



**Australian
Privacy
Foundation**

<http://www.privacy.org.au>

Secretary@privacy.org.au

<http://www.privacy.org.au/About/Contacts.html>

5 April 2011

Mr G. Porter
Elton Consulting
P.O. Box 1488
Bondi Junction NSW 1355

Dear Mr Porter

Re: Interim Review of the National Partnership Agreement on E-Health

Thank you for your call on the above matter.

The Australian Privacy Foundation (APF) is the country's leading privacy advocacy organisation. A brief backgrounder is attached.

I attach the APF's statement on the matter.

The document is intended for transmission to DoHA and the signatories to the Agreement.

I look forward to your call on Wednesday 6 April at 4:30pm, when I can clarify aspects of the Statement.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Roger Clarke', written over a faint, dotted rectangular box.

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

Australian Privacy Foundation

Statement on the National Partnership Agreement (NPA)

5 April 2011

1. The IHI legislation and regulations flew in the face of the long succession of submissions from human rights organisations, including those of the APF, indexed here:

<http://www.privacy.org.au/Papers/indexPolicies.html#HI>

It was therefore essential that the agency developing the system conduct a further, design-phase Privacy Impact Assessment (PIA). It failed to do so. That was in breach of government policies and public expectations.

2. As a result of the agency's failure to conduct a further, design-phase PIA:
 - consumer advocacy organisations are not clear about the details of the system
 - early indications are that the design contains major flaws from the privacy perspective
 - there is serious disquiet among many consumer advocates, especially those with particular concerns about privacy, e.g. those representing consumers with sensitive conditions
3. It is essential that:
 - the absence of a design-phase PIA be rectified (albeit in arrears)
 - that process include consultation with relevant consumer advocacy organisations
 - those consultations be enabled by the provision of sufficiently detailed information to enable those organisations to assess the proposal
 - the feedback from consumer advocacy organisations be responded to and reflected in the design and implementation of the scheme
 - a PIA report be published
4. The subsequent processes in relation to the PCEHR have also been inadequately performed by NEHTA, and extraordinarily poorly performed by DoHA. To avoid disasters of this nature occurring again and again, it is crucial that a comprehensive consultative framework for consumer advocacy organisations be established
5. The expectations of such a process have been communicated to NEHTA, DoHA and the Commonwealth Minister in a succession of communications between November 2010 and March 2011. A summary is attached, and the detailed submissions are indexed at:
<http://www.privacy.org.au/Papers/indexPolicies.html#eH>
6. It has been to the serious detriment of the entire scheme that these expectations were not reflected in the original National Partnership Agreement. The Commonwealth has failed to put appropriate arrangements in place. The NPA needs to be amended to incorporate them.
7. Specifically, the NPA needs to be amended such that:
 - consumers are not referred to merely as objects, but instead as critical stakeholders
 - multi-phase PIAs are declared to be an essential part of all projects within the initiative
 - consultation with consumer advocacy organisations is a requirement of all projects
8. Unless these corrective actions are taken, the eHealth initiatives will continue to accumulate a very bad reputation, as being for bureaucrats first, researchers and insurers second, clinicians third, and consumers a very poor last. As the initiatives are currently structured, they are set to reap a whirlwind of public and media discontent.
9. As the APF has previously voiced, the Commonwealth Privacy Commissioner is completely unacceptable as a regulator for eHealth. This is because the Privacy Act, the Privacy Commissioner's powers, and the Privacy Commissioners' performance are all far too weak to provide the regulatory impact necessary for the eHealth initiative. The NPA needs to be amended to remove the assumption that the Commonwealth Privacy Commissioner is relevant.

The PCEHR

A Meaningful Consultation Process for Consumer Advocacy Organisations

3 March 2011

Charter

- 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>

DoHA and NEHTA Commitment

- 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

Modus Operandi

- 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

- Resourcing sufficient to enable the group's operation

Australian Privacy Foundation

Background Information

The Australian Privacy Foundation (APF) is the primary national association dedicated to protecting the privacy rights of Australians. The Foundation aims to focus public attention on emerging issues that pose a threat to the freedom and privacy of Australians. The Foundation has led the fight to defend the right of individuals to control their personal information and to be free of excessive intrusions.

The APF's primary activity is analysis of the privacy impact of systems and proposals for new systems. It makes frequent submissions to parliamentary committees and government agencies. It publishes information on privacy laws and privacy issues. It provides continual background briefings to the media on privacy-related matters.

Where possible, the APF cooperates with and supports privacy oversight agencies, but it is entirely independent of the agencies that administer privacy legislation, and regrettably often finds it necessary to be critical of their performance.

When necessary, the APF conducts campaigns for or against specific proposals. It works with civil liberties councils, consumer organisations, professional associations and other community groups as appropriate to the circumstances. The Privacy Foundation is also an active participant in Privacy International, the world-wide privacy protection network.

The APF is open to membership by individuals and organisations who support the APF's Objects. Funding that is provided by members and donors is used to run the Foundation and to support its activities including research, campaigns and awards events.

The APF does not claim any right to formally represent the public as a whole, nor to formally represent any particular population segment, and it accordingly makes no public declarations about its membership-base. The APF's contributions to policy are based on the expertise of the members of its Board, SubCommittees and Reference Groups, and its impact reflects the quality of the evidence, analysis and arguments that its contributions contain.

The APF's Board, SubCommittees and Reference Groups comprise professionals who bring to their work deep experience in privacy, information technology and the law.

The Board is supported by a Patron (Sir Zelman Cowen), and an Advisory Panel of eminent citizens, including former judges, former Ministers of the Crown, and a former Prime Minister.

The following pages provide access to information about the APF:

- Policies <http://www.privacy.org.au/Papers/>
- Resources <http://www.privacy.org.au/Resources/>
- Media <http://www.privacy.org.au/Media/>
- Current Board Members <http://www.privacy.org.au/About/Contacts.html>
- Patron and Advisory Panel <http://www.privacy.org.au/About/AdvisoryPanel.html>

The following pages provide outlines of several campaigns the APF has conducted:

- The Australia Card (1985-87) <http://www.privacy.org.au/About/Formation.html>
- Credit Reporting (1988-90) <http://www.privacy.org.au/Campaigns/CreditRpting/>
- The Access Card (2006-07) http://www.privacy.org.au/Campaigns/ID_cards/HSAC.html
- The Media (2007-) <http://www.privacy.org.au/Campaigns/Media/>