

24 June 2015

PCEHR/HI Discussion Paper Feedback
Department of Health
MDP 1003
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Electronic Health Records and Healthcare Identifiers: Legislation Discussion Paper (the discussion paper).

Electronic Health technologies and solutions offer significant benefits, from better collaboration between Medical Practitioners and continuity of care, through to better quality of care and efficiencies. The Royal Australian and New Zealand College of Ophthalmologists (RANZCO) welcomes the opportunity to comment on the Commonwealth Department of Health discussion paper relating to the Personally Controlled Electronic Health Records (PCEHR) (1).

RANZCO's mission is to drive improvements in eye health care in Australia, New Zealand and the Asia Pacific Region through continuing exceptional training, education, research and advocacy. Underpinning all of the College's work is a commitment to best patient outcomes, providing contemporary education, training and continuing professional development, evidence-based decision making, collaboration and collegiality. RANZCO also seeks to educate the general public in all matters relating to vision and the health of the human eye and advocates for accessible ophthalmology cost effective services for patients.

The PCEHR commenced operation on 1 July 2012 with an infrastructure platform to facilitate sharing of patient information across care settings. As at 30 June 2014, the total number of consumers registered for an eHealth record was 1,735,082 (2). This low uptake represents less than 10% of the Australian population. Medical professionals had written clinical summaries for fewer than 100,000 of these records (2).

1. Executive Summary

- RANZCO supports individuals taking responsibility for their own health and recognises that PCEHR could empower and encourage patients to improve their overall health status.
- It has been well documented that the limited uptake of the PCEHR has resulted because of flaws in the current system design and implementation. A move to an opt-out model would remove the need for consumers to actively register for a PCEHR and at the same time retain the ability for consumers who have an explicit objection to having a PCEHR to opt-out.
- RANZCO supports the proposed PCEHR opt-out model of the Commonwealth Department of Health in broad terms.

- A PCEHR may provide ophthalmologists with additional sources of patient information and could be a mechanism for improved communication with other health professionals and for (or thereby) aligning clinical workflows. The My Health record has, however, limited clinical value for clinicians because the control of the medical information and data resides with the patient.
- The PCEHR Review recommended that payment for Medicare items relating to health assessments, comprehensive assessments, mental healthcare plans, medication management reviews and chronic disease planning items depend on the uploading of specific documents to the PCEHR system (1). RANZCO does not support either this proposal and changes to the Health Insurance Regulations (1975), or changes to the Regulation alone, because the decision to upload this information ultimately resides with the patient.

2. Background

On 19 May 2014, the Commonwealth Government released the report from the review of the PCEHR. The review investigated concerns regarding the progress in implementing the PCEHR system. An opt-out PCEHR model was recommended as a result of the review. There is international evidence from New Zealand and from the United Kingdom that provided safety and security issues are addressed that an opt-out model is well received. The summary care record rollout by the National Health Service in England contacted 45,997,228 people with an opt-out rate of just 1.4% (3). An opt-out PCEHR model is supported by the Consumer Health Forum (CHF), as stated below:

“Considering the current stage of the PCEHR roll-out and the lack of meaningful usage of the record, CHF reiterates its view that the PCEHR system will be more successful if it is to be opt-out, rather than opt-in. Our extensive consultation with consumers, consideration of the positions of other key stakeholder groups and review of international experience support and consolidate this position.”

Quote from Consumer Health Forum, submission to review of the PCEHR, 2014.

The Commonwealth Government conducted an extensive consultation process following the completion of the PCEHR review in 2014. Over 500 consumers, health care providers, health software vendors, private health insurance providers and medical indemnity insurance providers were consulted (4). The consultation on PCEHR review recommendations reported that lack of awareness of the PCEHR, difficulties in registering associated with the current registration processes or apathy on the part of consumers have been cited as reasons for low PCEHR engagement. Most consumers felt that they would have been more likely to register for the PCEHR had they been aware of its existence and had a better understanding of the purpose and benefits of having a record (4). The majority of consumers consulted supported a move to an opt-out model once they were made aware of the PCEHR, its purpose and benefits (4).

3.1 Legislative Proposals: Preliminary

3.1.1 Name of the PCEHR system

It is proposed that the PCEHR be renamed the My Health Record (1). RANZCO supports the name change as outlined in the discussion paper, along with the further measure to rename the Personally Controlled Electronic Health Records Act 2012 (PCEHR Act) to reflect this change.

3.1.2 Definitions

RANZCO supports clarification of terms used in the PCEHR Act and the Healthcare Identifiers Act 2010 (HI Act) such as “healthcare” and “health information” to ensure the PCEHR system is consistent with the operation of the Commonwealth privacy framework (1). This will result in information about healthcare provider organisations, including their healthcare identifier, no longer being treated as personal information.

RANZCO further supports the expansion of the term “identifying information” in relation to an individual to include a regulation-making power. This means that regulations can be put in place to enable the collection of other identifying information such as mobile telephone numbers or email addresses, the status of an individual’s healthcare identifier and the unique reference number of the individual’s driver licence, passport or Immicard, and the type of credential. RANZCO considers this information should not be stored once it has been used to verify the individual’s identity.

The verification process for patients living in remote locations of Australia (RA Zones 4-5) can be very challenging and therefore the PCEHR system should be linked to the Medicare system which has been improved greatly in remote areas. Re-inventing other systems which require personal information including drivers’ license or passport numbers is inefficient.

3.2 Legislative Proposals: Governance

The My Health Record governance arrangements must be transparent, accountable and developed in collaboration with key stakeholders. Fundamentally, the purpose of the legislation for the PCEHR should be to ensure that only people who have a genuine need and are authorised to do so are entitled to access a person’s PCEHR. RANZCO notes that the PCEHR Review identified serious concerns about current eHealth governance arrangements.

3.2.1 Establishment of Australian Commission for Electronic Health (ACeH)

RANZCO supports the proposed establishment of the ACeH to be responsible for all national eHealth systems, including PCEHR system operational activities (1).

3.3 Participation

3.3.1 An opt-out PCEHR system

RANZCO supports the PCEHR opt-out system as proposed by the Commonwealth Government (1). An e-health system that connects patient information across health care settings, and which can be accessed and contributed to by treating medical practitioners and other health practitioners will improve the safety and quality of medical care in Australia.

Patient considerations

RANZCO has concerns about how those who come from culturally and linguistically diverse backgrounds, persons with a disability, or people with limited or no access to the internet, will be made aware of the PCEHR and will be encouraged to participate. Individuals in these groups may not be frequent users of electronic communications and may not be able to access online information or services easily. The Commonwealth Government has an obligation to ensure that all vulnerable populations are both protected and informed in an opt-out PCEHR. Public awareness activities and training programs should be appropriately targeted by the Commonwealth Government to be inclusive of all Australians. Patients should be advised by the Commonwealth Government that, if they want to withhold certain information or limit access to specific parties, they will have the ability to lock their record accordingly.

For people who are blind or vision impaired, it is also important that any system is accessible and user-friendly. The Australian Government has endorsed the Web Content Accessibility Guidelines (WCAG) version 2.0 AA rating for all government websites and information systems (5). In collaboration with Vision 2020 Australia, RANZCO recommends that the Department ensures that the redevelopment of the My Health Record is aligned with these guidelines, considering the varied needs of users, and plan for accessibility from the outset; noting that not all people who are blind or vision impaired access information in the same way and that many individuals have a preferred format.

Health professional considerations

The My Health Record contains clinical summaries that are prepared by health professionals. Consequently, a PCEHR has practical clinical limitations for the treatment of the patient in respect of the content, accuracy and accessibility of the information. The patient may choose to remove or lock specific access from health care providers or alter the record for diverse reasons.

The consultation on PCEHR review recommendations identified that for clinicians, near universal usage envisaged with the move to an opt-out model of participation by individuals removed a part of their concerns regarding the current PCEHR system (4). Attention to building clinical utility of the current PCEHR system, building a wider clinician contribution base so all clinicians would benefit from information shared, and attention to their change management concerns are considered equally critical (4). RANZCO agrees with these views.

Research on the use of and attitudes towards 'eHealth' (the combined use of electronic communication and technology in healthcare) among the full range of licensed medical specialists including ophthalmologists was commissioned by the Commonwealth Department of Health in 2011 (6). The qualitative survey identified that Australia's medical specialists have a strong foundation for eHealth adoption and use, but are far from realising its full potential. Current use of eHealth activities for ophthalmologists included: clinical reference (66%); education (63%); show patients info during consult (49%); and view/record patient notes during consult (47%) (6). Desired uses included the ability to complete event summaries (54%), decision support for ordering tests (54%), and view diagnostic imaging (52%) (6).

A PCEHR may provide ophthalmologists with additional sources of patient information and could be a mechanism for improved communication with other health professionals and aligning clinical workflows. RANZCO supports the proposed legislative amendments whereby providers may access the consumer's PCEHR without seeking explicit consent unless they are specifically asked or locked out by the consumer from accessing their record to view information or to upload content. This will allow the development of automated provider software systems that minimise the impost on the clinicians whilst maintaining patient control of the My Health Record.

Clinicians involved in the PCEHR review recommendation consultation review process supported the inclusion of the following information in the PCEHR as a priority (4):

- allergies and alerts;
- current medications;
- current conditions;
- transfer of care summaries (eg. hospital discharge summaries); and,
- recent pathology and diagnostic imaging test results.

RANZCO supports the inclusion of this information, but also considers that other mechanisms are required for the prevention of adverse events, error, or over use of diagnostic imaging tests. Shared eHealth records for health professionals should be supported by governments because they complete clinician patient records. The Commonwealth Government is currently in the process of developing electronic hospital medication charts. This initiative is supported by RANZCO to reduce prescribing and dispensing errors.

Where existing data flows do not support analyses of quality of care, Australian clinical quality registries are efficient and effective in providing consumers, clinicians, management and government with information for managing and improving delivery of health services (7). RANZCO supports the option for patients to share information contained within the My Health record with quality patient registries. The development of this data exchange capability should be consistent with the ACSQHC Framework for Australian clinical quality registries (7).

Effective training tools and workshops should be made available to medical professionals to support the implementation of the opt-out My Health Record. The NPS has developed tailored training programs for health professionals participating in hospital electronic medication charts that are CPD accredited (8). RANZCO supports the development and funding of CPD accredited training programs by the Commonwealth Government relating to the implementation of the My Health Record.

RANZCO would welcome continued developments by the software vendors to reduce the administrative burden required by clinicians to access and upload clinical information. Increasing the usability for clinicians will support overall adoption of the system by providers. Appropriate management of the My Health Record file size is required to ensure that up to date information may be easily uploaded and accessed. The use of advanced technology platforms compatible with smart phones and tablets is also encouraged.

Opting out in trial regions

The Commonwealth Government has proposed to undertake a number of trials of different participation models for the PCEHR system in selected regions of Australia in 2016, including opt-out trials (1). The purpose of these trials is to:

- identify appropriate methods of targeting and delivering critical information to key audiences;
- assess the effectiveness of targeted communications, and education and training for healthcare providers; and,
- test implementation approaches.

These trials will inform future decisions about, and the optimal approaches for, maximising participation in the PCEHR system, including the possible adoption of an opt-out system for individuals. While the trials are being undertaken the system will continue to operate on an opt-in basis across the rest of Australia.

The legislative discussion paper proposes that there will be a period of two months in which individuals in trial regions will be able to notify the System Operator that they do not want a PCEHR (1). RANZCO considers that the minimum time period to opt-out should not be less than three months. Health professionals, government officials, relevant researchers and consumers should be involved in the development of the trial design. We consider that the trial sites should be piloted in highly educated population cohorts with national broad band network (nbn) support prior to the roll out to other sites representative of the Australian community demographics.

3.4 Obligations of parties

3.4.1 Obligation to enter into participation agreement (1)

RANZCO supports the reduction of red tape throughout the PCEHR system. It is important to ensure that the PCEHR Act guarantees that any use of a document in the PCEHR system or downloaded from the PCEHR system does not infringe copyright or commit data breaches. RANZCO also supports the proposal to amend the PCEHR Act requirement to report data breaches to include healthcare provider organisations and contracted service providers, ensuring that an individual's personal control over their information remains protected.

3.4.2 Centralising and simplifying participant obligations (1)

RANZCO supports the proposed move to centralise and simplify participant obligations, particularly to ensure that the PCEHR Act applies equally to all participants in the PCEHR system.

3.4.3 Obligation for organisations to have PCEHR policy (1)

The PCEHR Rules currently require registered healthcare provider organisations to have in place a policy that addresses certain PCEHR matters, such as security measures they will take and training they will provide to staff (rule 25). However, there is no requirement for this policy to address how the organisation will ensure data quality so it is proposed that this requirement be included. RANZCO supports the requirement for registered healthcare provider organisations to develop a PCHER policy that addresses how the organisation will ensure data quality.

3.4.4 Obligations on authorised and nominated representatives (1)

It is appropriate that the PCEHR Act currently provides for authorised representatives and nominated representatives to assist individuals to manage their PCEHR. The Australian Government has proposed that the responsibilities of authorised and nominated representatives be clarified to align with the proposed new Australian supported decision-making regimen, replacing the current obligation in the PCEHR Act for representatives to act in the best interests of the individual with obligations to:

- consider the will, preferences and rights of the individual when making a decision; and
- perform the role of authorised representative or nominated representative diligently and in good faith.

RANZCO supports this proposed amendment to the PCEHR Act.

3.4.5 Application of obligations on different types of entities (1)

While the PCEHR Act specifies how obligations apply to organisations that are trusts, partnerships and unincorporated associations, the HI Act does not directly acknowledge this and may cause some confusion around the legal status required of healthcare provider organisations. RANZCO supports the proposed changes to the HI Act application provisions to be consistent with the PCEHR Act.

3.4.6 Obligations to use PCEHR system (1)

The PCEHR Review recommended that payment for Medicare items relating to health assessments, comprehensive assessments, mental healthcare plans, medication management reviews and chronic disease planning items depend on the uploading of specific documents to the PCEHR system (1). The uploading of the above mentioned Medicare item by a health professional should be at the direction of individual patients because control of the PCEHR health record resides with them.

A number of health care providers may not have the technological capacity or sufficiently reliable internet access to upload Medicare plans to a patients PCEHR. The perceived administrative burden could also create a disincentive for some health professionals to complete Medicare Health Assessments if the PCEHR. RANZCO does not support the proposed changes to Medicare payments for health professionals. Consequently, the Health Insurance Regulations (1975) should not be amended as part of the My Health Record opt-out legislative package.

3.4.7 Obligation for System Operator to notify decisions (1)

The PCEHR Act requires the System Operator to notify individuals and entities about decisions to cancel, suspend or vary an individual's or an entity's registration (section 51 and 53). Currently, notification of these decisions must be given in writing, which can take time. RANZCO agrees with the proposed changes to permit the System Operator greater flexibility by allowing the System Operator to choose how notifications would be made.

3.4.8 Obligation for System Operator to retain records (1)

The PCEHR Act currently specifies that any record about an individual that is uploaded to the National Repositories Service (NRS) must be retained for 30 years after the death of the individual or, if the date of death is not known, for 130 years after the record was uploaded (section 17).

RANZCO supports the proposed change to amend this requirement so that records are retained for the longer of:

- 30 years after date of death; or,
- if date of death not known, 130 years from the individual's date of birth.

3.4.9 Obligation for System Operator to provide system testing (1)

RANZCO supports the addition of a function to allow the PCEHR System Operator to develop and implement a test environment which can be made available to vendors and clinicians, providing an opportunity to test and provide feedback on how systems operate and interact before they are implemented.

3.5 Privacy

3.5.1 Notification of PCEHR use (1)

There are currently a host of access control mechanisms that prompt notifications and alerts to individuals when certain activities occur in relation to their PCEHR. RANZCO supports the establishment of a further notification to alert an individual when their PCEHR is opened or used.

3.5.2 Temporary suspension of access to a PCEHR (1)

While there are currently some provisions allowing the System Operator to suspend access to a PCEHR in specified circumstances, some circumstances are not covered by the legislation. RANZCO supports the proposal to allow suspension of access to a PCEHR by representatives if there is a risk to the individual, or to participants in the PCEHR system in these circumstances:

- a threat to the security of the record or the PCEHR system or the System Operator is concerned that such a risk may exist. This risk could occur, for example, where the System Operator becomes aware that a person (not the individual) is trying to cancel an individual's registration, or access an individual's PCEHR, without authority; or,
- an issue or suspected issue with the individual's (or their representatives') identity or other technical or operational issue.

3.5.3 Collection, use and disclosure of information (1)

RANZCO notes the current complexity of the HI Act and PCEHR Act related to the collection, use and disclosure of information and the purposes for which these actions are allowed. We support the proposal to simplify these authorisations by moving from a prescriptive approach, which specifies how an entity carries out an activity, to a principles-based approach, which would list the information that is protected, the entities who are authorised to collect, use and disclose it, and the purposes for which information can be collected, used and disclosed.

RANZCO supports the two-way exchange of error identification with AHPRA and HI Service Operators. RANZCO also supports proposed further clarification on certain authorisations, particularly in relation to allowing certain other records, such as those used by the NDIS, to use healthcare identifiers to ensure the owners of the records are accurately identified, similar to recent changes made to the HI Act to allow healthcare identifiers to be associated with aged care records in certain limited circumstances.

3.5.4 Penalties for misuse of information (1)

The HI Act and PCEHR Act, together with the Privacy Act, currently provide penalties for misuse of information and healthcare identifiers. RANZCO supports the proposal to explore changes to the range of enforcement and penalty options available should a person breach the PCEHR Act. RANZCO agrees that more serious misuses of PCEHR information and healthcare identifiers should be subject to criminal penalties, as well as retaining civil penalties such as monetary fines or injunctions for less serious breaches.

3.6 Reviews

3.6.1 Review of the legislative changes (1)

RANZCO supports an independent review two years after the proposed changes to the HI Act and PCEHR Act are made, to ascertain whether the changes have been effective and meet stakeholder requirements.

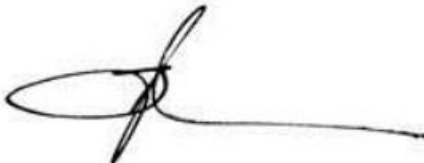
3.6.2 Privacy Assessments of AHPRA (1)

RANZCO supports the proposal to ensure that the Information Commissioner can conduct assessments and carry out investigations of AHPRA in respect of its handling of healthcare identifiers.

4. Conclusion

RANZCO would like to thank the Department of Health for the opportunity to comment on the Electronic Health Records and Healthcare Identifiers: Legislation Discussion Paper. We would be grateful if your team could contact RANZCO Advocacy Officer, Suzanne Lyon, at slyon@ranzco.edu, when further information becomes available of the next stage of the process.

Yours sincerely



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5. References

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