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Tuesday, 19 October 2021

Brownwyn Taylor
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Victorian Department of Health

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Dear Bronwyn Taylor

Re: HEALTH LEGISLATION AMENDMENT (INFORMATION SHARING) BILL 2021

The Australian Privacy Foundation (APF) is the country's leading privacy advocacy organisation. We are concerned that the pernicious Health Legislation Amendment (Information Sharing) Bill 2021 (the Bill) was passed last week by legislative Assembly; it is currently moving through the Legislative Council for consideration[1]

SUMMARY

1. The APF asks Victoria's Legislative Council to pause the Bill's passage and send it back to the lower house for amendment, requesting a more thorough community consult than has occurred. Some information must be withheld from the collection enabled by the Bill, especially where there is no patient consent. Patient health and wellbeing, even lives, are at stake here.
2. The Bill should be returned to the Legislative Assembly immediately for review and community consultation.
3. Weakening the Victorian Privacy Principles to enable the Bill should be reviewed in light of this refreshed work.

BACKGROUND

This Bill is disproportionate, infringing the most fundamental rights of Victorians, including privacy rights; it will collect and use each patient's current and retrospective medical and health information. The information used and collected by the Victorian Department of Health (VDoH) will be drawn from all public and private sector health services, as well as mental health and ambulance services, to form an apparently complete record of every Victorian person's highly sensitive and private information.

Unlike the Federal My Health Record system, Victorians will have no ability to consent to or opt-out of the process.

APF concerns underpin these issues. We question the proportionate functionality and security of the proposed Electronic Patient Health Information Sharing System described in the Bill, which is also known as the Centralised Information System (CIS). APF requests advice on the following matters:

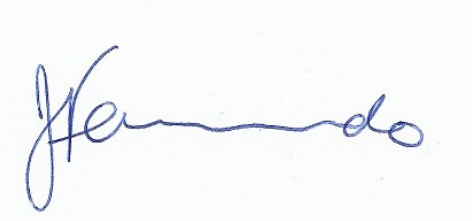
1. How and when does the VDoH intend to advise the community of the Bill?
2. The removal of the current protections provided by the Victorian Health Privacy Principles (HPPs) 6, HPP 1.3 and HPP 1.5 are needed to enable the Bill. What actions has VDoH planned to uphold principles of privacy and medical confidentiality to be weakened by the Bill in due course?[2]
3. Neither the Bill nor the 2nd Reading Speech refer to a Privacy Impact Assessment of the Bill and government discussion of the CIS has not conspicuously occurred in the public domain. An informed discussion of the Bill requires community access to this information.
4. Under the present Bill the scope of the data collection, the format, operational and security oversight of the CIS will be left to the discretion of the VDoH Secretary, which is totally unacceptable.
5. The Bill authorises the collection of data prior to a review of implemented controls, access policy and operational readiness. This practice is unprecedented in 'real life'.
6. The Bill contains no obvious data protection policy or sunset clause that ensures secure disposal once the information stored is no longer required for medical care.
7. The Bill eliminates the confidentiality of the doctor-patient relationship, eroding an individual's trust in their treating clinicians. This will also erode community health and wellbeing because vulnerable people may well choose not to seek clinical attention when needed, fostering illness and even death.[3]
8. Patients are statutorily precluded from seeing a copy of their own health record.
9. While penalties for unauthorised access to information stored in the CIS are listed in the Bill, the scope of what actually constitutes authorised access is vague. When combined with the exemption of the system from Freedom of Information (which is understandable in some explicitly prescribed circumstances) or legislative oversight, the use of this database and access rights to data stored in the CIS is opaque. The present Bill does not prohibit the information stored in the CIS from being used for purposes beyond the direct care of patients, such as statistical analysis, law enforcement, or even by political parties.

Apparently, the CIS is intended for the sharing of patient data for their clinical benefit and public health outcomes, but it lacks detail on how patients, medical providers or practitioners will benefit from this system relative to a risk/benefit calculation.[3] In medical practice, only a dozen or fewer

sentinel events need communication to emergency clinicians for patient care. The Bill is clinically destructive.

There is an urgent need for transparent, robust privacy and security mechanisms to be implemented across the State, given the rapid pace of technological privacy threats, if the community is to trust digital health implementations into the future. 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

The APF thanks Jasmine Russell for her contributions to this letter.

REFERENCES

1. Health Legislation Amendment (Information Sharing) Bill 2021, Victorian Legislation, October 2021. https://www.legislation.vic.gov.au/bills/health-legislation-amendment-information-sharing-bill-2021
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3. Australian Doctors Federation (ADF) Rushed Vic Government Health Database Law raises more questions than answers, Media Release. 14 October 2021. https://ausdoctorsfederation.org.au/2021/10/14/rushed-vic-government-health-database-law-raises-more-questions-than-answers/