PCEHR/HI Discussion Paper Feedback
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ACS Response to PCEHR Legislation Discussion Paper June 2015
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Introduction
The ACS welcomes the opportunity to respond to Electronic Health Records and Healthcare Identifiers: Legislation Discussion Paper.

This document builds on the report of Review of the Personally Controlled Electronic Health Record (December 2013) (referred to as "the Review" in this document) and the Deloitte Report[1] on the public consultations that occurred.

Who is ACS?
The ACS was formed in 1966 and is Australia's peak body for ICT professionals with around 22,000 members nationally. A core function of the ACS is the assessment and accreditation of its members as Certified Technologists and Certified Professionals. Assessments are conducted against the Skills Framework for the Information Age (SFIA) as part of an internationally recognised and independently assessed professionalism scheme. To retain professional status ACS requires certified members to undertake ongoing professional development activities, which ensures currency of knowledge and skills of its members.

ACS also conducts research-based advocacy on behalf of members on public policy issues relating to the digital economy and the impact of ICT on productivity growth and standards of living in the Australian economy. As a vendor neutral organisation with no direct commercial interests in

1 http://health.gov.au/internet/main/publishing.nsf/Content/17BF043A41D470A9CA257E13000C9322/$File/Report%20-%20Consultation%20on%20PCEHR%20Review%20Recommendations%20-%20Sep2014.pdf

particular technology products or services, the ACS is able to provide a genuinely balanced view with a focus on good public policy outcomes.

ACS is a member of a number of international ICT bodies including the Seoul Accord which provides mutual recognition of accredited academic computing programs that prepare graduates for professional practice in ICT, and the International Federation for Information Processing (IFIP) which represents IT Societies from 56 countries or regions, covering five continents with a total membership of over half a million.

For more information about the ACS, please see http://www.acs.org.au.

ACS Response

Overall the ACS agrees with the underlying principle of the PCEHR system:

> "Communication of health information is a vital part of effective healthcare, and the accurate identification of individuals, individual healthcare providers and healthcare provider organisations is critical in all health communication[2]."

While the scope of the document is to be considered as legislative content, some detail appears to be more operational or procedural.

The document masks a number of important issues while providing considerable information that is not particularly relevant to the legislative changes being considered.

The changes canvassed in this document are high level changes however they may have significant lower level consequences.

The Deloitte Report is particularly important as it purports to give a summary of the views of both consumer and interested parties.

[2] Electronic Health Records and Healthcare Identifiers: Legislation Discussion Paper

In terms of individual sections of the Discussion Paper, our comments on specific sections are as follows:

Section 2.3 Healthcare Identifiers Service

The mention of identifiers being useful for secure messaging appears unrelated to the overall legislation. "Secure messaging" is undefined, and there is no discussion of how errors in this process would be reported or managed.

Section 2.7 Consultation to Date

The summaries in *2.7 Consultation to date* are reasonable reflections of the conclusions of the Deloitte Report with some differences.

Differences in wording perhaps unintentionally change the meaning. For example the Executive Summary of the Deloitte Report contains the following statement:

> "For vendors, the critical implementation issues relate to a known timeframe for software development and redevelopment, a consultative approach to development of specifications and standards, use of international standards wherever relevant, and sufficient lead time and resources to implement the standards and specifications (or change) into their software ahead of the specification/standard becoming a requirement."

This was a direct result of the consultations with Software Vendors where one of the Consultation Areas was "Vendor views on supporting and a standards and compliance driven approach to further development of the PCEHR".

This was reflected in 2.7 by the statement:

> "Vendors consider that greater use can be made of international standards rather than having to adopt standards specifically designed in Australia. They also want more stability around standards, and want to know in advance when they will be introduced or changed and what they will contain so they can plan their business accordingly."

The difference is significant and we note that the use of international standards is more strongly advocated in this discussion paper document. The ACS supports the adoption of international standards, in particular for future interoperability of healthcare systems globally, and noting the increasing trend for Australians to seek healthcare overseas. Further, Standards Australia generally espouses an approach where Australia adopts international standards in preference to locally developed standards wherever international standards are suitable - because this improves international competitiveness and opportunity, and is more likely to provide stability.

In the context of stability, the ACS acknowledges that a newly created Standard may take up to 24 months to settle as it progresses through a Technical Specification or Draft Standard for Trial Use (DSTU) to become a full Standard.

Another of the consultation outcomes includes the need for on-the-ground help, which is unlikely to be available in the quantity and of the quality needed. The ACS recommends that ease of use and simplicity of the clinical engagement should be a KPI for the PCEHR system. New systems need to closely follow the existing clinical workflow in order to be fully adopted.

Section 3.1.2 Definitions

The ACS supports the clarification of "healthcare" which aligns with the Australian Law Reform Commission (ALRC) recommendation and appears to exclude insurance organisations from access to the PCEHR.

The ACS agrees that the definitions of "healthcare" and "health information" should align. The ACS asks for a broader examination of whether the Privacy Act should change with every future change to information management. Or alternatively, the Privacy Act might not need to alter if suitable attention is paid to the wording of the PCEHR legislation.

The proposed distinction between healthcare providers and organisations allows greater flexibility without impacting privacy.

The "identifying information" canvassed in the document suggests that information such as mobile phone number and email address be collected to allow contact and that transitory records of identifying documents be kept while an individual's identity is verified. The proposed

legislation therefore assumes that individuals have a mobile phone, an email address, a passport or a driver's licence. This is unlikely for many Australians living in poverty, young teenagers, and those in aged care and other assistive facilities.

Providing the operator with flexibility to require additional information *if it is necessary* is a broad statement, with no determination of who decides the necessity of the additional information, and the grounds for which a decision should be made.

We ask if the existing Medicare Card numbers are sufficient to assist in the identification of individuals, noting that some children of separated parents might have two attached to each parent's card.

It is essential that such regulation regimes include simple and transparent control and advice processes.

Section 3.2.1 Establishment of ACeH

There are a number of differences between the model proposed in the Review and that proposed in this discussion paper.

The major differences are that the proposed ACeH Board will be composed of individuals with expertise rather that representatives of sectors or organisations and that the skills stipulated include "IT systems and innovation including health informatics" as well as, most importantly, governance.

Given that the whole eHealth system is IT-enabled it would be useful to specifically include in its membership people with expertise in the governance of IT. It is also noted that what is described as "governance" in the Review, particularly, reflects ideas of governance that are contrary to contemporary views of governance and in most cases would be much better described as "management".

Section 3.2.2 HI Service Operator

The intent to change the HI Act to allow changes to the HI Operator is positive and it is hoped that consideration will be given to bringing this role under ACeH to help alleviate potential privacy concerns relating to insurance organisations.

Section 3.3.1 An opt-out PCEHR system?

Support for an opt-out model has been rigorously questioned as reported in the Deloitte Report and it seems clear that the conclusion stated in the Executive Summary is valid:

> "Consumers overwhelmingly support the concept of an opt-out model for participation and personalised controls, even whilst recognising they may not be significant users. Their greatest concerns are that healthcare providers may elect to opt out. Issues of information security and misuse still exist but are not predominant concerns. Clinicians recognise that the proposed changes will remove some of the barriers to their use of the system, but not all. Opt-out must be accompanied by improved content (and contribution from a broader group of clinicians) and attention to the work load/cost implications that may fall on the shoulders of healthcare providers as the changes are rolled out."

The paper describes a very measured trial and progressive roll out of Opt-Out. The ACS argues that a great deal of the detail offered should be determined by regulation rather than legislation.

The success criteria for the trial, and the length of time of the trial are not addressed.

During the trial period, the ability to opt-out should be easy and not onerous. The paper does not clearly state the hurdle requirements for proving identity in order to successfully opt-out. The paper mentions mail posted to an individuals' address, suggesting that opting out could be a slow process, and problematic if the address details are not updated with Medicare. The ACS recommends that care be taken to ensure that opting out is as simple as possible.

The paper does not clearly state the mechanisms used to determine if a representative has the authority to act on behalf of an individual. In terms of privacy, the legislation needs to account for specific scenarios, such as children wishing to keep some consultations private, divorcing and separated couples, individuals moving into and away from the geographic location of the trial, young adults overriding their parents' authority to claim exclusive rights to their records.

The key privacy concern is that individuals can have a record created without their knowledge or consent, and therefore do not know about setting access controls, monitoring activity, etc. The legislation assumes that the majority of individuals will have significant knowledge of the PCEHR and be fully engaged with its implementation, as well as their obligations to ensure that their privacy is preserved. This suggests a potential scenario of privacy options needing to be explained during medical consultations.

The role of Medicare must be carefully considered in the governance arrangements. It could be argued that the Chief Executive Medicare should not retain the current level of discretion.

Care is needed when releasing de-identified data. There are known risks of re-identification from pooled data. The arrangements for individuals providing consent must provide rigorous safeguards to ensure that the privacy and the rights of the individual are not violated. Researchers would need to accommodate the fact that the PCEHR is a summary only, and that individuals can choose whether data is or is not uploaded to their records.

ACS recommends that the secondary use of data is overseen via a Data Governance Committee, or that the legislation details who determines the appropriate secondary use of the data.

The proposal for registering healthcare provider organisations and other entities seems completely inconsistent with the Opt-Out model for consumers. The Deloitte Report states in the Executive Summary:

> "The majority of consumers and some providers also strongly believe that provider participation should be made mandatory or at the very least also move to an opt-out model of participation to drive provider participation and contribution of information to the PCEHR."

The ACS recommends this more rational approach if the Opt-Out model for individuals is to succeed.

Section 3.4.3 Obligation for organisations to have PCEHR policy

The Policy requirements are unclear. It appears that the level of security and data quality can be determined via a separate policy for each organisation. This introduces significant risk when organisations share data.

As a minimum, standard policies should be in place for:

- Data Quality
- Missing data
- Data security
- Sharing data
- Privacy

Section 3.4.8 Obligation for System Operator to retain records

The ACS notes that the costs of storing data is decreasing and the number of records should not be the deciding factor in setting the length of time for retention. The retention time should perhaps be set by regulation rather than by legislation.

It should be noted that uploaded data may not be relevant for future consultations, particularly if the records were created many years earlier.

Section 3.5 Privacy

Regulations proposed in this area must be subject to rigorous scrutiny including public scrutiny.

Section 3.5.1 Notification of PCEHR use

The "default" access control mechanisms should reflect maximum security and privacy provisions. The ability to be advised when an individual's records is accessed is welcomed.

Section 3.5.2 Temporary suspension of access to a PCEHR

The paper describes suspension in the event of a threat, but leaves the definition of threat open to broad interpretation, by more than one entity. It does not explain how an individual can reinstate their record after a suspension.

Section 3.5.3 Collection, use and disclosure of information

The paper proposes that the changes do not "relax the privacy framework", but does not define which privacy framework it is referring to.

The discussion of the retention of information for security purposes does not define the risk, or who determines the risk. Overall this section of the paper is too broad and open to interpretation.

Section 3.5.4 Penalties for misuse of information

It seems that misuse of PCEHR information including healthcare identifiers must be subject to a consistent and graduated penalty regime. The penalty system should provide a graduated enforcement regime giving the courts discretion on how to deal with an offence. This should include criminal penalties for more serious misuse as well as civil penalties for minor and, perhaps, unintended misuse. However, the penalties for individuals seem very high.

It is conceivable that an entity may misuse healthcare identifiers in an attempt to perform a range of inappropriate actions from passing itself off as a healthcare provider to attempting through use of the identifier to inappropriately access or change one or more PCEHRs.

Thus there should be opportunity for additional penalties and remedies where multiple offences are being committed.

Section 3.6 Reviews

The PCEHR system should operate under an expectation of continuous improvement. There should be provision for problems with the system to be recorded and, if appropriate, remedied, well before the scheduled review. To enable interim remediation, there should be scope for some adjustment of the system through use of regulation rather than needing to resort to legislation at every instance.

In preparation of this submission, the ACS acknowledges the contribution of Associate Professor Trish Williams of Edith Cowan University.

If you require any further information regarding this submission, please contact Athol Chalmers, ACS Director, Policy and Public Affairs at Athol.Chalmers@acs.org.au or on 0466 793683.

Yours sincerely

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