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25 February 2011

Sharon McCarter, Assistant Secretary, eHealth Systems Branch, DoHA Dr Mukesh Haikerwal, National Clinical Lead, NEHTA

cc. Kathryn Bramwell, Director, e-Health Systems Branch, DoHA Bettina McMahon, Head of Policy and Privacy, NEHTA

Dear Sharon, Mukesh

Re: PCEHR – Consumer Consultation and Project Governance

The NEHTA process during January and February has been, at long last, a positive experience. Although there have been some deficiencies in the process, the atmosphere has been good, there has been engagement, and there have been constructive exchanges, and learning (on both sides).

Unfortunately, neither DoHA nor NEHTA has addressed the governance issue in any meaningful manner. Now that the short, 3-event NEHTA consultation is over, both agencies have mouthed platitudes, but have put nothing in place, and have thereby effectively reserved the right not to continue the dialogue.

During the four meetings between November and February, consumer organisations have continually expressed frustration about this failure. Key sources of information are as follows:

- the Key Issues documents arising from the NEHTA events
- the APF's communications addressing specific sub-topics within the governance area. See:
 letter of 8 November 2010 to the NEHTA CEO. at:
 - http://www.privacy.org.au/Papers/PCEHR-Fleming-101108.pdf
 - letter of 15 November 2010 to the NEHTA Clinical Lead, at http://www.privacy.org.au/Papers/NEHTA-PCEHR-Process-101115.pdf
 - letter of 25 January 2011 to the NEHTA Clinical Lead, at http://www.privacy.org.au/Papers/PCEHR-CRG-Ltr-110125.pdf
 - email of Mon, 14 Feb 2011 08:13:40 to Kathryn Bramhall
 - email of Tue, 22 Feb 2011 09:14:44 to Kathryn Bramhall and Sharon McCarter
- Peter Brown's letter on 18 February 2011, which quite explicitly addressed both the NEHTA context (i.e. system design) and the broader context for which DoHA has responsibility

I had understood that NEHTA was to bring to the third meeting on 23 February specific proposals, or at least options, relating to consultation with consumer groups.

To our serious disappointment, NEHTA did not do so. 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 openended 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.

During the whole of the last decade, discussions with DoHA and NEHTA about eHealth have been a dreadful experience. There have been occasional discussions, but no coherent plan, no corporate memory, no outcomes, and the mere pretence of consultative processes. Consumer advocacy organisations have been trained to be highly distrustful of both agencies.

The NEHTA activities during February and March have gone a considerable distance towards more positive attitudes on both sides. But both of your organisations have failed to address the governance issues that have been put before you frequently and in some detail. As a result, there is no arrangement in place for ongoing consumer representation, despite the lateness of the hour, and the rapidity with which the project is moving.

In the absence of any concrete proposals from you, we now have no option but to take the matter up directly with the Minister.

Yours sincerely

Roger Clarke Chair, for the Board of the Australian Privacy Foundation (02) 6288 1472 Chair@privacy.org.au