The Royal Australian and New Zealand College of Radiologists®

13 July 2015

Sent via email: ehealth.legislation@health.gov.au

PCEHR/HI Discussion Paper Feedback
Department of Health
MDP 1003
PO Box 9848
CANBERRA ACT 2601

Dear Mr Madden,

Re: RANZCR response to eHealth Records and Healthcare Identifiers: Discussion Paper

Thank you for providing the Royal Australian and New Zealand College of Radiologists (RANZCR) with the opportunity to comment on the Electronic Health Records and Healthcare Identifiers: Legislation Discussion Paper.

RANZCR is the peak bi-national body for setting, promoting and continuously improving the standards of training and practice in diagnostic and interventional radiology for the betterment of the people of Australia and New Zealand. This includes supporting the training, assessment and accreditation of trainees; the maintenance of quality medical care and standards; and workforce mapping to ensure the appropriate availability of staff to support the sectors in the future. At all times, RANZCR seeks to promote the best standards of practice for patient treatment and care and to ensure that all Australians have access to quality radiology services.

Please find attached the RANZCR response to the Electronic Health Records and Healthcare Identifiers: Legislation Discussion Paper

If we can provide further information, please contact Mr Mark Nevin, Senior Executive Officer, Faculty of Clinical Radiology via mark.nevin@ranzcr.edu.au.

Yours Sincerely,

Mark Nevin

Senior Executive Officer, Faculty of Clinical Radiology

RANZCR response to Electronic Health Records and Healthcare Identifiers: Legislation Discussion Paper

Introduction

The Royal Australian and New Zealand College of Radiologists (RANZCR) is the peak bi-national body for setting, promoting and continuously improving the standards of training and practice in diagnostic and interventional radiology for the betterment of the people of Australia and New Zealand. This includes supporting the training, assessment and accreditation of trainees; the maintenance of quality medical care and standards; and workforce mapping to ensure the appropriate availability of staff to support the sectors in the future. At all times, RANZCR seeks to promote the best standards of practice for patient treatment and care and to ensure that all Australians have access to quality radiology services.

Thank you for providing RANZCR with the opportunity to comment on the Electronic Health Records and Healthcare Identifiers: Legislation Discussion Paper (or 'Discussion Paper') and for granting us an extension to the original deadline. RANZCR has been closely involved in previous consultations on the PCEHR and we hope our comments assist the Department in progressing this initiative.

The RANZCR e-Health Reference Group and the Joint ADIA/RANZCR Informatics Working Group have reviewed the Discussion Paper and would like to make the following comments on relevant sections.

2.1. Personally controlled electronic health record system

RANZCR supports the PCEHR and the Department's efforts to increase consistency, ease of use and participation rates. We agree that communication of health information for accurately identified individuals is vital to improve outcomes, particularly in diagnostic imaging.

RANZCR feels that the description of a PCEHR on page 4 of the Discussion Paper should be revisited. A PCEHR is not a 'summary of key health information' but rather a repository of a portion of health and health-related information for an individual. Moreover, the wording 'assembled from' is also misleading, since information in a PCEHR is 'submitted by' a range of unrelated organisations without any oversight in its assembly.

2.3 Healthcare Identifiers Service

RANZCR acknowledges the potential value of individual healthcare identifiers for record matching, including the matching of diagnostic imaging studies performed at different times and places, however, it should be noted that more work needs to be done to develop a standard approach to the adoption of IHIs in existing file formats in diagnostic imaging (notably DICOM), and to promote the adoption of such an approach.

2.6 Timeframes

RANZCR feels that given the lack of clarity over certain proposals in the Discussion Paper (see comments below), the timeframes quoted in the document are too short; in particular, RANZCR is concerned that the proposed introduction of legislation to Parliament in August 2015 (page 25 of Discussion Paper) will not allow sufficient time for resolution of issues raised in the current consultation. Consideration could be given to circulating an Exposure Draft of the proposed legislation, which would make clearer what is being proposed.

2.7 Consultation to date

RANZCR feels that implementation of the PCEHR should focus on improving the value of the PCEHR to clinicians. There is wide agreement (notably from the AMA) that the results of diagnostic tests should be available in the PCEHR. Much work has been done on how these results could be uploaded to the PCEHR, but to date there has been little reason for individual providers to add such uploads to their existing tasks. Support for providers willing to send data to the PCEHR would give much-needed momentum to the incorporation of diagnostic imaging. This support should be provided to providers both locally and nationally.

We would like to add that there are existing standards and profiles for information-sharing and interoperability between diagnostic imaging providers and referrers. These working systems should be leveraged and built on, as far as possible, rather than duplicated by new systems built from scratch. This will be particularly important as the sector moves to more seamless sharing of images as well as reports. These issues are discussed further in 'Securing Quality Outcomes: Systemised Access to Digital Images' a joint publication of the RANZCR and the Australian Diagnostic Imaging Association (ADIA).[1]

3 Legislative proposals: PCEHR system and HI Service

3.1 Preliminary

3.1.1 Name of the PCEHR system

RANZCR supports the change of name of the new system as the original name generated confusion, by virtue of being an acronym, and also by seeming to refer to the patient's actual healthcare record which is retained by the healthcare provider. 'My Health Record' is clearer and more easily distinguishable from the patient's 'true' health record which is retained by the healthcare provider.

3.1.2 Definitions

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. If we do not amend the Privacy Act, inconsistencies would arise and healthcare providers could be subject to different privacy arrangements depending on whether or not they are using the PCEHR system.

RANZCR agrees that 'health-related disability, palliative care and aged service[s]' should be included in the definition of 'healthcare' and that this should be consistent across healthcare legislation. Those services are integral to patient care and the information pertaining to them could influence healthcare decision-making. We agree that insurance assessments should not be included in the revised definition of healthcare, however we would caution that services such as screening can make a significant contribution to healthcare outcomes and should not be forgotten in these discussions.

Furthermore, we agree that healthcare information should include information about the 'physical, mental or psychological health or disability of an individual' as these are central to individuals' health and wellbeing.

RANZCR agrees with the proposed distinction between healthcare providers and organisations on page 9 of the Discussion Paper. Notwithstanding this, there are a range of barriers to healthcare providers participating in the PCEHR. We would like to see a concerted effort to resolve those for diagnostic imaging and are happy to support the Department of Health and others in these efforts.

3.2 Governance

3.2.1 Establishment of ACeH

RANZCR agrees with the proposal for the newly established ACeH to assume responsibility for the PCEHR operational activities, currently undertaken by the Department of Health, in addition to the broader eHealth systems operations currently managed by NEHTA. RANZCR also supports the proposal for the Department of Health to retain responsibility for the national eHealth policy.

The ACeH Board should have strong representation from clinicians, information technology experts and providers of healthcare services. It will also be important to secure active participation and commitment from the jurisdictions, particularly in promoting the PCEHR as a tool to bridge the gap

[1] Securing Quality Outcomes: Systemised Access to Digital Images is available here: http://www.ranzcr.edu.au/quality-a-safety/ehealth

between public hospital systems and general practice. RANZCR looks forward to ongoing stakeholder engagement and consultation with the ACeH.

3.3 Participation

3.3.1 An opt-out PCEHR system?

RANZCR agrees that 'opt out' is in principle a better model, however the model being proposed is unclear, particularly for those who are already registered with Medicare but do not have a PCEHR. Further details are not provided until much later in the Discussion Paper and these remain unclear. RANZCR agrees with the proposal to trial 'opt out' in particular geographical regions prior to national roll out and we look forward to seeing the results of the trial.

We are worried about the potential for further confusion on individual consent for individuals, practitioners and healthcare providers. The current model of 'standing consent' has already been complicated due to the interplay with States and Territories legislation which lead to the requirement of 'express consent' for the upload of some diagnostic test results, irrespective of any standing consent. We have major reservations about the practical operation of the system down the track when patients with a PCEHR attend for services under a greater variety of consent circumstances. We feel it is critical that the same model of standing consent apply to all individuals, irrespective of whether they opted in or chose not to opt out from a PCEHR, unless it would contravene another specific piece of legislation (such as disclosure of HIV/AIDs in pathology testing).

The timeframes for the trial period should be extended to make it practicable for the System Operator to obtain the consent of individuals in trial areas who do not opt out, before uploading Medicare and other data; this would not prevent the prompt creation of PCEHRs for the purposes of the trial.

RANZCR would welcome further details on the methodology of the trials and the methods and criteria proposed for their subsequent evaluation.

3.4 Obligations of parties

3.4.3 Obligation for organisations to have PCEHR policy

RANZCR recognises the value of organisations maintaining their own PCEHR policies.
The meaning of 'data quality' on page 17 of the Discussion Paper is unclear. RANZCR agrees that information uploaded to a patients PCEHR must be clear and specific to that individual, however we are concerned that the term 'data quality' could be interpreted in a range of ways, some of which would require substantial changes in current practices across the healthcare sector. While such changes may well be desirable, their introduction will need careful planning and appropriate resourcing. This is particularly the case in diagnostic specialities, where the 'data quality' of our outputs is substantially dependent on the information contained in the referrals that radiologists receive. At present the PCEHR is intended only to be a collection of documents from which little atomic data will be available. This will hinder the development of software designed to leverage the availability of comprehensive healthcare information on an individual. In future, if diagnostic images are brought into the purview of the PCEHR, there will need to be extensive discussion around the 'data quality' requirements for such images. We would favour a requirement for information uploaded to the PCEHR to be accurate, to the best of the provider's knowledge.

3.4.6 Obligations to use PCEHR system

We have major reservations about imposing penalties on providers (through non-payment of rebates) as the current system is still in its infancy and there are several shortcomings in the design of the system which have hindered uptake. We strongly favour prioritising delivering a workable system, getting the majority of consumers signed up, and supporting providers on implementation.

Consider: In what circumstances should healthcare providers not be required to upload a health assessment, comprehensive assessment, mental health plan, medication review report or chronic disease plan?

The specific meaning of 'healthcare assessment' and 'comprehensive assessment' in the PCEHR Review of December 2014 is unclear. Principles and rules already exist to determine when information should not be uploaded to the PCEHR. As noted under 3.4.6 we do not believe that financial penalties should be imposed on providers at present.

3.4.8 Obligation for System Operator to retain records

RANZCR agrees with the proposed amendment on record retention.

3.4.9 Obligation for System Operator to provide system testing

RANZCR strongly supports the provision of test environments to vendors and other stakeholders.

3.5 Privacy

3.5.1 Notification of PCEHR use

Regarding contacting individuals and sending text/email notification messages, we think this may have advantages, however the individuals involved should have agreed to this, and have the ability to opt out down the track if they no longer wish to receive these communications. Notwithstanding this, we are unsure how practical it would be to notify individuals each time their PCEHR is opened. For example, would an individual receive multiple notifications, if multiple clinicians have an individual's PCEHR open at the same time? Moreover, we would welcome further clarification of the anticipated benefits that derive from notifying an individual that their PCEHR is being accessed by a clinician.

3.5.3 Collection, use and disclosure of information

Third party information
We agree that some third party information can be relevant to patient care and it should be possible to include it.

Handling of healthcare identifiers by prescribed entities
RANZCR is concerned that the proposal to allow other uses of healthcare identifiers, by regulation, is vaguely worded and appears open-ended. Given the sensitivities around linkage of government records, it may be more prudent to present each 'additional use' for public consideration, and seek specific legislative approval for it.

Healthcare identifier searching capabilities
We are also concerned at the lack of detail or explanation regarding permitting the HI Service Operator to 'undertake actions which would enable resolution of the identity' on page 22. In advance of supporting this change, we would wish to know what 'actions' might be undertaken in those circumstances.

Handling by Australian Health Practitioner Regulation Agency (AHPRA)
We are also confused as to the meaning of AHPRA having a role in improving healthcare providers' adoption of healthcare identifiers, by including it in regular professional renewal activities. Some healthcare practitioners do not need to have a HPI-I, and the possession of an HPI-I should not be a condition of, or tied to, ongoing registration.

3.5.4 Penalties for misuse of information

Consider – in relation to PCEHRs: A PCEHR contains sensitive information about an individual.
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? Or should misuses of PCEHR information incur only civil penalties?

RANZCR believes that the penalties for misuses of PCEHR information should be tailored to the severity of the offence, and the consequences for individuals involved. Notwithstanding this, criminal penalties seem harsh while individuals are getting used to a new system, and some flexibility should be applied to demonstrably accidental misuse. Furthermore, introducing criminal penalties without clear, justified reasons would be a deterrent to participation in the PCEHR.

Consider – in relation to healthcare identifiers: As well as health information, PCEHRs may also contain an individual's healthcare identifier.
Healthcare identifiers are simply a number. They do not contain any health information. At present, the HI Act imposes criminal offences only for misuse of healthcare identifiers.
Do you consider that misuse of individuals' healthcare identifiers should continue to be a criminal offence?
Would it be more useful to introduce civil penalties for less serious misuses of healthcare identifiers for individuals? For example, to allow a more graduated range of enforcement options.

RANZCR agrees with the proposal to introduce civil penalties for less serious misuses of healthcare identifiers for individuals, and to adopting a graduated range of enforcement options.

Other comments

RANZCR notes that while the broader adoption of IHIs and the PCEHR in diagnostic imaging offers potential long-term benefits to both providers and patients, previous discussions have made clear that these are only likely to accrue once electronic referrals are widely adopted in the sector. There is as yet no agreed plan on how such adoption is to occur, The RANZCR and ADIA jointly produced (in 2013) a Roadmap for the application of e-health to diagnostic imaging, entitled 'Securing Quality Outcomes: Systemised Access to Digital Images'.[1]

RANZCR would wish to have an opportunity to review the exposure draft of the pending legislation to understand better the intentions and the potential obligations on healthcare organisations**.**

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