

**Response to:  
Electronic Health Records and Healthcare Identifiers:  
Legislation Discussion Paper**

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1. As affiliated health information/informatics scholars, we welcome the review into the personally controlled electronic health record and healthcare identifiers service and the discussion of ways these systems are able to more effectively and efficiently operate. We also welcome the Government's focus on addressing the recommendations of the previous reviews and the need for change to ensure system viability and data quality.
2. In this document, we will not attempt to address all the issues identified in the paper. Rather, this document comments on areas that we are able to provide input and insight of relevance to our field of health information and management.
3. Disclaimer: The following is a report of our opinion based on the legislative discussion paper and should not be taken as theory or fact.

SECTION 3.1.2 DEFINITIONS: EXPANDING "IDENTIFYING INFORMATION" (p. 10).

4. We recommend the Government provides greater specification on how any additional information, such as a mobile telephone number, email address or driver licence number, can be used, who can access this information and to who this information is disclosed. This is to minimise the potential for misuse.

SECTION 3.2.1 ESTABLISHMENT OF ACeH: ACeH BOARD (p. 11).

5. We commend the Government on its recommendation to establish the Australian Commission for Electronic Health (ACeH).
6. We recommend the Government includes a health information management expert on the ACeH Board or an advisory committee. The current proposal includes technical expertise but does not include management expertise, including usability, non-technical interoperability, ownership, data quality and workforce impact expertise, as well as providing expertise on the already identified areas of privacy and security. This correlates with the recommendations of the Health Workforce Australia *Health Information Workforce Report* (October 2013).

SECTION 3.3.1 AN OPT-OUT PCEHR SYSTEM? (p. 12).

7. We commend the Government on its recommendation to trial an opt-out system approach and support the cautious method proposed in the paper.
8. We commend the Government for retaining the right of consumers to limit the access to certain documents in their record. Consumers have been doing this for centuries when they choose not to disclose information during a consultation with a healthcare practitioner, and we view this functionality within the PCEHR as an electronic process of the same thing.

SECTION 3.4.1 OBLIGATION TO ENTER INTO PARTICIPATION AGREEMENT (p. 16).

9. We commend the Government on its recommendation to abolish the participation agreement. However, we have identified a number of implications that were not addressed in the paper that will be impacted by this change.
10. We recommend the Government provides greater specification on ownership, particularly during instances of incorrect information being added to a record. Given the recommendations made under intellectual property, who will be responsible for ensuring data quality?
11. We recommend the Government be transparent on how data breaches are detected and the process thereafter. Other than individuals monitoring the access to their record through alerts, there is no detail on how the Government intends to monitor the system for data breaches.
12. We recommend the Government be transparent on how it intends to address accountability and risk management, particularly around the two issues discussed above.

SECTION 3.4.8 OBLIGATION FOR SYSTEM OPERATOR TO RETAIN RECORDS (p. 19).

13. We recommend the Government amends the requirement (b) to include an alternative date where the date of birth is not known, such as on occasion in Aboriginal Australian or refugee populations.

SECTION 3.5.1 PRIVACY: NOTIFICATION OF PCEHR USE (p. 19).

14. We recommend the Government provides greater specification on the definition and criteria of "an emergency" so that this is not left open to interpretation and the potential for a breach of privacy.
15. We recommend the Government ensures that individuals are made aware of the option of access alerts. For example, a standard question or pop-up text that needs to be acknowledged when an individual accesses their record for the first time, or communicated at the same time information about the trial is provided to individuals.

SECTION 3.5.4 PENALTIES FOR MISUSE OF INFORMATION (p. 23).

16. We support the recommendation for criminal penalties for the misuse of any health information, and believe penalties should be brought in line across all three Acts. Given recent precedents in changes to other legislation, such as the Criminal Code Act in relation to identity crimes, we believe this recommendation is appropriate.

If you would like to discuss any aspect of this document, please contact Dr Kerryn Butler-Henderson, [Kerryn.Butlerhenderson@utas.edu.au](mailto:Kerryn.Butlerhenderson@utas.edu.au), or Dr Tony Sahama, [T.Sahama@qut.edu.au](mailto:T.Sahama@qut.edu.au).

Yours sincerely,



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