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9 June 2009

The Hon Nicola Roxon MP MG 50 Parliament House Canberra ACT 2600

Dear Minister Roxon

Re: Health card plan

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.

Recent reports in the The Age and on Sky News Online suggest the government is considering the introduction of a card to carry patient health information [1]. Evidently you have indicated to that it would be up to the individual to decide what information to store on the card and how to tailor views, suggesting that no significant privacy concerns remain to be addressed [2]. This is far from the case.

Firstly, neither the government nor NEHTA have developed a widely consulted and accepted e-health records privacy and personal health information security framework with patient control as the central principle thus far despite spending billions of dollars of tax payer funds to develop concepts such as a health card. Without this framework, Australian patients are caught up in the realm of reactive detail and press releases, rather than in determining the principle decisions which can be used to found a good discussion of e-health proposals. The APF supports commentators quoted in the articles who are worried by the prospect of function creep, data integrity (based upon who updates the card) and identity fraud [1, 2]. The APF request your office to urgently work through the governance and transparency problems associated with efforts to implement e-health **prior** to proceeding with consideration of the card.

The APF supports e-health record proposals that draw on best practice in clinical systems development to protect patient privacy. By adopting a widely-consulted and accepted national framework for e-health privacy and personal information security these proposals put patients in effective control of their own sensitive health record information. As Garling points out (Point 1.211), trust and confidence in e-health

systems is essential, not only for wider public acceptance but also for critical matters like public health (willingness to disclose sensitive data, including infections) and individual access to essential personal medical services (for example, sexual or psychiatric problems) [3].

Secondly, the APF notes that all Australians will be assigned a number to which they can volunteer to add information from their medical histories. Presumably the number would act as a link to individual patient data. The confidentiality and security of patient data will, as you point out, be of paramount concern to the government if the numbering system is implemented [1]. Thus, a national framework for e-health privacy and personal information security is of paramount importance.

If every Australian is to be issued a unique number, an identifier, then the APF is concerned the numbered card is not simply a redesigned Australia Card [4]. If citizens are to have any confidence in the system at all, the card ought not be linked to any other federal, state or territorial Government service, as was once intended for the doomed Australia Card. Neither should information on the card be available to nor published by any third party such as bars, clubs, insurers, corporations providing personal health records, employer-sponsored health-services and so forth. Thus, we request your response to the following questions with regard to the identifiers.

- Will the unique number be noted on the mooted health card? That is, will every Australians be issued with a Medicare card and a health card with a unique identifier on it? If relevant, how will the number be stored on the card?
- Will the assignment of a unique number be mandatory for all Australians? Will it be mandatory for visitors to Australia?
- Can you assure the public that the number will never be used for any secondary purpose at all?
- Will the function of the card be able to be manipulated by future governments?
- Where will the government store the number and why must the government have access to it? The APF opposes the commonly understood information security threat afforded by storing all citizen numbers in a single data base.
- If a person is "mugged" and their Medicare card is stolen, can the number or health card be used to identify an individual?
- How do you plan to protect the public against identity fraud?
- What risk and privacy frameworks have been established for the numbered card?
- If an individual does not consent to participation in the health card, will they be denied Medicare support or access to services from GPs and other providers as has occurred in the UK?

(http://www.computerworlduk.com/management/government-law/public-sector/news/index.cfm?newsid=15042)?

E-health records benefit some patients, especially the aged or chronically ill. However the APF is worried a faulty e-health implementation and the failure to address privacy in a systematic and respectful way may encourage further doubts about shortcomings linked to e-health initiatives more generally, especially as has occurred overseas. Hence, we welcome this opportunity to provide input into the health card plan and unique identifier plan and await your response to our questions.

Yours sincerely

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REFERENCES

[1] Harrison, D. Health card plan sparks privacy concerns. The Age, June 9 cited 9/6/09 http://www.theage.com.au/national/health-card-plan-sparks-privacy-concerns-20090608-c0uk.html

[2] Sky News Online Govt developing all-purpose health card cited June 8, 2009. http://www.skynews.com.au/health/article.aspx?id=339998

[3] Garling, J. [2008] <u>Special Committee of Enquiry into Acute Care Services in NSW Public Hospitals http://www.lawlink.nsw.gov.au/lawlink/Special_Projects/ll_splprojects.nsf/pages/acsi_index</u>

[4]Greenleaf, G (1987) <u>The Australia Card: towards a national surveillance system</u>. cited June 9, 2009. http://austlii.edu.au/itlaw/articles/GGozcard.html