

# ACHI COMMENTS

on the

## NEHTA PCEHR - Key Points Concept of Operations

***Note: these comments apply to the Information Requirements of both the SHS and ES documents.***

### Key points

#### **Draft Concept of Operations: Relating to the introduction of a personally controlled electronic health record (PCEHR) system.**

This document is a summary of key points. You can find the full Draft Concept of Operations: Relating to the introduction of a PCEHR at:

<http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/pcehr-document>

#### **1. Overview**

eHealth is an important part of the Australian Government's health reform agenda which aims to deliver a better deal for patients and secure the long-term sustainability of Australia's health system.

To provide better access to health information, the Australian Government is developing the Personally Controlled Electronic Health Record (PCEHR). This system will enable the secure sharing of health information between an individual's healthcare providers, while giving the individual control over who can access their ehealth record.

The Government has invested \$466.7 million to develop the basic functionality required to establish the PCEHR System that will grow over time. This first release will give all Australians from July 2012 the option to sign up for a PCEHR.

The PCEHR System will build on the foundation laid by the introduction of the National Healthcare Identifiers for individuals, healthcare providers and healthcare organisations as well as the National Authentication Service for Health, standard clinical terminologies and methods for communicating health information between healthcare providers such as discharge summaries and electronic referrals.

#### **ACHI Comments:**

During the College's review of the PCEHR "Shared Health Summary" and "Event Summary" Information Requirement documents, the question who is the intended user of the SHS and ES in the PCEHR arose in many places. This is an important distinction as the needs of patients and doctors are quite different and in some areas contradict each other.

Depending on for whom the Shared Health Summaries and Event Summaries inside the PCEHR is being created will determine who provides the content and how

the content is added into the PCEHR: If the PCEHR is intended for the patient, which doctor(s) will provide the clinical content? If the PCEHR is intended for clinicians, will it be populated electronically and how will the data quality be assured?

**Recommendation KP.1:** *That the Continuity of Care Program Team clarify the intended users of the SHS and ES in the PCEHR.*

While at this point in time the purpose of the PCEHR is not clear to patients and clinicians, we expect that the discussions on this will prevail. In this context, the success of the Scottish Emergency Health Summary<sup>1</sup> is impressive as it allows consumers to put up information (including a statement that there is none) that assists those providing health care to them in an emergency. This encourages participation as people are clear about what it is for and more than 80% of Scots now have an Emergency Health Summary record. Some patients will want more than others and to have it used for other purposes, but its principal function is clear, intuitive and has proven its success.<sup>2</sup>

Medicines reconciliation is on the agenda in Scotland as their use of the emergency summary is being extended. Again, the purpose is readily apparent to the consumers, such as those seeing a number of providers frequently or travelling regularly. A discharge summary has validity as part of an emergency summary as a lot of people re-attend the hospital within a month or have to see primary care providers that they do not know.

**Recommendation KP.2:** *That the Continuity of Care Program Team clarify the purpose of the SHS and ES to the intended users of the PCEHR.*

Regarding the use of the SHS and ES in the PCEHR, it can be expected that initially users will be unclear as to their uses and the type of information they would like to see and possibly add to the PCEHR. Regarding adding personal health information and concerns, we need to accept that patients will be embarrassed and change their minds. Also, health information will be expressed in a way that is acceptable to them at the time but when they see the effect on others they will want to change it.

**Recommendation KP.3:** *That the Continuity of Care Program Team be aware that the understanding of the PCEHR users will initially be minimal and that their perceptions of the PCEHR's use and usefulness will change over time.*

During the College's review of the PCEHR "Shared Health Summary" and "Event Summary" Information Requirement documents, the Continuity of Care Program Workshop and the Teleconference, the issue of the useability of the SHS and ES in the PCEHR was repeatedly raised. Clinicians, health service providers and health informaticists each raised different aspects of the ease of use of the PCEHR as users today expect a very high level of useability from computer systems and software. For most users - professional and consumers alike - benchmarks for computer useability are their iPhone or iPad, their Gmail, Facebook or Yahoo accounts. Most expect intuitive user interfaces with one-click operation. Software companies today spend much effort to ensure that their products show maximum useability as they have found that lack of useability has become a serious barrier to success-

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<sup>1</sup> See [www.epractice.eu/en/cases/nhssecs](http://www.epractice.eu/en/cases/nhssecs)

<sup>2</sup> The Socio-Economic Impact of NHS Scotland's Emergency Care Summary, see [www.ehr-impact.eu/downloads/documents/EHRI\\_case\\_ECS\\_V11.pdf](http://www.ehr-impact.eu/downloads/documents/EHRI_case_ECS_V11.pdf)

ful adoption of their products. From its review of the SHS and ES information requirements and the SHS and ES examples the College believes that more work on the useability of the SHS and ES needs to be undertaken as a priority. The College is concerned that consumer adoption of the PCEHR could be substantially affected if useability reviews and improvements of the SHS and ES are not undertaken.

**Recommendation KP.4:** *That the Continuity of Care Program Team ensure that all aspects of the SHS and ES in the PCEHR undergo a professionally guided useability review in cooperation with clinicians and consumers and the findings of these reviews are applied to the functional design.*

A recent paper "Consumer empowerment versus consumer populism in healthcare IT." by Don Simborg MD, Founding Member, American College of Medical Informatics and former HL7 International Board member, in which he is quite critical about the role and success of consumer-driven EHRs<sup>3</sup>:

Simborg is concerned about that the *"aim is to create a new and intelligent information system totally controlled by the consumer which integrates personal information with clinical knowledge in an accessible manner:-*

- *On the information side, only the patient has access to all of his or her medical information across the fragmented provider system, so let the patient aggregate this information or cause it to be aggregated in one place under consumer control*
- *Only the patient knows the extent and nature of his or her own non-provider based health activities*

*IT "populists" claim that only the patient should control which of the healthcare information components should be shared with which providers and when. On the knowledge side, IT populists claim that, since no physician can possibly keep up with all of the advances in medicine, glean from the experts in every field the latest evidence and best practices, and provide expert-level decision support via the now complete, independent ("untethered") personal health record (PHR).*

The research paper then says:

- *No matter how good the consumer-controlled PHRs are or become, most patients require and/or desire to see a highly qualified, personable, trustworthy, available-over-the-long-term healthcare provider.*
- *Every such provider must maintain a medical record about the patient for clinical, business and legal reasons. Increasingly those records will be electronic.*
- *Therefore at or before the time of every encounter with the doctor the consumer, simply provides the provider (or his/her system) with the now complete set of patient information available from the patient's untethered PHR. The IT populists solve the elusive "interoperability" problem.*
- *Care providers are struggling to convert to electronic health records. It is not an easy process.*
- *Over time providers develop a form of "muscle memory" in navigating through the displays and entry screens so that it becomes familiar and easy. At that point, and only at that point, they also begin to experience the benefit of elec-*

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<sup>3</sup> Simborg, D. W. "Consumer empowerment versus consumer populism in healthcare IT." J Am Med Inform Assoc 17(4): 370-2.

tronic availability of patient information coupled with the decision support benefits of expert knowledge.

- *With only 6-15 minutes allotted to each visit, the clinical record review (patient's + provider's) must be done quickly. If the care provider has an electronic system, there is usually some type of summary screen and the provider knows how to navigate quickly from this to the most recent interval information or other relevant information. Imagine now the patient handing the provider a printout (or transfer of an electronic copy in human readable format) from the patient's PHR at each encounter. Given current time pressures for brief visits, even with an existing patient with prior encounters, most care providers simply would not take the time to review the PHR system records in addition to looking at their own records. The workflow for the provider to incorporate external record information into their existing system is formidable from a manual entry perspective – it would be too time consuming for this to work.*

The US research identifies the following specific problems with a personal EHR:

- *There is a problem with consumer-controlled PHRs that will be difficult to overcome. That is the trust that the information has not been altered by the consumer after receipt from its original source. The insistence by some that consumers have the right to do whatever they please with their information, including altering physician-established diagnoses and changing certified laboratories' reported result values is a misguided attempt at empowerment. It is simply unnecessary and undermines the ability of the provider to consider the source.*
- *Ideally, the PHR and EHR systems would tag each item of information with its original source, with appropriate contact information that would allow verification, as described above.<sup>4</sup>*
- *Another problem is the application of independent clinical decision support in PHRs uncoupled from providers. An example of this problem is the application of drug interaction alerts. For example, few patients are in a position to know when it is appropriate or safe to override drug interaction warnings.*
- *Uncoupling these processes has the potential to induce patients to make independent decisions regarding their medications (which, without provider input, might have adverse consequences for the patient) and to uncouple the information in the respective records.*
- *Synchronizing information between multiple databases is difficult and usually incomplete at various points in time. The cost and complexity of synchronizing patient information among multiple providers caring for the same individual is only compounded if the many PHRs must also be synchronized.*

Having identified these problems with a personally controlled EHR, Simborg offers this solution:

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<sup>4</sup> The author conflates certified laboratory reports, which is fact, with physician-established diagnosis, which is a human professional opinion. Consumers may disagree with the latter but not the former. Consumer information stored on records must be limited to fact rather than professional opinion.

Consumers have the human right to control information about themselves. Whatever is finally implemented it can not contradict the Universal Declaration on Human Rights ([www.un.org/en/documents/udhr](http://www.un.org/en/documents/udhr))

*The solution would be to provide an electronic interface between a patient's PHR and the provider's EHR in a manner that allows integration with the provider's existing system so that the new information is incorporated in a seamless manner consistent with the semantics and format of the existing EHR. Otherwise, the electronic copy of the PHR would be no better than the paper copy.*

*Patients can be empowered to take control of their personal health by using provider-controlled personal health records assuming informaticians have solved the same problems of interoperability that would need to be solved anyway to make untethered PHRs work. Patients could still control which provider(s) are involved in the exchange of their personal information through electronic interfaces. They could still instruct that all or parts of that information be withheld from such a transfer. Tethering the PHR brings together the needs of both the provider and patient in optimizing the brief encounters they have with each other without the adverse consequences of uncoupling these systems.*

**Recommendation KP.5:** *That the PCEHR Concept of Operations Team and the Continuity of Care Program Team review and consider the Simborg research.*

In this context, an EHR scoping review<sup>5</sup> published in July 2011 should be noted. The review found "*that, because primary care physicians play a key role in patient health, PHRs are likely to be linked to physician electronic medical record systems, so PHR adoption is dependent on growth in electronic medical record adoption. Many PHR systems are physician-oriented, and do not include patient-oriented functionalities. ... Differences in patient motivation to use PHRs exist, but an overall low adoption rate is to be expected, except for the disabled, chronically ill, or caregivers for the elderly.*" This study by McMaster University published by the US National Institutes of Health also found that "*although there is a large amount of survey, observational, cohort/panel, and anecdotal evidence of PHR benefits and satisfaction for patients, more research is needed that gathers evidence to evaluate the results of PHR implementations in the context of works such as the Delone and McLean model of information systems success.*<sup>6</sup> At this point, there is little solid evidence from RCTs or other studies of proven effectiveness in improved patient health outcomes through the use of PHRs. More research is also needed that addresses the current lack of understanding of optimal functionality and usability of these systems, and how they can play a beneficial role in supporting self-managed healthcare."

This research supports the College's view that the purpose, users and data sources of the SHS and ES in the PCEHR need further work.

**Recommendation KP.6:** *That the PCEHR Concept of Operations Team and the Continuity of Care Program Team review and consider the very recent McMaster with regards to the purpose, users and data sources of the SHS and ES in the PCEHR.*

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<sup>5</sup> Personal health records: a scoping review, J Am Med Inform Assoc. 2011 July; 18(4): 515–522 ( see [www.ncbi.nlm.nih.gov/pmc/articles/PMC3128401](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3128401) )

<sup>6</sup> Delone WH, McLean ER. The Delone and McLean model of information systems success: a ten-year update. J Manag Info System 2003;19:9–30.



From the text of this "Key Points - CONCEPT OF Operations" document, it appears that the general expectation is now that a "first release will give all Australians from July 2012 the option to sign up for a PCEHR" eg. this first phase will be limited to give the public the capability to set up an "account" in the PCEHR system. This document - while listing the many benefits of an electronic health record - does not give any more specific function details. Combined with DoHA CIO Paul Madden's recent statement<sup>7</sup> that the full implementation cycle of the PCEHR might take until 2020, it could be assumed that this may be the "first phase" of a phased implementation over the next ten years. Consequently, this first phase might be characterised as a "Personally Controlled Electronic Health Diary", eg an electronic "aide-memoire" for patients with multiple healthcare encounters and maybe multiple conditions that require treatment. This "health diary" could be augmented by MBS/PBS claims data already currently available in the Medicare Australia systems. As Medicare Australia also manages the Individual Health Identifier (IHI), the linking of this information to the PCEHR account of Australians who have opted in to setting up a PCEHR account would be quite easy and reliable.

Such an initial EHR could provide the benefits outlined in this "Key Points" document without attracting the concerns listed in our recent Response to the Concept of Operations<sup>8</sup>.

Similar to any other user-maintained online record, patients would have full responsibility for their health diary but it would not be seen as clinically definitive, so avoiding the concerns of "duplication" of information and the currently unclear medico-legal position of the PCEHR.

The initial health diary implementation phase of the PCEHR would be of substantial benefit to patients with conditions that make it beneficial for them to keep track of their recent medical history, medications and test results for situations where they cannot access their regular GP (eg "grey nomads") or become incapacitated - see the "*disabled, chronically ill, or caregivers for the elderly*" in the recent scoping review quoted above. This would overcome the concerns of limited user buy-in and also address the issue of PCEHR rejection by those with strong privacy concerns.

It is expected that these "motivated" patients will ask their doctors to upload clinical information into their PCEHRs and it is believed that their GPs would generally respond positively to these requests as an up-to-date PCEHR health diary that can be accessed by interstate GPs and emergency departments also benefits them as the physician responsible for the long-term care of their patients. This approach may also mitigate concerns regarding the potential for tension or a lack of trust to interfere with the doctor-patient relationship.

The access control afforded to the patient detailed in this document, the ConOps and the legislative issues paper is also consistent with the view that the PCEHR is intended to be a personal diary for the patient and not a comprehensive, accurate and complete electronic health record which would be required for healthcare providers to be confident to use this as a primary and trusted information source and acceptable basis for making clinical decisions with regard to clinical investigation,

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<sup>7</sup> [www.theaustralian.com.au/australian-it/low-cost-high-security-systems-that-hinge-on-giant-virtualised-computers-cloud-computing-catches-on/story-e6frgaxk-1226061374157](http://www.theaustralian.com.au/australian-it/low-cost-high-security-systems-that-hinge-on-giant-virtualised-computers-cloud-computing-catches-on/story-e6frgaxk-1226061374157)

<sup>8</sup> Response to PCEHR Draft Concept of Operations, ACHI, June 2011, [www.achi.org.au/docs/ACHI\\_Response-PCEHR\\_ConOps\\_V1.2.pdf](http://www.achi.org.au/docs/ACHI_Response-PCEHR_ConOps_V1.2.pdf)

diagnosis, treatment and ongoing management of patients across a broad range of clinical care scenarios and settings.

However, the College believes that consumer interest alone is not sufficient to ensure the long-term sustainability of the PCEHR. The recent decision of Google Inc to close down their "Google Health" personal health record<sup>9</sup> is further evidence that consumer interest in PHRs is not sufficient to support their ongoing operation.<sup>10</sup>

Of course, this consumer-focussed phase should only be a starting point as the most of the research indicates that the healthcare benefits of a consumer-driven system are very limited; tangible benefits only accrue from emergency data (eg. the Scottish Emergency Health Summary referred to above) or a record curated and validated by a 'nominated provider', who must be a health professional who is capable of understanding the patient's continuing comprehensive care, medications, etc.

**Recommendation KP.7:** *That the PCEHR Concept of Operations Team and the Continuity of Care Program Team give consideration - if the purpose of the PCEHR is to be for the consumer - to an initial "Health Diary" phase.*

**Recommendation KP.8:** *That the PCEHR Concept of Operations Team and the Continuity of Care Program Team give consideration - if the purpose of the PCEHR is to be for Clinicians - to what processes are required to create an EHR that is curated and validated by a health professional who can be relied on to understand the patient's diagnosis, continuing comprehensive care needs, medications, etc*

## 1.1 The need for a PCEHR System

One of the many challenges faced by the Australian health system is that health information is held in dispersed records across the country. In many healthcare situations, quick access to key health information about an individual is not always possible. Limited access to health information at the point of care results in:

- A greater risk to patient safety.
- Increased costs of care and time wasted in collecting or finding information.
- Unnecessary or duplicated treatment activities.
- Additional pressure on the health workforce.
- Reduced participation by individuals in their own healthcare information management.

The PCEHR System will enable better access to important health information, allowing individuals to view their important health information when and where they need it. They will also be able to share this information securely to healthcare providers involved in their care.

This will result in:

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<sup>9</sup> <http://googleblog.blogspot.com/2011/06/update-on-google-health-and-google.html>

<sup>10</sup> <http://blogs.msdn.com/b/familyhealthguy/archive/2011/06/26/yes-thanks-we-ve-heard-about-google-health.aspx>

- Improved continuity of care for individuals accessing multiple healthcare providers by enabling key health information to be available where and when it is needed.
- Access to consolidated information about an individual's medicines, leading to safer and more effective medication management and reductions in avoidable medication-related adverse events.
- Enabling individuals to participate more actively in their healthcare by improved access to their health information.
- Improved diagnostic and treatment capabilities through better access to health information.
- Improved care coordination for individuals with chronic or complex conditions by enabling the individual's healthcare team to make better-informed decisions at the point of care.

### **ACHI Comments:**

These are well-accepted general benefits of electronic health records (EHRs) for individuals with chronic and/or complex health conditions. However, the proposed PCEHR is not yet an EHR which has the listed benefits, so care should be taken to manage the expectations of clinicians and the public on the PCEHR to not be at risk of "underdelivering".

Furthermore, a parallel system of EHRs fitted over the broad range of existing practice records may not be generally beneficial. The lumping together of various chronic or complex conditions is unhelpful as patients are not diagnosed with "complex ill health" or "chronic ill health" but a combination of specific conditions. The PCEHR may be administratively useful in this context (i.e. demographics, appointments, etc.) but appears to support neither combined medical conditions nor team-based care.

It is the view of the College that there is reasonably strong evidence of the need for quality EMR / EHR systems in the hands of primary care and hospital clinicians and other healthcare providers but as stated above the evidence of usefulness of Personal Health Records (PHRs) - such as the initial phase of the PCEHR represents - is quite weak.

***Recommendation KP.9:*** *That the various functional phases of the PCEHR over the next decade be clearly outlined to ensure that stakeholders understand what functions and benefits will be delivered at which point in time.*

## **1.2 The PCEHR System**

The PCEHR System aims to place the individual at the centre of their own healthcare by enabling access to important health information when and where it is needed by individuals and their healthcare providers.

Individuals will be able to choose whether or not to have a PCEHR, and if they choose to participate, they will be able to set their own access controls. With the individual's permission, key pieces of health information may be viewed by participating healthcare providers across different locations and healthcare settings.



## 1.3 Participation

### 1.3.1 Individuals

Individuals will be able to register for a PCEHR from July 2012. Those who choose to participate will have the opportunity to experience the following benefits:

- Access to their health information
- Receive improved healthcare
- Be more informed about their healthcare choices

Individuals may also nominate representatives (such as family members and carers) to help manage their PCEHR. Authorised representatives (such as parents and guardians), will also be able to register individuals in their care and access their PCEHR. Additional processes will be put into place to manage access when the child becomes older and is able to manage their own PCEHR.

Individuals will be able to withdraw at any time from the PCEHR System. A PCEHR is not mandatory for receiving healthcare services.

#### **ACHI Comments:**

It is not clear how dot point 2 above will be achieved.

Point 3 above appears to point to new information provided about healthcare choices ...

**Recommendation KP.10:** *That the PCEHR Concept of Operations Team and the Continuity of Care Program Team clarify the meaning and function of the "Be more informed about their healthcare choices" feature.*

### 1.3.2 Healthcare providers and organisations

Healthcare organisations will be able to access the PCEHR System from July 2012. Healthcare organisations that choose to participate will have the opportunity to:

- Access health information more efficiently
- Ensure safer healthcare
- Deliver more effective healthcare

## 1.4 Personal control

Central to the PCEHR System is the concept of personal control. Participating individuals can have control over their PCEHR in the following ways:

- **Decide whether or not to have an active PCEHR:** The PCEHR System operates on an opt-in model, where individuals elect to register and create a PCEHR. At the point of registration, individuals establish their PCEHR by consenting to the terms and conditions of the PCEHR and set their access controls. Individuals may de-activate their PCEHR at any time.

#### **ACHI Comments:**

It is not clear if this access is direct or via the PCEHR operator.

**Recommendation KP.11:** *That the PCEHR Concept of Operations Team clarify the means of consumer access to the PCEHR access controls.*

- **Access information in their PCEHR:** Individuals will be able to view any health information contained in their PCEHR.

#### **ACHI Comments:**

It is not clear if this viewing access will exist from the day the consumer signs up.

***Recommendation KP.12:** That the PCEHR Concept of Operations Team clarify when consumer full viewing access commences.*

- **Set controls around healthcare provider access:** Individuals can determine and change settings around access to their PCEHR to participating healthcare organisations involved in their healthcare. Individuals may choose from a range of approaches to setting and managing these controls. Where the individual requires emergency care access controls may be overridden.
- **Authorise others to access their PCEHR:** Individuals can nominate other persons (such as carers and family members) to access health information in their PCEHR.
- **Choose which information is published to and accessible through their PCEHR:** Individuals can request healthcare providers to not send information to their PCEHR. There will be optional advanced mechanisms to more closely manage access to certain information.
- **View an activity history for their PCEHR:** The PCEHR System will provide an audit trail where individuals can view a history of actions on their PCEHR.

#### **ACHI Comments:**

It is not clear if this history viewing access is direct or via the PCEHR operator.

***Recommendation KP.13:** That the PCEHR Concept of Operations Team clarify the means of consumer PCEHR history viewing access.*

- **Make enquiries and complaints:** Individuals can make enquiries and complaints in relation to the management of personal information in their PCEHR and the PCEHR System

#### **ACHI Comments:**

It is not clear if this complaints process is direct or via the PCEHR operator.

***Recommendation KP.14:** That the PCEHR Concept of Operations Team clarify the means of consumer PCEHR complaints process.*

The above clarifications are useful but with this level of control provided to the consumer it is hard to assess the interest of practitioners in undertaking "quality control" of the information held in their PCEHR. There are also some gaps in the list above that require clarification.

In the consumer context, the College believes that access to information held in the PCEHR where a patient has decided to 'Opt Out' (i.e. deactivate their PCEHR) needs to be clarified:

In an emergency situation will healthcare providers have access to information retained in a deactivated record?

How long will information be retained in a deactivated record?

Is it possible for an individual to have their PCEHR deleted (rather than just deactivated) if they request it, considering that the PCEHR is only a copy of the original health information or medical record(s) held by health providers.

**Recommendation KP.15:** *That the PCEHR Concept of Operations Team clarify the operation and access modalities of deactivated PCEHR records.*

Merging of information held in multiple PCEHR records: is it possible and does a process exist for information held in multiple (maybe pseudonymous) PCEHRs pertaining to a person to be merged or linked?

Enabling the creation of pseudonymous PCEHRs may impact on care delivery to patients where emergency access to an individual's PCEHR is required. Clinical care may be compromised if the individual has important information held in a pseudonymous PCEHR that is inaccessible to health providers in an emergency situation.

**Recommendation KP.16:** *That the PCEHR Concept of Operations Team clarify the operation and access modalities of pseudonymous PCEHR records.*

## 1.5 Privacy and security

Health information within the PCEHR System will be protected through a combination of legislation, governance arrangements and security and technology measures. Some of the technical and non-technical controls include:

- Accurate authentication of users accessing the PCEHR System.
- Robust audit trails.
- Proactive monitoring of access to the PCEHR System to detect suspicious and inappropriate behaviour.
- Rigorous security testing, to be conducted both before and after the implementation of the PCEHR.
- Education and training of users of the system.
- Requirements that healthcare providers and organisations comply with specific PCEHR System business rules and other relevant legislation.

Individuals will be able to make enquiries and lodge complaints regarding suspicious or unauthorised access to their PCEHR.

### **ACHI Comments:**

These controls are in line with current best practice on health IT systems technical security best practice. ACHI notes that this functionality relies on the revised privacy legislation being enacted and the National Authentication System for Healthcare (NASH) being fully implemented to cover all healthcare provider staff.

**Recommendation KP.17:** *That the support of the PCEHR's Privacy and security functionality by legislation and NASH be clearly stated to ensure consumer confidence in the protection of their healthcare information.*

**Recommendation KP.18:** *That the security risks caused by human factors be assessed and mitigated.*<sup>11</sup>

Robust data encryption should be applied to all patient information stored in PCEHR systems and repositories – encryption of all PCEHR systems should be a fundamental requirement. All agencies (including commonwealth, state government or NGOs), private sector organisations and individuals (i.e. not just health-care providers and organisations) that are permitted access to PCEHR systems or PCEHR information stored in repositories or datastores (e.g. for the purpose of system administration, operation, research or any other authorised purpose) should at a minimum comply with privacy, security and confidentiality requirements as specified in existing commonwealth and state privacy and health record legislation. In addition, specific PCEHR legislation should include specification of the purposes for which authorised access to the PCEHR systems and data will be granted, administered, monitored and how privacy and security breaches will be dealt with (i.e. enforcement, penalties etc).

**Recommendation KP.19:** *That the encryption security measures of all PCEHR systems and associated repositories or datastores be detailed and risk-assessed.*

## 1.6 Governance

There will be the establishment of appropriate governance structures and mechanisms to manage the national PCEHR program and its operation. During the PCEHR planning phase to June 2012, the primary accountability for the PCEHR system is with the Minister for Health and Ageing. Planning responsibility for the PCEHR system's implementation into the broader health sector, and its strategic fit with state and territory health policies, is with the Australian Health Ministers' Conference.

### ACHI Comments:

The College noted in its recent Response to the Draft PCEHR Concept of Operations that the details of the proposed PCEHR governance structures and mechanisms are still to be published for public comment. Appropriate governance structures should not be an afterthought

It would appear that the Governance framework has not yet been developed – this is a critically important issue that should be completed ASAP. It would be preferable for a draft framework to be completed and distributed for public comment prior to being finalised.

The Governance framework should:

- a. provide a high level of transparency and accountability
- b. include engagement of the critically necessary stakeholder communities
- c. provide a comprehensive list of all governance bodies and entities, inter-relationships between the entities, lines of reporting and authority, detailed roles and responsibilities, process for constituting and establishing

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<sup>11</sup> <http://healthcareitnews.com/news/top-5-most-common-gaps-healthcare-data-security-and-privacy>

- governance entities, list of constituents of the governance entities, schedule of meetings of governance entities
- d. reports, meeting agendas, minutes and other documentation to be made publicly accessible.
  - e. mechanism for registering governance related issues or complaints online via a publicly accessible website that will be addressed by the appropriate governance entity (with communication of the issue status, any actions taken and final outcome from the appropriate governance entity to the person or organisation registering the issue)
  - f. detail any legal requirements of the various governance bodies or entities described under the PCEHR Governance arrangements that may be specified in the proposed PCEHR legislation, in particular with regard to the roles and responsibilities of relevant agencies and organisations authorised to perform or assist with the following:
    - i. design, develop, implement, maintain, support, operate, monitor, audit or assess the performance of the PCEHR system (including access to the system and PCEHR information);
    - ii. investigate alleged criminal activity or breach associated with operation, access to, or management of the PCEHR system; or
    - iii. investigate complaints from individuals (or authorised or nominated persons) or health providers relating to PCEHR access (and controls), record creation, population of the records, record content or unauthorised use or misuse of PCEHR information.

Please refer to ACHI comments in the CONOPS review submission v1.2 (pages 24 and 27-28).

***Recommendation KP.20:*** *That the proposed PCEHR governance structures and mechanisms are promptly exposed for public input.*

### **More information on the eHealth agenda**

Please visit our new eHealth Information site at: <http://www.ehealthinfo.gov.au/>  
This website provides information on the PCEHR, healthcare identifiers, eHealth sites, as well as more general ehealth information through the form of text, interactive diagrams and videos. It is a resource which we will be updating regularly.

You can also find relevant video links below:

<http://www.youtube.com/watch?v=3IOoUMwSGMI&feature=relmfu>

<http://www.youtube.com/watch?v=usTGPRQVZ0A&NR=1>