



**Australian
Privacy
Foundation**

enquiries@privacy.org.au

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

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APF submission to PCEHR System: Proposals for Regulations and Rules paper

The Australian Privacy Foundation (APF) is the country's leading privacy advocacy organisation and welcomes this opportunity to influence the Australian national health reform agenda. I write as Chair of the Health Sub Committee of the APF and refer to the Personally Controlled Electronic Health Record (PCEHR) system Proposals for Regulations and Rules paper. The rapid timeline for submissions has shaped our response. This submission refers only to key issues within scope of the paper. Finally, we avoid repeating points made in previous submissions and evidence to Senate inquiries, which list our many concerns and are published or linked on our web page at <http://www.privacy.org.au/>.

1. The proposal paper does not include any drafts of proposed regulations and rules despite its title. **The APF is puzzled by the oversight.**
2. Arguments to ensure the system is “opt out” are based on the assumption that consumers and clinicians must comply with PCEHR machine system environments rather than the environments working to support and improve high quality patient care outcomes. An “opt-out” system will erode consumer and clinician confidence as evidence from overseas and in peer reviewed publications suggest. **The APF supports the current voluntary nature of consumer and clinician enrolment into the PCEHR system.**
3. The proposal paper does not clearly indicate how the system will operate in practice. Informed consent for PCEHR system registration is not possible at present. **The APF maintains that the long list of unresolved issues that are raised in the proposal paper is alarming.**
4. **The APF is concerned that term “healthcare provider” remains unspecified.**
5. The extent of Government stewardship of private information is deeply troubling. Section 3.2 mistakenly indicates that consumers will be able to participate directly in the PCEHR system. In fact consumers may be able to populate or oversee particular fields but in most instances this is not possible except through legally authorised third party representatives such as physicians or

government services. **The APF is worried that this situation will magnify potential conflict of interest that may arise from handling of private health information by third parties and bureaucrats.**

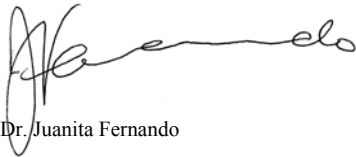
6. If the system is truly personally controlled, as the name suggests, then consumers must have full and direct control over most aspects of the record, including the right to audit access to information stored about oneself. We suggest that clinicians may require the creation of a separate electronic health record for clinical purposes. The “one-size-fits-all” approach specified in the proposal paper is impractical and unlikely to foster community trust in the system. **The APF reiterates its position: it is unacceptable to establish a national e-health record system for consumers that they cannot read independently of a third party.**
7. The System Operator will not be required to take the advice of advisory committees or to provide reasons why it has chosen not to do so. Also, there will be no independent review of the terms and conditions of the Service Operator’s various and conflicted functions in the context of the PCEHR system. **The APF believes this is ineffective and likely to erode consumer and clinician trust in the system.**
8. **The APF is very concerned that the proposed “no access” control option has been removed from the current Bill.**
9. The unremunerated administration of the PCEHR will impose an overall burden on clinician practices and organisations. International experience shows the additional cost to update the electronic record twice (the local system plus the PCEHR system) could result in patient records not updated, thereby jeopardising patient care outcomes. **The APF is troubled by the prospect of increased numbers of unintentional patient care errors as a direct consequence of the PCEHR system implementation.**
10. The APF has been advised by many professional staff, both information communication and clinical experts, of fundamental operational shortcomings. More work must be done to ensure the PCEHR system basics will function effectively before implementation. **The APF considers the date for system implementation needs to be delayed until full functionality of the current system can be guaranteed.**
11. PCEHR system security underpins consumer privacy. The system cannot ensure privacy without robust network security supports, including human factors controls. Security, and so privacy, is not adequately addressed in the proposal paper. The proposal assumes the privacy of individuals through technical controls, effective and transparent governance and legal protections. This is not the case and we are dismayed to be receiving increased consumer contact about current breaches of their e-health record; system implementation is likely to accelerate these. **The APF believes the omission of security and privacy information will impact on consumer confidence, jeopardising PCEHR system success.**
12. The APF is concerned by the fact that governance frameworks will be retrofitted to the PCEHR system. This suggests poor project management processes and ineffective oversight of the system. The lack of

accountability of the System Operator, as referred to in point 6, exacerbates this. **The APF suggests these concerns indicate that government PCEHR system priorities exclude consumer and clinician requirements.**

- 13.** The proposal paper does indicate some attempt has been made to address issues which consumers have shown are critical to their acceptance of the PCEHR system. For instance, it is pleasing to note that Section 3.1 includes consumer healthcare representatives into the Independent Advisory Council to help provide expert advice to the System Operator and ensure stakeholder input on the operation of the PCEHR system. However there is no indication of whether such representation includes NGO consumers. **The APF believes it is critical that such representation includes NGO consumers.**

Despite this proposal paper and feedback sought through earlier submissions and inquiries, uncertainty continues to surround “how the privacy applications and administrative and technical machinery of the PCEHR system will affect those who provide it, those who consume it and those who monitor it”. In short “the potential for the system to improve health outcomes, a claim which is rarely questioned”... except by the APF and like organisations seems to have ... “become almost a secondary consideration in ... government discussions of the PCEHR” ... system¹. Ultimately, given rushed timelines for consultation, implementation, the problems outlined herein and the long list of unresolved matters listed in the proposal paper, the APF queries whether the authorities are actually designing an e-health system for the majority of well Australians along with the minority who are ill (i.e. all Australians) or are they simply designing a rich database of information that will benefit health administration and research outcomes.

Yours sincerely



Dr. Juanita Fernando

Chair, Health Sub Committee
Australian Privacy Foundation

Contact Details for the APF and its Board Members are at:
<http://www.privacy.org.au/About/Contacts.html>

Dr Fernando is in Medicine, Nursing & Health Sciences
Monash University 03 9905 8537 or 0408 131 535
<mailto:Juanita.Fernando@monash.edu>

Associate Researcher, Centre for e-Health, University of Wollongong
Dr Fernando is a former councillor of the Australasian College of Health Informatics. <http://www.achi.org.au/>

REFERENCE:

1. Jolly, R. Personally Controlled Electronic Health Records Bill 2011. Social Policy Section, Parliament of Australia. 7 February 2012. <http://202.14.81.34/Library/pubs/bd/2011-12/12bd100.pdf>