

Opening Statement



Law Council
OF AUSTRALIA

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My Health Records Amendment (Strengthening Privacy) Bill 2018

Opening Statement: Senate Community Affairs References Committee

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1. My name is Morry Bailes and I am the President of the Law Council of Australia. As the Committee would be aware, the Law Council is the peak national body representing the legal profession in Australia.
2. I would like to thank the Committee for the opportunity to provide evidence to its inquiry the My Health Record System.
3. The Law Council welcomes the additional privacy protections contained in the My Health Records Amendment (Strengthening Privacy) Bill 2018. This includes:
 - a. Removal of the ability of the My Health Record System Operator to disclose health information in My Health Records to law enforcement agencies and government agencies without an order by a judicial officer or the healthcare recipient's consent; and
 - b. A requirement for the System Operator to permanently delete health information stored in the National Repositories Service for a person if they have cancelled their registration with the My Health Record system.
4. However, the Law Council holds a number of concerns related to the My Health Record system. The opt-out mechanism remains problematic given the sensitive nature of health information and particularly when applied to the secondary use of My Health Record data. The Law Council considers that the need for healthcare recipients to opt-out of the secondary use of their data is at odds with the underlying principles in both Commonwealth and State privacy laws. These principles provide that a health entity that holds information about a patient can only use or disclose the information for the particular purpose for which it was collected unless the patient has explicitly consented to secondary use or disclosure. The Law Council therefore recommends that a patient must provide explicit consent if their health information is obtained for a secondary use or disclosure.
5. Further, the Law Council is concerned that the system is vulnerable to unauthorised access, in particular by an individual with parental responsibility for a child who may not be the primary caregiver, including individuals who may be a perpetrator of family violence.
6. The Law Council supports the decision to ensure the My Health Record system is not accessible to health or life insurers, as this is critical to retaining the trust and confidence of the public. The Law Council also supports the availability of comprehensive databases to support health, clinical and medical research, subject to appropriate protection of privacy.
7. However, the Law Council is concerned that the secondary use of My Health Record System data for research is not generally well understood by the public. Further education should be provided to ensure that healthcare recipients are fully informed that their health data may be used for secondary purposes and that it is an opt-out process in circumstances where a healthcare recipient is already registered for a My Health Record.

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promoting justice and the rule of law.*

8. The Law Council recommends that it is preferable that the default for secondary research use of My Health Record data is to require the informed consent of the healthcare recipient. This consent can be readily sought and obtained through the user settings and communication channels facilitated by the My Health Record system between individuals and prospective researchers.
9. The Law Council's second key concern is that the My Health Record system is vulnerable to unauthorised access in the context of separated families who may misuse information available from a child's health records.
10. An authorised representative of a healthcare participant includes a person with parental responsibility. The Law Council understands that either party who is an authorised representative can access, amend or delete a child's My Health Record. The definition of parental responsibility under the *My Health Records Act 2012* (Cth) is very broad. A person has parental responsibility if they are a parent of a child and have not ceased to have parental responsibility because of a court order made under the *Family Law Act 1975* (Cth) or the law of a State or Territory. Further, the definition of parental responsibility includes a person who merely has an order that a child spend time with a person. Frequently a parent may retain parental responsibility for a child whilst simultaneously being subject to an interim or final parenting order preventing them from contact with the child, or alternatively requiring their contact with the child to occur only under supervised conditions due to the parent posing an unacceptable risk of harm to the child.
11. A parent may also be subject to a State-based Apprehended Domestic Violence Order (**ADVO**) preventing contact or communication with a child or the other parent and preventing them from locating the other person or child. A person subject to an ADVO from a State Court will still hold parental responsibility for a child under the Family Law Act and would therefore still be considered an authorised representative under the current My Health Record system. This means that they may be able to ascertain the residential address of the child and the other parent. This creates serious issues for children and parents who may be at risk of harm if their location was to be disclosed through the My Health Record system to the perpetrator of violence.
12. In the Law Council's view, the legislation needs to protect the location and identity of victims of family violence from being shared with perpetrators even if the perpetrator falls within the definition of a person with parental responsibility under the *My Health Record Act*. This can be achieved by amending the definition of parental responsibility under the Act so that a person has parental responsibility for a healthcare recipient if under a parenting order the child is to spend unsupervised time with the person, and including a provision that a person does not have parental responsibility if the person has a restraining order or personal protection order preventing them from spending time with the child.
13. Further recommendations in relation to the inquiry will be contained in the Law Council's forthcoming submission.

My colleagues and I are happy to answer any questions the Committee may have.

Thank you.

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