The Australian Privacy Foundation (APF) is the country's leading privacy advocacy organisation. I am writing in my capacity as Chair of the Health Sub Committee of the APF.

I refer to NEHTA's strategic plan which articulates how the Authority plans to support the national vision for e-health. It plan repeatedly states that "NEHTA is in a unique position to drive the e-health agenda in Australia" (p.29). The APF would like to agree with the assertion but was disappointed to note the plan does not seem to take advantage of the authority's "unique position" with regard to supporting a national vision for e-health and reveals little information that isn't already publicly available.

Noteworthy information in the plan fostered the development of a number of questions, as listed below.

1. The document defines the term “E-health” this way: “E-health is the electronic collection, management, use, storage and sharing of healthcare information” (p.2) The APF disagrees with the definition and we cannot map it back to a source. From where was the NEHTA definition drawn?

2. The plan frequently refers to 'stakeholder' and once to an 'outside stakeholder'. As has occurred several times in the past, we once more request your definition of the term. Certainly some NEHTA documents are clear the word ‘stakeholders' does not refer to consumers but does refer to jurisdictions, industry associations and peak bodies [Organisations invited to attend the NEHTA Stakeholder Reference Forum, http://www.nehta.gov.au/component/docman/doc_download/815-srf-organisations-invited; Stakeholder Reference Forum, http://www.nehta.gov.au/about-us/stakeholders].

The document distinguishes between 'stakeholders' and 'consumers'. Yet the International Standards Organisation (ISO) defines a stakeholder this way: “… a person or group concerned with, affected by, or perceiving themselves to be affected by an organization
NOTE 1 A decision maker is also a stakeholder.

NOTE 2 The term "stakeholder" includes but has a broader meaning than "interested party."

Thus we would appreciate understanding your rationale for the segregation of consumers from the stakeholder group. Why does NEHTA not consider consumers to be stakeholders?

3. Given stakeholders are not consumers, the panel in each section that outlines anticipated benefits for stakeholders (see p.10 for instance) reads as if outlining how e-health may provide market benefits for the organisations listed in Point 1. Is this the case?

4. NEHTA's Mission Statement suggests that consumers are important participants in the e-health process- "...working openly, constructively and collaboratively with consumers ... (p.5)", so why does the bulk of NEHTA's plan focus on stakeholders rather than consumers? Why does NEHTA so tightly control feedback so that ordinary consumers are not invited to attend various consultations? Why is it that when we speak with colleagues they are invited to provide feedback on some issues and we are not and vice versa. It is difficult to be confident in NEHTA's strategic plan when these weaknesses are self-evident.

5. The Plan calls for a strengthened media presence (p.25) to increase awareness of the "scope and benefits" of e-health to the community yet almost objectifies consumers. They are the targets of public relations campaigns and are not equals with whomever NEHTA consults regarding the Australian e-health framework.

6. The Plan makes a very brief mention of governance by commenting that this is part of a future work stream outlined in the National E-Health Strategy and will underpin NEHTA's strategic priority (p.29). This doesn't seem logical. How can one manage a project without an underpinning?

7. Is NEHTA deliberately excising 'consumers' from 'users' of the system (p.24)? It is difficult to come to any other conclusion as we read the document. Yet the document also points out that "The key to successful adoption is consumer ... acceptance of e-health (p.25). The use of language in the Strategic Plan is very confusing.

8. Finally, NEHTA's Chief Executive is quoted in the Australian as saying "We have considered our future work program based on the (Deloitte) strategy and other important work completed this year, including the National Health and Hospital Reform Commission recommendations" [NEHTA releases strategic plan. Dearne, K. October 2, 2009. http://www.australianit.news.com.au/story/0,25197,26155170-15306,00.html].

Yet key sections of the Deloitte strategy and the recommendations from the NHHRC recommendations are clearly overlooked in NEHTA's strategic plan. For instance, the Deloitte report warns of the dangers to e-health of devising "a centralised bureaucratic governance model", emphasising that "e-health's foundations should be predominantly driven by the health care participant and
The evidence suggests, despite NEHTA's protestations of transparency and public consultation, that the reverse is true.

The APF is concerned the shortcomings listed in this document will impede the development of an effective e-health system for Australians. NEHTA's plan seems to be out of step with its own mission statement. We request your response to our feedback on NEHTA's Strategic Plan as soon as practicable in the hopes of dispelling our concerns.

Yours sincerely

Chair, Health Sub Committee
Australian Privacy Foundation

Dr Fernando is in Medicine, Nursing & Health Sciences
Monash University
Phone: 03 9905 8537 or 0408 131 535
Mail to: juanita.fernando@med.monash.edu.au

Contact Details for the APF and its Board Members are at:
http://www.privacy.org.au/About/Contacts.html