

17 November 2017

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Dear Dr Fodero

**Law Council submission on the Development of a Framework for Secondary Use of My Health Record Data Public Consultation Paper**

1. Thank you for the opportunity to comment on the *Development of a Framework for Secondary Use of My Health Record Data Public Consultation Paper (Consultation Paper)*. The Consultation Paper sets out matters relevant to the development of a framework that will govern the secondary uses of My Health Record system data collected under the *My Health Records Act 2012 (Cth) (Act)*.
2. Due to time constraints regarding the preparation of this submission, the Law Council is not a position to offer comments on all of the questions set out in the Public Consultation Paper.<sup>1</sup> However, we offer the following comments on some significant aspects of the consultation for your consideration, which have been adopted from the input provided to the Law Council by Law Society of New South Wales, one of its constituent bodies.<sup>2</sup> The Law Council is also grateful for input from the Law Society of South Australia, and the assistance of its Privacy Law Committee of the Business Law Section and Elder and Succession Law Committee in the preparation of this submission.

**Background**

3. The My Health Record system is intended to allow authorised healthcare providers, such as doctors, pharmacists, specialists, hospitals or allied health professionals, to access health information about healthcare recipients at any time. Apart from information that is provided by the healthcare recipient, the system contains a copy or a summary of health information held by healthcare provider organisations. In 2018, My Health Record participation arrangements will switch to an opt-out participation

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<sup>1</sup> Department of Health and HealthConsult, *Development of a Framework for Secondary Use of My Health Record Data Public Consultation Paper* (1 September 2017) <<https://consultations.health.gov.au/health-systems-policy-division/developing-a-framework-for-the-secondary-use-of-my>>.

<sup>2</sup> The Law Council exists to represent the legal profession at the national level, to speak on behalf of its Constituent Bodies on national issues, and to promote the administration of justice, access to justice and general improvement of the law. Through its constituent bodies and sections, the Law Council effectively acts on behalf of more than 60,000 lawyers across Australia.

arrangement.<sup>3</sup> This means that a My Health Record will be created for every Australian, unless they take active steps not to have one.

4. Under the Act, health information in a My Health Record may be collected, used and disclosed 'for any purpose' with the consent of the healthcare recipient.<sup>4</sup> In addition, one of the functions of the System Operator is 'to prepare and provide de-identified data for research and public health purposes'.<sup>5</sup> Before this can be done, a framework for secondary use of My Health Record system data must be established.

### **Use of the 'opt-out' model**

5. The Law Council notes that it is anticipated that as the My Health Record develops and expands the types of information captured, the database will become an important resource for health, clinical and medical research.<sup>6</sup> The Government's decision to switch creation of a My Health Record from opt-in to opt-out in 2018 is expected to stimulate active use of the My Health Record system. The Law Council supports the availability of comprehensive databases to support research, subject to appropriate protection of privacy. Safeguards must be put in place to ensure the privacy of the individual, informed consent and the proper use of their personal information.
6. The Law Council does not consider that the policy decision to adopt an opt-out model for creation of My Health Record supports a further decision to adopt an opt-out model for secondary uses of My Health Record (i.e. health, clinical and medical research). Rather, the Law Council recommends that the opposite should be the case: that is, that the default creation of a My Health Record for an individual should lead to policy caution in adopting a default consent for secondary uses of that individual's My Health Record. Measures should be adopted in the framework to require 'opt in' for the use of personal data for secondary purposes to ensure that any use of personal data is by consent, as required by the legislation.
7. The Law Council considers that when regard is had to the potential impact of a default consent for secondary uses upon public trust in the My Health Record system, as well as the limited clinical utility of data available through the My Health Record system (given the ability of individuals to control that data), it is preferable that the default for secondary research use of 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.
8. In any case, the Law Council considers that, except in specific circumstances (ie specific research), for which there should be additional consent sought, data should be at all times de-identified. Regardless of what model is adopted, it will be important to ensure that any de-identification is subject to strict governance requirements, with some third party oversight and appropriate assurance.

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<sup>3</sup> Department of Health and HealthConsult, *Development of a Framework for Secondary Use of My Health Record Data Public Consultation Paper* (1 September 2017) 2, 6 <<https://consultations.health.gov.au/health-systems-policy-division/developing-a-framework-for-the-secondary-use-of-my>>.

<sup>4</sup> *My Health Records Act 2012* (Cth) s 66(2).

<sup>5</sup> *Ibid* s 15(ma).

<sup>6</sup> Department of Health and HealthConsult, *Development of a Framework for Secondary Use of My Health Record Data Public Consultation Paper* (1 September 2017) 6 <<https://consultations.health.gov.au/health-systems-policy-division/developing-a-framework-for-the-secondary-use-of-my>>.

9. The Law Council considers that the use of personal data (de-identified) should be predominantly for the purpose of medical research and public health policy, and there should be limited or no access of personal data to private enterprise including insurers (other than for medical research / public health policy, whereby an appropriate ethics and other protocols should be adopted). Consideration should be given to amending the legislation which allows the use of personal data 'for any purpose' to a more restricted set of criteria.

#### Public trust in the My Health Record system

10. The Law Council is concerned that when My Health Record participation starts to operate on an opt-out basis in 2018 many citizens will not turn their minds to whether their sensitive health data might be available for research purposes without their explicit and informed consent. We note that the information held on a healthcare recipient's My Health Record is regarded by many individuals as highly sensitive and intimate. This perception of the information may well strengthen as the range and depth of information accumulated on My Health Record progressively expands and as particularly sensitive information, such as genomic data and genomic related disease dispositions, is added.
11. Given the sensitivity of the information, there is a risk that adoption of a default availability of My Health Record data for secondary research use may promote public concerns as to the purpose of the database and erode public trust and the social licence to operate the My Health Record system. The Law Council notes that it is important for the Government to nurture this trust and social licence and not to take any step that might erode the willingness of citizens to facilitate population of their My Health Record with all relevant and useful health information. For these reasons, we consider that the use of an opt-out model for secondary use may have an adverse impact on active uptake of the My Health Record system.

#### Impact on the elderly

12. The Law Council is concerned about the possibility of confusing or mistaking identity for individuals with similar names as a result of recording and holding details via computer records, and the potential this could have on an individual's vital and immediate treatment. The Law Council considers that this area should be tightly monitored and that secondary use of the records is not to be encouraged.
13. The Law Council trusts that these comments are of assistance. Please contact Dr Natasha Molt, Deputy Director of Policy, Policy Division (natasha.molt@lawcouncil.asn.au or on (02) 6246 3754) in the first instance with any questions.

Yours sincerely



**Fiona McLeod SC**  
**President**