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25 January 2011

Dr Mukesh Haikerwal, National Clinical Lead, NEHTA

cc. Andrew Howard, CIO, NEHTA
Bettina McMahon, Head of Policy and Privacy, NEHTA
Melanie Goldwater, Privacy Manager, NEHTA
Liz Jones, Engagement Analyst
Catherine Bramwell, DoHA

Dear Mukesh

Re: Consumer Reference Group

Congratulations to yourself and your team on a great start to consultations. My quick summary on the positive bits was that a lot of the design requirements and features put forward were good, and the group that's been formed was pretty good, and the facilitation was professional, and the vibe was fine.

There are of course some aspects that need to be addressed. But, as far as possible, I'm very happy that we can work within the context set by the event, and relate our comments and further proposals to the framework that you've set up.

Enclosed with this letter are the following:

- some concerns about **governance and information provision matters** (attached)
- a couple of **specific comments** about the subject-matter of the meeting of 20 January, which there was no opportunity to raise, and which may have been a layer too deep to raise at the time in any case (attached)
- a draft **Checklist of Consumer Concerns**. I believe that this (or something like it) needs to be a CRG-owned document, to be used as a reference-point against which iterations of the design documents can be assessed (in a separate file, PCEHR-CRG-ChkLst-110125.rtf)

I look forward to your responses to these items.

I appreciate that they may fall within the bailiwicks of various people and that responses may be piecemeal rather than consolidated. Please feel free to provide copies to anyone appropriate.

Regards

Roger Clarke
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Australian Privacy Foundation

The PCEHR Consumer Reference Group
Comments following the Meeting of 20 January 2010

Governance and Process Matters

Governance

- The CRG is being heavily invested in by consumer reps and advocates (and by NEHTA)
- Many delegates voiced concerns about previous half-starts without carry-through
- The PCEHR's design quality, and its public acceptance, will be harmed if the stop-start of the past happens again, or if the CRG's own corporate memory is lost

It's therefore very important that the CRG's **longevity** is assured. At present, we understand the commitment to be only to hold three such meetings over 6 weeks. The CRG needs to be declared as a commitment for at least the life of the early phases of the scheme, i.e. into 2013.

It's also important that the CRG's **constitution** be articulated. That implies in particular:

- a published membership list, including contact-points, especially email
  [some were received 24 Jan, but only for those who were present on 20 Jan]
- a means for within-group communications. (The computing skills are varied, so a Wiki may not be an effective solution. An e-list may suit the participants better)
- a mechanism for notifying any consumer segments that are missing representation
- clarity about the reporting lines. In a multi-stakeholder context like this, the norm is for there to be a Steering Committee – although the Board of NEHTA plays that role under the structure that's in use in this case. So the CRG needs to be declared to have a direct line to the NEHTA Board
- treatment and visibility commensurate with other Stakeholder Groups, e.g.
  http://www.nehta.gov.au/about-us/clinical
  http://www.nehta.gov.au/about-us/stakeholders

Information Provision

- It's critical that **substantive documentation** be received **in advance of each meeting**. The little that was provided before the last two meetings looked backwards not forwards
- No background information was provided about **the current conception of the PCEHR**.

  Not only did delegates have no idea what the current proposition was, everyone had hold of a different part of the elephant, and interpreted the conversations differently. (I raised this with Les at morning tea, but no overview was provided)
- No statement was provided about the **working objectives for the July 2012 release**.

  I tried to get into play the suggestion that there are categories of people likely to be early adopters, and categories of providers they interact with and who are likely to be able to be enticed into early use of the scheme ('low-hanging fruit'). Given that we had no idea who was going to use it, and what they were going to use it for, the attempted vote on 'most valuable information' was pointless
- It's important that **substantive documentation** be received **<u>during</u> the meeting**.
  The facilitator said during the meeting that we would be getting something, but nothing happened.

  A copy of the slide showing the eight Requirements, and copies of the question slides, would have been very helpful. (Everyone would have been comfortable with footers that said PROVISIONAL, NOT FOR RELEASE or some such confidentiality constraint, and even if such documents reach media, most media players are responsible enough not to publish)
  [Copies have since been received, but 4 days after the event]

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Some Specific Comments

1. Choice / Opt-in re Participation

1a. What's the minimum data-set?
Are any items obligatory?
(Note that date-of-birth and address are highly sensitive for some people)

1b. Can it contain just a selective list of those items that are critical to the patient?
Can it suppress some if the patient wants it that way?

2. Choice re Withdrawal

It's very important to patient trust that the patient be able to withdraw, at any time, both temporarily (by locking or fully blocking their PCEHR) or permanently (by deleting their PCEHR)

2a. What happens to a 'deleted' PCEHR, i.e. is it expunged or retained?

2b. Who does a locked / deleted PCEHR remain accessible to, under what circumstances?

3. Emergency Access to the PCEHR

Case Study – The PCEHR Sceptic
Someone registers, and puts up three clusters of data:

(1) the absolutely minimal amount of **identifying / demographic / base data** including the standard unique error (e.g. in the spelling of the street-name) in order to assist in tracing data-leakage

(2) **data that the patient would like to be available in an emergency** (always assuming that the patient is able to be identified), e.g.
- particular Conditions (at patient choice, with provider advice)
- particular Allergies (at patient choice, with provider advice)
- particular Medications (at patient choice, with provider advice)
- Blood-Group
- Donor Status

(A sceptic will not currently put Donor Information in the Donor Register because Medicare runs it, and historically HIC / Medicare has been highly untrustworthy with personal data)

(3) **something else sensitive, as a honey-pot**, to see if it leaks

3a. It is to be assumed that Emergency Override gains access to group (2), but:
- does it gain access to (1) as well?
- does it gain access to (3) as well?

3b. Is Emergency Access deniable?
i.e. if the whole PCEHR is Locked, does the Emergency Override work?

3c. If access is Protected (currently the model is by means of a Provider Access Code, PAC), does the Emergency Override work?

4. Extraneous Access to the PCEHR

The list of organisations with demand powers is huge.

4a. Are people informed about the organisations that can gain access?

It will greatly undermine patients' confidence if they load data into the PCEHR on the understanding that it's only to be used for their treatment, and is "personally controlled" by them, but then discover that the data is accessible by a large number of organisations in a wide variety of circumstances.