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Monday May 4 2009

Dr Christine Bennett
Chair
The National Health and Hospitals Reform Commission

Dear Dr Bennett

Re: Response to the supplementary paper- Person-controlled Electronic Health Records

The Australian Privacy Foundation (APF) congratulates the National Health and Hospitals Reform Commission (NHHRC) with regard to several aspects of the interim report "Person-controlled Electronic Health Records".

1. The committee discussion of e-health analyses the strategic level of patient care as well as organizational one.
2. The report recognises the long overdue need to provide additional resources for new equipment, change management and the training required to successfully implement e-health [1]
3. The report also points to the possible need for financial incentives provided by government to underpin e-health initiatives.
4. With the exception of "motherhood" statements, the patient viewpoint has long been absent from government-linked publications [2, 3]. We are therefore particularly pleased to note the Committee's recognition of Australians as individuals who are entitled to own and control their own sensitive health information.
5. Finally, after several years and the expenditure of 5 billion dollars of taxpayer's money, the supplementary paper finally stipulates due dates by which time the public can expect e-health deliverables [4].

Nonetheless, the APF also requests further information about some of the less clear aspects of the report.

1. The paper supports the notion of the patient purchasing a Person-controlled Electronic Health Record (PEHR). In this instance, where or to whom does one complain if circumstances dictate such?
2. Are Australians being primed for the advent of Microsoft's HealthVault or Google's PEHR or some other commercial endeavour?
3. We do not follow the UHI argument provided in the report. Logically speaking and based on NEHTA's track record thus far, UHIs will be stored in a central data base. As the report itself recognises, centralised databases require only a single point of failure to facilitate data breach (p14). Why are government issued UHIs stored on a central database required to authenticate entries into a PEHR?
4. The paper indicates that PEHRs will eliminate the duplication of tests with each clinician a patient consults (p.7). Yet anecdotally we know that clinicians generally refer their patients to

testing services linked to their own practice to ensure results that support reflection over a diagnosis. Why will a PEHR eliminate duplicate testing? Hasn't the duplication of tests actually proved useful in several cases of misdiagnosis?

5. The paper indicates that patients will own and control access to the PEHR and may be able to tailor clinician views according to authorisation (p.5). If this is the case, with what guidance will patients be provided to tailor views?
6. The report outlines the need for communications and marketing strategies to encourage "significant benefits and safeguards of the proposed e-health approach" (p.17). Will the strategies also indicate the privacy dangers inherent in e-health solutions and educate patients in eradicating known threats?
7. Is the term EHR used throughout the paper in such a manner that it's a plural or general term, or is it used as though it's a singular?

Finally, a virtual centralised database is no different to a physical centralised database. Vast databases, whether they store UHIs or PEHRs, do not work as the report itself recognises (p 14).

1. Diseconomies of scale and scope greatly exceed economies of scale
2. Health care data isn't universally understandable but depends on context
3. Consolidation into a single database produces a 'honey pot' that attracts break-ins and unauthorised secondary uses.

We would be happy to clarify any of the points made herein. Thank you for this opportunity to comment on the supplementary paper.

Yours sincerely



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References:

1. Fernando, J. & Dawson, L. 2008. "Clinician assessments of workplace security training- an informatics perspective". eJHI 3: 1 p.e7 cited May 4 2009, [http://www.ejhi.net/ojs/index.php/ejhi/article/view/3\(1\)%3Ae7](http://www.ejhi.net/ojs/index.php/ejhi/article/view/3(1)%3Ae7)
2. NEHTA - National E-Health Transition Authority "The future is E-health". Cited May 1 2009. <http://www.nehta.gov.au/>
3. KPMG for NSW Health "An Evaluation of the Healthelink Electronic Health Record Pilot (Summary Report)". Cited May 1 2009. <http://www.healthelink.nsw.gov.au/evaluation>.
4. Hall, L. "Paper patients' notes out, digital records" in The Sydney Morning Herald. May 2 2009. 2 e-pages .Cited May 4 2009, <http://www.smh.com.au/national/paper-patients-notes-out-digital-records-in-20090501-aq6k.html> .
5. Clarke, R. (2003) "Open Source Licensing", Cited May 1 2009. <http://www.rogerclarke.com/EC/OSLic.html>