



**Australian  
Privacy  
Foundation**

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3 March 2011

The Hon Nicola Roxon MP  
Minister for Health and Ageing

Dear Minister

**Re: PCEHR – Consumer Consultation and Project Governance**

Consumer advocacy organisations are very concerned about the failure of your portfolio department to establish a credible consultation arrangement with them in relation to the PCEHR.

For more than a decade, consumer advocacy organisations have been marginalised – invited to occasional meetings, but with no coherent consultation plan, no follow-through, and little evidence of any assimilation of what they have said. There has been no commitment to a process, and no corporate memory. Advocates have become deeply frustrated with this state of affairs.

On 30 November 2010, you said that "DOHA will ... take the lead role in ensuring comprehensive stakeholder engagement across the [PCEHR] program ... The arrangements that we are putting in place will ... ensure there are robust assurance and governance provisions around the implementation of the program ... And yes, that governance will include consumers ... We will work with all parties to ensure that a strong governance framework is in place ahead of the national system being delivered" ( pp. 6-7).

The promised open, public consultation is very welcome. But the complexities of the health sector are so great that the general public will not get down to the devil in the details. Consumer advocacy organisations have deep knowledge of the needs of each category of healthcare consumer, and of the practicalities and the subtleties of healthcare data. Ongoing engagement with consumer advocacy organisations is therefore critical to the PCEHR's success.

The Department has failed to implement your commitment to comprehensive engagement and robust assurance and governance. NEHTA ran a loosely-structured Roundtable in November 2010, and three consultation sessions in January-February 2011. But, despite continual requests from participants, those events concluded without a permanent group being established. The Department, meanwhile, has done nothing to ensure that the group's expertise and commitment is utilised.

We request that you instruct the Department to recover the harm done to your reputation by instituting a meaningful long-term arrangement, as described in the attachment to this letter.

Yours sincerely

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## Australian Privacy Foundation

### The Personally Controlled e-Health Record (PCEHR) A Meaningful Consultation Process for Consumer Advocacy Organisations

Statement of 3 March 2011

Consumer advocacy organisations have been denied an effective voice throughout the development of the PCEHR initiative, from its beginnings about 1999 within the HealthConnect Division of the Department of Health & Aging (DoHA), through the first 4 years of the National eHealth Transition Authority (NEHTA) under Ian Reinecke, and into the current phase.

Participants from a wide array of consumer organisations had learnt to be distrustful of both DoHA and NEHTA, because of the absence of any consultative framework, sporadic once-off meetings, the absence of documents to pump-prime discussions, the absence of outcomes or carry-through, the continual staff turnover, the absence of any corporate memory, and the absence of evidence of the incorporation of consumers' perspectives into the emergent design.

NEHTA held a 3-event consultation in Jan-Feb 2011, which at last achieved some genuine interaction on substantive issues. A great deal of effort was invested in the events, by both advocates and NEHTA's professional staff. But both NEHTA and DoHA refused to put the consultation process on a firm footing, and thereby effectively reserved the right not to continue the dialogue.

The APF has written multiple, successive submissions on this matter, indexed here:  
<http://www.privacy.org.au/Papers/indexPolicies.html#eH>  
It also has a documented policy on the requirements of meaningful consultation processes:  
<http://www.privacy.org.au/Papers/PS-Cons-101106.html>

Given the advanced state of the PCEHR project, and the rapidity with which it is proceeding, it is imperative that the backlog in consumer representation be made good very quickly.

#### **The following is a summary of APF's perception of the features of a suitable process:**

- A defined group of organisations with sufficient scope to ensure broad representation, and means of identifying and inviting additional and replacement organisations
- A defined constitution or charter, over which the group itself has strong influence
- A lifetime commensurate with the initiative (i.e. committed to at least the end of 2012)
- Treatment and visibility equivalent to that accorded other stakeholder groups
- Clarity about the lines of communication between the group, on the one hand, and:
  - senior levels of relevant government agencies
  - other relevant groups, in particular the NEHTA Clinical Reference Groups:  
<http://www.nehta.gov.au/about-us/stakeholders>
- Commitment by the senior executives of relevant agencies to engagement with the group, including participation in meetings, responses to communications, documentation of outcomes, efforts to sustain corporate memory, and follow-through on undertakings
- A *modus operandi* for the group, including:
  - a published membership list, including contact-points, especially email
  - means for within-group communications, e.g. an emailing list, or a workable e-forum
  - meetings of the group together with relevant officers of government agencies
  - agendas for those meetings, over which the group itself has strong influence
  - substantive papers distributed in advance of each meeting
  - a practical approach to confidentiality and security issues
  - documentation of the outcomes of meetings
- Joint meetings of the group with other stakeholder groups (the so-called 'four pillars')
- Resourcing sufficient to enable the group's operation