

PCEHR Legislation Issues Feedback
Department of Health and Ageing

By email: ehealth.legislation@health.gov.au

Re: Submission on the Exposure Draft Personally Controlled Electronic Health Record Bill & Explanatory Memorandum

Thank you for the opportunity to make a submission on the Exposure Draft of the Personally Controlled Electronic Health Record (PCEHR) system (the Bill) and the Explanatory Memorandum (the EM).

I note that the Department of Health and Ageing (the Department) has not yet published our submission on the Draft Concept of Operations (Con ops) on its website despite the fact that this was brought to the Department's notice in my submission on the PCEHR System Legislation Issues Paper. I also note that the Analysis of Key Themes from the Public Consultation Process on the Draft Concept of Operations Relating to the introduction of a Personally Controlled Electronic Health Record System (the Analysis), groups the 165 submissions on the Con ops into only four 'stakeholder groups' which are Members of the Public, Healthcare Bodies, Healthcare Workers and Researchers and ICT Industry Associations and Vendors. Government regulators such as Privacy Commissioners do not appear to be represented in any of these groups, which leads me to the conclusion that my submission on the Con ops may not have been taken into consideration in the analysis. I am particularly concerned by the dearth of reported feedback on the section in the Analysis relating to the 'Opt-in' model. In my submission on this matter I supported the use of the opt-in model and noted the following short-coming of the 'opt out' model:

...an 'opt-out system will unreasonably interfere with the privacy choices of individuals, as they will lose control of who among health practitioners will-

- Have access to their health information, and
- Have authority to upload objective data and subjective opinion about them.

In my view being able to make a conscious choice regarding these two issues maintains a longstanding public policy that enables the community to have effective control of the management of their health.

The voluntary nature of participation by individuals is the corner-stone of a PCEHR system and I while am pleased to see that this is now reflected in the Bill I believe that benefits of the opt-in model should be clearly articulated in the final version of

the Con ops in order to reinforce its importance in the on-going operation and administration of the PCEHR system.

Below are my comments in relation to the mooted privacy regime for the PCEHR system. In making these comments I note that the Department has not issued a report following its receipt of submissions on the PCEHR System Legislation Issues Paper. In the absence of such a report it is not clear what consideration, if any, was given to the submissions provided in response prior to the development of the Bill and the EM¹.

While I have raised my concerns about the privacy regime in previous submissions I suggest that they bear re-statement in light of my comments above and in the context of the Bill and EM themselves.

Part 4: Privacy Regime

I note that the EM states that 'the privacy arrangements' in the Bill have been 'modelled on the Commonwealth Privacy Act and the National Privacy Principles made under that Act'² and that the PCEHR legislation will not displace existing obligations for individual healthcare providers and healthcare provider organisation under Commonwealth, State and Territory health privacy laws where those laws are not inconsistent with the *Privacy Act 1988* (Cth) (the Privacy Act).

In my submission on the Issues Paper I noted that if the PCEHR legislation were to take into account the existing privacy obligations operating under State, Territory and Commonwealth health privacy law (and require PCEHR participants not currently governed by those laws to 'opt-in' to the Privacy Act), it would be likely that PCEHR health information would be dealt with inconsistently across Australia. Such inconsistencies would be likely to arise in the day to day decision-making about collection, use and disclosure under the PCEHR system. For instance certain matters included in the access provisions for the private sector HRIP Act are not mirrored in NPP 6 or in Part 4 of the Bill³. In my view these differences can not easily be glossed over as this could result in very different outcomes for the same conduct depending on the jurisdiction in which the matters arises.

¹ In this regard note that my submission on the Issues Paper was sent to the Department on 25 August 2011 and the Exposure Draft Legislation was released on 12 September 2011 requiring that submissions be received by 28 October 2011. If the Department is serious about achieving the best policy outcomes for healthcare clients and practitioners in its implementation of the PCEHR, I suggest that it should allow sufficient time to make submissions, be transparent in its consideration of those submissions and refrain from a tendency to cherry-pick certain views and instead, seek to reflect across-the-board input from all stakeholders.

² I note that the Bill does not include a requirement to notify individuals about certain matters relating to the collection of their health information (cf HPP 4 and NPP 1.3). Notification of the purposes of collection, possible recipients and intended uses is a vital component of consent.

³ See section 25 of the HRIP Act.

It is also possible that inconsistencies will arise in context complaint handling by State, Territory and Commonwealth privacy regulators. Inconsistencies in outcomes for complaints could lead to the perception of unfairness in the context of health privacy complaints arising under the PCEHR system, notwithstanding the application of different standards arising from the same or similar facts.

I suggested that in order to avoid these inconsistencies there should be separate PCEHR privacy legislation/framework applying equally to all PCEHR participants, private and public, small and large business, health care providers and system operators which would displace the existing privacy obligations only to the extent that they concern matters relating to the operation or administration of the PCEHR system. This has been the position of this Office in previous submissions on the privacy governance mechanisms for the PCEHR and I do not resile from this view.

Thank you again for the opportunity to make these submissions on the PCEHR Bill and EM and I look forward to future participation on this very important initiative.

Yours sincerely

John McAteer
Acting Privacy Commissioner
Information and Privacy Commission