

General Comments

If the Commonwealth moves to an opt-out model for the PECHR, consideration will have to be given to the interaction with relevant NSW legislation to ensure that an opt-out model can operate in NSW. For example:

- health privacy principle (HPP) 15 in the Health Records and Information Privacy Act 2002 prevents health information being included in a health records linkage system (such as the PCEHR) without consent unless an exemption applies, such as the organisation is lawfully authorised not to comply with HPP 15.
- s56 of the Public Health Act 2010 places strict limits on the disclosure of HIV information without consent and may limit HIV information being included on the PCEHR without consent.

The Commonwealth should consult with NSW on the drafting of any legislation to move to an opt-out scheme and on whether any amendments to NSW legislation are required.

| Page No. | Section Heading                                   | Reference  | Comment/Suggested amendment   |
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| 9        | 3.1.2 Definitions – Clarification of “healthcare” | <i>‘Consider: The PCEHR Act definitions for “healthcare” and “health information” should align as closely as possible to those equivalent terms in the Privacy Act to ensure the PCEHR system is consistent with the operation of the Commonwealth privacy framework.’</i> | The definition of “health information” in the NSW Privacy Manual For Health Information (2015) is consistent with the proposed definition to include information about the physical health, mental health or disability of an individual. |

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| 10       | 3.1.2 Definitions - Expanding "identifying information" | <p>'For example, it is intended that regulations be made that would prescribe the following information as identifying information:</p> <ul style="list-style-type: none"> <li>• a mobile telephone number and email address – this would allow the System Operator to collect and use this information to notify individuals of access to their PCEHR or other matters by email or SMS, rather than by post, in accordance with the individual's preferences;</li> <li>• the status of an individual's healthcare identifier (IHI) – this would improve the ability of the HI Service Operator to manage an individual's choice to opt-out;</li> <li>• the unique reference number of the individual's driver licence, passport or Immicard, and the type of credential (driver licence, passport or Immicard) – this would allow the PCEHR System Operator to collect this information, and disclose it to the Document Verification Service, in order to verify the identity of an individual who chooses to opt-out. The System Operator will not store this information once it has been used to verify the individual's identity.</li> </ul> | <p>It is noted that the amount of identifying personal information being retained will increase as part of the My Health Record operating processes. Stakeholders would need to have a level of comfort that their identifiable information is secure.</p> |
| 12       | 3.3.1 An opt-out PCEHR system?                          | <p><i>'Note: Opt-out participation means that instead of enabling individuals (or their representatives) to choose to have a PCEHR, the system automatically creates a PCEHR for individuals unless they (or their representatives) choose <b>not</b> to have one.'</i></p>  | <p>It is important that clear messaging regarding the implications of the opt-out participation model is communicated to stakeholders, including general practitioners and consumers.</p>  |

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| 14       | <b>3.3.1 An opt-out PCEHR system? – Opt-Out transition in trial regions</b>               | <i>'Any person who becomes eligible for a PCEHR after this two month period, such as newborns, will not automatically get a PCEHR and if they want a PCEHR they will need to apply to register under the opt-in process.'</i>   | Providing clear and further clarification regarding the registration arrangements of newborns to the Child electronic Health Record (CeHR) is important.  |
| 16       | <b>3.4.1 Obligation to enter into participation agreement – Data breach notifications</b> | While the PCEHR Act does not currently impose this obligation on healthcare provider organisations and contracted service providers, the participation agreements do. <sup>1</sup> Given the proposal to abolish participation agreements, it is proposed to amend the PCEHR Act requirement to report data breaches to include healthcare provider organisations and contracted service providers. | It is suggested that the amended PCEHR Act reflects that notifications of data breaches are mandatory.  |
| 16       | <b>3.4.1 Obligation to enter into participation agreement – Data breach notifications</b> | <i>'clarify how healthcare providers and other entities can handle healthcare identifiers and other information, ensuring information can be obtained and used as is required to support safe and effective information sharing and recording; and'</i>   | Suggest the following amendment:<br><i>'clarify how healthcare providers and other entities can <u>securely</u> handle healthcare identifiers and other information, ensuring information can be obtained and used as is required to support safe and effective information sharing and recording; and'</i> |
| 17       | <b>3.4.3 Obligation for organisations to have PCEHR Policy</b>                            | <i>'Requirements for other participants in the PCEHR system to also have policies would be introduced. This is to ensure that all participants in the PCEHR system have appropriate security and information handling practices in place.'</i>  | Extensive consultation with stakeholders, such as general practitioners and jurisdictions, may be needed to ensure all measures are implementable.  |

<sup>1</sup> Clause 4.4(ii) of the healthcare provider organisation participation agreement and clause 7.2(b) of the contracted service provider participation agreement

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| 19       | <b>3.4. Obligation for System Operator to provide system testing</b>   | <i>'It is helpful for test environments to be available to vendors and other stakeholders so they have an opportunity to test how systems operate and interact before they are implemented.'</i>  | Suggest the following amendment:<br><i>'It is helpful for test environments to be available to vendors and other stakeholders so they have an opportunity to test how systems operate, are secured, and how they interact before they are implemented.'</i> |
| 21       | <b>3.5.3 Collection, use and disclosure of information - Handling of healthcare identifiers by prescribed entities</b> | <i>'As recommended by the HI Review, it is proposed to include a mechanism which would allow health-related organisations to be listed in Regulations so that they are permitted to handle healthcare identifiers and associated information as part of assisting organisations in their registration and participation in the PCEHR system.'</i> | In alignment with the proposed definition of "healthcare information" (Section 3.1.2), it is important that health-related organisations which view and/or use health information be listed in Regulations to permit their use of healthcare identifiers.   |
| 23       | <b>3.5.4 Penalties for misuse of information</b><br><br><b>In relation to PCEHRs</b>                                   | <i>Do you consider that more serious misuses of PCEHR information should be subject to criminal penalties (including the possibility of imprisonment), as well as retaining civil penalties (monetary fines, injunctions, etc.) for less serious breaches?</i>  | It is suggested that the proposed penalties align with penalties associated with misuse of the Telecommunications Act (1997) and Amendment (2006).  |
| 23       | <b>3.5.4 Penalties for misuse of information</b><br><br><b>In relation to healthcare identifiers</b>                   | <i>Do you consider that misuse of individuals' healthcare identifiers should continue to be a criminal offence?</i>   | It is suggested that the proposed penalties align with penalties associated with misuse of the Telecommunications Act (1997) and Amendment (2006).  |