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Professor Anne Simmons AM
Chair
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Dear Professor Simmons,

Re: Electronic Medical Record link to adverse health outcomes and APP10

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

I refer to the Victorian Coroners report Finding Into Death Without Inquest where the use of Electronic Medical Records (EMR) contributed to an individual's death. EMRs and Electronic Health Records (EHR) are presently contributing to a series of adverse events, even deaths, occurring throughout Australia.⁽¹⁾ The evidence has illuminated a key digital health software challenge. The challenge represents fundamental privacy risks, where end-user error working with an EMR/EHR can foster unintended, real life consequences caused by data integrity and availability failures.

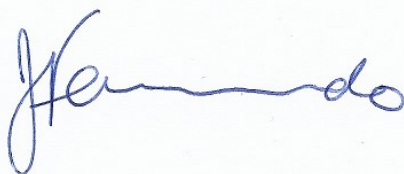
These failures include software usability shortcomings, poor end-user training, unfamiliarity with the proprietary and the unstandardised range of EMR/EHR systems presently used by health care organisations; all elements that are well documented as the basis adverse health care outcomes.⁽²⁾ Yet the Australian Privacy Principle (APP) 10 stipulates that all APP entities must take reasonable steps to ensure the personal information it collects is accurate; the entity must also take reasonable steps to ensure the personal information it uses or discloses is accurate, up to date, complete and relevant, having regard to the purpose of the use or disclosure.⁽³⁾ But well known EMR/EHR errors published in the Coroner's report endure, a core data privacy protection problem.

The quality, integrity and usefulness of data in EMR/EHR records is part of the risk/benefit equation inherent in privacy protection. That is that privacy is a matter of risk. If the collection and use of private and sensitive data is of great benefit to the individual concerned, then a risk is worth taking. Conversely, if there is no benefit then the risk should be minimised as far as possible. In the case of personal and sensitive health data, there is the risk that personal health data may be misused or mismanaged. The risk is compounded if the data is incorrect and/or misleading. The APF maintains that 'information privacy' is not about making things strict for data users in order to restrain obvious abuses; it is about good data practice. Thus it is just as much about promoting the recognition that high data integrity and quality in EMR/EHR records, good enough to avoid disasters or shortcomings related to the purpose of a specific use, is every individual's right.

The APF is very concerned about the privacy risks outlined by the Coroner's report. Would you please outline plans that the Therapeutic Goods Administration have formulated to address the real life privacy standards issues pertaining to the My Health Record system/ EMRs I have outlined here?

I look forward to your reply, and would be happy to help with developing responses to these issues.

Yours sincerely



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ACKNOWLEDGEMENT

I acknowledge and thank the members of the APF Health Committee for their guidance herein.

REFERENCES

1. Victorian Coroners Court of Victoria at Melbourne. Finding Into Death Without Inquest, Coroner Caitlin English, Deputy State Coroner. COR 2019 6921., pp. 6-13. https://www.coronerscourt.vic.gov.au/sites/default/files/2021-03/lanFraser_692119.pdf
2. Kim, Mi & Coiera, Enrico & Magrabi, Farah. (2016). Problems with health information technology and their effects on care delivery and patient outcomes: A systematic review. Journal of the American Medical Informatics Association : JAMIA. 24. 10.1093/jamia/ocw154. https://www.researchgate.net/publication/311898687_Problems_with_health_information_technology_and_their_effects_on_care_delivery_and_patient_outcomes_A_systematic_review/link/5f45b2f192851cd3022ece17/download
3. Office of the Australian Information Commissioner. (July 2019) Australian Privacy Principle guidelines. <https://www.oaic.gov.au/privacy/australian-privacy-principles-guidelines/?start=0&tags=87> 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 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 <https://privacy.org.au/publications/by-date/>
- Media <https://privacy.org.au/home/updates/>
- Current Board Members <https://privacy.org.au/about/contacts/>
- Patron and Advisory Panel <https://privacy.org.au/about/contacts/advisorypanel/>

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

- The Australia Card (1985-87) <https://privacy.org.au/About/Formation.html>
- Credit Reporting (1988-90) <https://privacy.org.au/campaigns/consumer-credit-reporting/>
- The Census (2006) <https://privacy.org.au/campaigns/census2006/>
- The Access Card (2006-07) <https://privacy.org.au/campaigns/id-cards/hsac/>
- The Media (2007-) <https://privacy.org.au/campaigns/privacy-media/>
- The MyHR (2012-) <https://privacy.org.au/campaigns/myhr/>
- The Census (2016) <https://privacy.org.au/campaigns/census2016/>