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MEDIA RELEASE

14 November 2011

NEHTA Blacklists Privacy Advocate on a Pretext

Embargoed until 23:59 Monday 14 November 2011

The National eHealth Transition Authority (NEHTA) is well-advanced in its design for its Personally-Controlled Electronic Health Record (PCEHR).

It has kept privacy advocates at arm's length, throughout the process, 2008-11.

NEHTA has failed to provide constructive responses to serious and specific expressions of concern about consultation processes, and about deficiencies in the design process.

The Australian Privacy Foundation (APF) is the nation's primary advocate for the privacy interest. It was formed in 1987, and has made many hundreds of submissions on matters of public concern.

APF has provided over 20 detailed submissions to NEHTA in relation to the PCEHR.

NEHTA has previously excluded APF nominees from some events by imposing a lengthy and non-negotiable non-disclosure agreement (NDA) containing highly-objectionable clauses.

This week, NEHTA found a new way to keep unwelcome advice away from its staff.

Following a meeting in October, APF provided a submission detailing serious problems with the design process. Nine days later, NEHTA delivered comments that showed the organisation had no intention of doing anything about those problems. APF's nominee emailed blunt criticism in return.

NEHTA has branded some unspecified part of an APF email as bullying and/or harassment.

The APF has explained that NEHTA's interpretation is unjustified.

Despite that, NEHTA has excluded APF's nominee from any participation in NEHTA events.

NEHTA has failed in its most important functions – coordinating the application of IT to healthcare, underwriting inter-operability among eHealth systems by means of negotiated standards and protocols, and ensuring that all stakeholders are integrated into the undertaking.

To get safe ehealth records, the design has to be bravely open to patients' concerns while there is still time to fix things. Designs based on political imperatives and timetables from above are doomed to failure.

This latest over-reaction provides a further demonstration of how NEHTA invests massive energy in avoiding messages that are inconsistent with its senior executives' song-sheet.

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SUPPORTING MATERIALS

For the Sequence of Events, the Email, the Accusations and Demands, and the Responses, see http://www.privacy.org.au/Media/MR-NEHTA-111114-Sp.pdf

BACKGROUND

NEHTA has avoided meaningful engagement with privacy advocates throughout its existence.

After the failure and departure of its first CEO, NEHTA finally drew clinicians inside the fold.

But communications with consumer and privacy advocates have remained distant and sporadic.

There is no framework, and no persistent consultation structure or processes.

During 2008-12, NEHTA has been developing an eHealth record scheme, currently called the PCEHR.

APF has made 12 public submissions on substantive matters associated with the PCEHR, and, at NEHTA's request, has left several other submissions unpublished.

In addition, it has made 10 submissions relating to the serious inadequacies in the process.

These are indexed at:

http://www.privacy.org.au/Papers/indexPolicies.html#eH

SUMMARY OF THE CONSULTATION PROBLEMS

In November 2010, a letter to NEHTA's CEO summarised the issues:

http://www.privacy.org.au/Papers/PCEHR-Fleming-101108.pdf

The letter drew attention to **the indicators of good and bad consultation processes**: http://www.privacy.org.au/Papers/PS-Cons-101106.html

"Over the last five years, your organisation has held various events, but not as part of a coherent process. The contributions have not been cumulative, there has been no carry-through on outcomes from the events, and the previous senior staff-member was side-lined and left in frustration. The lack of a coherent process is all the more surprising in view of frequent statements by NEHTA staff that privacy concerns are a serious impediment to progress in eHealth".

NEHTA's CEO replied, http://www.privacy.org.au/Papers/NEHTA-Consn-Reply-101112.pdf, affirming "NEHTA's commitment to a methodical and cumulative approach to engagement with privacy advocacy organizations":

The very next meetings failed the test.

A comprehensive list of the problems was sent on 10 Dec 2010, on pp. 2-3: http://www.privacy.org.au/Papers/NEHTA-PCEHR-101210.pdf

On 25 Feb 2011, APF wrote again:

http://www.privacy.org.au/Papers/PCEHR-Consultn-Ltr-110225.pdf

"The short sessions on governance matters involved no summary of the points made by participants, no responses to the points made by participants, no propositions, no alternative models, and no options. There were just a few open-ended questions. The frustration among participants should have been very apparent to NEHTA staff, and if it wasn't then APF draws it to attention herewith. To our further disappointment, the presentation by DoHA at the meeting on 23 February was long on aspiration and devoid of any concrete undertakings in relation to the issues that have been placed on the table".