-service>.

Kruys, E. PCEHR: Who is the customer? (slideshow) Doctor's bag blog.

<http://doctorsbag.wordpress.com/2013/07/29/pcehr-who-is-the-customer/>

McDonald, K. Update: Incorrect PBS data added to PCEHR. Pulse IT; 13 May 2013.

http://www.pulseitmagazine.com.au/index.php?option=com_content&view=article&id=1424:incorrect-pbs-data-added-to-pcehr&Itemid=328

Kruys, E. Why is the health consumer always wrong? Doctor's bag blog.

<http://doctorsbag.wordpress.com/2013/07/26/health-consumer-always-wrong/>

13. Can I correct mistakes recorded in my PCEHR in a timely fashion by communicating with the system operator or their agents?

No

When you lodge a complaint about the accuracy of your record, an internal investigation will occur. Results of the investigation may be communicated to you in “due course”. We understand that even when the complaint is proven, information stored on one’s PCEHR is not necessarily updated. Both the misinformation and new information (if relevant) remain stored in the database supporting one’s PCEHR because every diagnosis initiates the superseding of a preceding record and both documents are retained.

McDonald, K. Privacy Commissioner Reveals Investigative Powers Over PCEHR, Pulse IT; 2 July 2012
http://www.pulseitmagazine.com.au/index.php?option=com_content&view=article&id=1056:privacy-commissioner-reveals-investigative-powers-over-pcehr&catid=16:australian-ehealth&Itemid=328

Kruys, E. PCEHR: Who is the customer? (slideshow) Doctor’s bag blog.

<http://doctorsbag.wordpress.com/2013/07/29/pcehr-who-is-the-customer/>

Department of Health and Ageing. Personally Controlled Electronic Health Record (PCEHR) - Privacy Impact Assessment Report; Chapter 8 - Governance of the broader PCEHR System.

<http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/pcehr-legals-pia-toc~chapter-8>

McMillan, J. Australian Information Commissioner. EXPLANATORY STATEMENT to F2013L01085. Personally Controlled Electronic Health Records Act 2012: PCEHR (Information Commissioner Enforcement Powers) Guidelines 2013.

http://www.oaic.gov.au/images/documents/privacy/applying-privacy-law/legally-binding-privacy-guidelines-and-rules/Explanatory_Statement_-_PCEHR_Enforcement_Guidelines.pdf

14. Can I control access to the information stored about me in my PCEHR record?

Yes and No.

The Shared Health Summary provides a consolidated view of the consumer’s PCEHR. It provides information about an individual’s allergies and adverse reactions, medicines, medical history and immunisations. We believe consumers cannot presently limit clinician access to the Shared Health Summary. Consumers can put data into the Personal Notes section of the PCEHR but they are the only people the system will allow to access the data.

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 meaningfully controlled by any authority (see 9 above).

Department of Health and Ageing. Participant Agreements.

http://www.ehealth.gov.au/internet/ehealth/publishing.nsf/content/providerregistration_participationagreement

Department of Health and Ageing. Concept of Operations: Relating to the introduction of a Personally Controlled Electronic Health Record System; 4.4.2 Consolidated View.

http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/PCEHRS-Intro-toc~ch4~4_4~4_4_2

15. Will complaints to the Office of the Australian Information Commissioner about privacy intrusions into my PCEHR record be pursued in accordance with law?

Yes and No.

Not all complaints to the Office of the Australian Information Commissioner are recorded or actioned. The Information Commissioner may choose not to act on proven breaches at all.

McDonald, K. Privacy Commissioner Reveals Investigative Powers Over PCEHR, Pulse IT; 2 July 2012
http://www.pulseitmagazine.com.au/index.php?option=com_content&view=article&id=1056:privacy-commissioner-reveals-investigative-powers-over-pcehr&catid=16:australian-ehealth&Itemid=328

McMillan, J. Australian Information Commissioner. EXPLANATORY STATEMENT to F2013L01085. Personally Controlled Electronic Health Records Act 2012: PCEHR (Information Commissioner Enforcement Powers) Guidelines 2013.

http://www.oaic.gov.au/images/documents/privacy/applying-privacy-law/legally-binding-privacy-guidelines-and-rules/Explanatory_Statement_-_PCEHR_Enforcement_Guidelines.pdf

Department of Health and Ageing. Personally Controlled Electronic Health Record (PCEHR) - Privacy Impact Assessment Report; Chapter 8 - Governance of the broader PCEHR System.
<http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/pcehr-legals-pia-toc~chapter-8>

16. Where is the PCEHR data stored?

We understand some PCEHR information will be stored in a centrally managed series of data-bases that are stored locally. It is not clear whether any PCEHR data is stored off-shore or in the cloud. (See 16 for further information)

National E-Health Transition Authority (NEHTA). Clinical Documents & PCEHR Infrastructure pages.
<http://www.nehta.gov.au/our-work/clinical-documents>

17. Can I download a copy of data onto patient devices e.g. smartphone or computer tablet?

No.

Also, clinician access to this privilege is unclear at present and no adequate response is currently available. However the advertisement at

https://www.youtube.com/watch?v=UKz7pBhJvOY&feature=player_embedded#t=0s suggests patient information will be downloaded to a clinician's computer tablet or smartphone.

Presently, many hospitals do not permit tablets to access the network due to security concerns. Consumers may access a portal version of their health record. In the future access to your record may be possible on the individual's computer tablet or smart phone, but we believe this is not the case yet. At present, access to the patient portal seems to be mediated by health authorities.

18. What rights do I have if data I entered or have uploaded is wrong or misused?

This is a grey area.

If you can demonstrate that you have suffered significant financial impact as a result of wrong or misused data stored in the PCEHR, you may be able to litigate.

The Crown and its agents are exempt from all liability resulting from PCEHR system data breaches. The PCEHR System Operator, the Service Operator, and the Chief Executive Medicare are authorised to collect, use and disclose to participants in the PCEHR system the healthcare identifier and the identifying information of a person seeking to be recognised as an authorised representative of a consumer by the PCEHR System Operator. The Service Operator is the Secretary of the Health Department.

All other rights to act depend on the judgement of the System Operator and the Office of the Australian Information Commissioner. If in their discretionary judgement, proven complaints about a breach is deemed significant, reasonable and practical it may be actioned by health authorities.

Healthcare Identifiers Amendment (PCEHR System Information) Regulation 2013- F2013L01269.

<http://www.comlaw.gov.au/Details/F2013L01269/Explanatory%20Statement/Text>

Personally Controlled Electronic Health Records Act.

http://www.austlii.edu.au/au/legis/cth/consol_act/pcehra2012473/

Office of the Australian Privacy Commissioner. Privacy Fact Sheets.

<http://www.oaic.gov.au/privacy/privacy-resources/privacy-fact-sheets/>

19. Must I be “computer savvy” to fully participate in the PCEHR system?

Yes and No.

PCEHR registrants will require some familiarity with using the Internet for full access to information and legislation supporting the system. For instance, advice to consumers frequently refers to various “fact sheets”, FAQs, training, legal frameworks and self- training options. To obtain access to the information, consumers must be able to navigate the Internet and piece together fragmented information over various Australian government web sites.

Office of the Australian Privacy Commissioner. Privacy Fact Sheets.

<http://www.oaic.gov.au/privacy/privacy-resources/privacy-fact-sheets/>

Department of Health and Ageing. Personally Controlled Electronic Health Record (PCEHR) - Privacy Impact Assessment Report. <http://www.yourhealth.gov.au/internet/yourhealth>

20. Who is responsible for “downstream” use of information stored in my PCEHR record?

In the first instance, you are. Downstream use of information is generally governed by measures currently outlined in the federal Privacy Act, 1988, and by state and territorial arrangements. The measures are generally enacted after the affected person lodges a complaint deemed sufficiently significant to be recorded and/or followed up by the Office of the Australian Information Commissioner or a similar health authority.

Office of the Australian Privacy Commissioner. Privacy Fact Sheets.

<http://www.oaic.gov.au/privacy/privacy-resources/privacy-fact-sheets/>

Department of Health and Ageing. Concept of Operations: Relating to the introduction of a Personally Controlled Electronic Health Record System;4.6 Reports

Department of Health and Ageing. PCEHR Essential Information Online.

<http://www.ehealth.gov.au/internet/ehealth/publishing.nsf/content/home>

Brettingham-Moore, C. Prescription data stored on pharmacy computers fail ANAO audit ,Medical Observer, June 4 2010.

21. Are there concerns about consumer registration assistant training?

Yes.

Consumer registration assistants have been deployed to over 250 healthcare sites including hospital lobbies, outpatient clinics and Centrelink offices to conduct consumer awareness activities and assisted registration for the PCEHR.⁽⁵⁾

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.

Patients report that MediCare Locals have convened sessions with general practice staff to encourage them to approach patients in waiting rooms with “assisted registration”.

Patients have reported being approached in Centrelink waiting areas by registration assistants to register them for a PCEHR.

Patients in rehabilitation have reported feeling pressured by health practice staff to encourage them to join the PCEHR system with “assisted registration”.

Almost 500,000 Australians have registered into the system but only 3,818 have populated Shared Health Summaries. From this evidence, we infer a variety of people have been ‘incentivised’ to register with the system.

McDonald, K. Contractors hired for PCEHR but Medicare Locals not happy. Pulse IT; 6 June 2013. http://www.pulseitmagazine.com.au/index.php?option=com_content&view=article&id=1459:contractors-hired-for-pcehr-but-medicare-locals-not-happy&catid=16:australian-ehealth&Itemid=328

Kaye, B. PCEHR still too difficult: GP. Medical Observer. <http://www.medicalobserver.com.au>

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.

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

Kruys, E. Beware of the PCEHR legal risks; Doctor’s bag blog.

<http://doctorsbag.wordpress.com/2013/05/10/beware-of-the-pcehr-legal-risks/>

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.

RACGP. Personally controlled electronic health record (PCEHR); Royal Australian College of General Practitioners' web site.

<https://www.racgp.org.au/your-practice/e-health/ehealthrecords/pcehr/intopractice/>