



**Australian  
Privacy  
Foundation**

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30 January 2017

Mr Tim Kelsey  
CEO  
Australian Digital Health Agency  
[yoursay@digitalhealth.gov.au](mailto:yoursay@digitalhealth.gov.au).

Mr Kelsey,

**Re: Australian Privacy Foundation Submission to the Australian Digital Health Agency's National Digital Health Strategy**

**Standing of the Australian Privacy Foundation**

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The Australian Privacy Foundation (the APF) is the nation's premier civil society organization concerned with privacy.

Its membership includes lawyers, academics, information technology experts, health informatics fellows, communication policy analysts and non-specialists. It has been recognised through invitations to provide testimony in parliamentary inquiries and other consultations regarding data protection, along with participation in high-level international fora. A brief backgrounder is attached.

Introduction

The following submission has been prepared by the Australian Privacy Foundation as part of the consultation process by the Australian Digital Health Agency (ADHA) currently underway to develop a National eHealth Strategy

We note that a number of documents exist that would indicate that various strategic decisions regarding ADHA's activities in the current financial year have already been made and, we assume, are in progress.

The APF has no comment to make on any particular eHealth or other "Digital Health" initiative, however with the increased power of big data, and associated health information systems and technology, we believe it is important that appropriate safeguards be built in to all initiatives, both current and proposed.

The fundamental position of the APF is that privacy is a dynamic, risk management issue.

At its most basic, the risk to privacy of any initiative, system or action should be assessed in terms of the value to the individual of that initiative, system or action.

As such, we strongly recommend that ADHA fully describes and justifies the value to the individual of any initiative it is either currently working on, or proposes, as well as defines and describes the risk

management actions it has, or will, incorporate in order to ensure that the privacy of all individuals who are potentially impacted by ADHA's strategy is adequately protected.

Health care is rapidly moving into new areas including personal and precision medicine. All of these areas involve innovative mechanisms for acquiring, analysing and using patient data. We also note that there is a common theme at multiple levels of healthcare from the World Health Organisation down to move to a Patient Centric model of health care.

## **Patient Centric Healthcare**

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We draw your attention to the American Health Information Management Association's view on Patient Centric healthcare. [<http://library.ahima.org/doc?oid=103412>]

*Patient-centric healthcare can be difficult to describe. There is not much evidence to define just what types of healthcare or health IT systems positively impact patients and engage them in their care, Rein says.*

*However, three characteristics of patient-centric care have emerged. A patient-centered healthcare system gives patients the ability to communicate effectively and immediately with their providers. It provides patients access to information that is important and useful for them, when they need it.*

*Finally, patient-centered health IT allows providers to look holistically at an individual and treat them through the coordination of other providers.*

*"There are a number of other things you can build onto that, but we are still at the very, very beginning of what I imagine will be a huge innovation curve," Rein says. "At this point we are not exactly sure what, truly, patient-centered healthcare is.*

*"I think everybody just agrees that we don't really have it."*

In the light of the rapidly changing field of healthcare, in this submission the APF is concentrating on the privacy implications of Patient Centric health care and is largely informed by the above source.

In our view privacy in a Patient Centric environment means that there should be a recognition that privacy is a dynamic issue; the needs and constraints associated with a patient's privacy can change according to circumstances. In general, risks to patient privacy should be commensurate with the value of sharing their data, as seen by the patient.

It is APF's recommendation that any strategy developed by AHDA for eHealth in Australia should adopt a Patient Centric view; specific solutions and initiatives should comply with this perspective and they should have clearly defined purposes and value. If existing solutions do not comply with this perspective, they should be replaced or modified to comply.

We contend that in order to maximise the use of patient health data as well as for the patient to have proper input and control over privacy aspects of that data, the scope of Australian health record data should include that managed and stored by any Australian health service provider. The scope should also include any personal or health data provided by the patient (in addition to that provided by health care professionals) and integrated with other Australian health record data.

## Recommendations regarding privacy in a Patient Centric Health environment

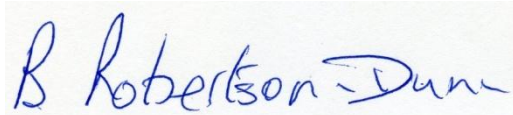
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The following are essential health information data related privacy principles that should be applied to any and all eHealth initiatives that emerge from the ADHA strategy.

1. The patient owns their data;
2. The patient should be able to decide who is (or are) to be the custodians of their health data;
3. The patient owns and controls their data sharing policies. This control should extend to the patient deciding that no health data should be kept by a third party of any sort;
4. Data sharing policies should be dynamic and context dependent;
5. Patient health data must be capable of being treated as an integrated whole so that privacy can be managed and achieved on the basis of all health and related personal data, not just some;
6. Patient Health data should be primarily managed from the perspective of the patient, their needs and their privacy;
7. Patient health data, as perceived by the patient, should include all of their available health data;
8. Notwithstanding the patient's perspective, all health data created by pathology, specialists and other health service providers should be capable of being integrated into the patient's health data in a way that is meaningful from a health care perspective;
9. People who access patient data should have a health care based need to know and should justify that need to know at the time of access;
10. The patient should be able to find out who (at the individual level) has seen their data and why;
11. Patient health data should be stored, made accessible and have privacy controls imposed in as near real-time as possible;
12. Patient health data should be as accurate and consistent as possible. This is obviously a difficult requirement; notwithstanding this difficulty, the system that manages the data should be capable of detecting inconsistencies and highlighting them to both the patient and health care professionals;
13. Secondary use of patient data should only be done on an explicit consent basis;
14. Specific and explicit consent should be sought if patient health data is to be linked to other personal data;
15. Any data that is extracted from or used by non-healthcare third parties should have an explicit life and purpose, after which it is destroyed; and
16. There should be a dispute resolution process, overseen by a body independent of government and health professionals which has the power to review and enforce privacy mitigation actions, correct data, as perceived by the patient and award appropriate compensation.

Thank you for giving us the opportunity to provide this submission. We would be happy to discuss the issues and recommendations raised in this submission during the development of ADHA's National Digital Health Strategy

Yours sincerely

A handwritten signature in blue ink that reads "B Robertson-Dunn". The signature is written in a cursive style and is set against a light blue rectangular background.

Dr Bernard Robertson-Dunn  
Chair, Health Committee  
On behalf of the board of the APF  
Bernard.Robertson-Dunn@privacy.org.au

## References

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Selected submissions regarding the Health Strategy, My Health Record and associated legislation

National Digital Health Strategy, Submission to Dept of Health (14 Apr 2016)

<https://www.privacy.org.au/Papers/DoH-DigHlthStrat-160414.pdf>

eHealth Bill – Senate Committee on Community Affairs Report, Letter to Senators (10 Nov 2015)

<https://www.privacy.org.au/Papers/Sen-PCEHR-151110.rtf>

Opt-Out and the PCEHR, Letter to Senators (30 Oct 2015)

<https://www.privacy.org.au/Papers/Sen-PCEHR-151030.rtf>

Health Legislation Amendment (eHealth) Bill 2015, Submission to Senate Standing Committee On Community Affairs (28 Oct 2015)

<https://www.privacy.org.au/Papers/Sen-eHealth-151028.pdf>

PCEHR/IHI Legislation, Submission to Dept of Health (24 Jun 2015)

<https://www.privacy.org.au/Papers/DoH-PCEHR-150624.pdf>

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 Patrons The Hon Michael Kirby AC CMG and The Hon Elizabeth Evatt AC, 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>