

REVIEW OF THE PERSONALLY CONTROLLED ELECTRONIC HEALTH RECORD (PCEHR)

AIIA Response

NOVEMBER 2013

ORGANISATION DETAILS

Submitted by:

Australian Information Industry Association
39 Torrens Street ACT 2612

02 6281 9411



Suzanne Campbell

Chief Executive Officer
Australian Information Industry Association
s.campbell@aia.com.au

INTRODUCTION

The Australian Information Industry Association (AIIA) is the peak national body representing multinational and domestic suppliers and providers of a wide range of information technology and communications (ICT) products and services.

We represent over 400 member organisations nationally, including global brands such as Apple, EMC, Google, HP, IBM, Intel, Microsoft and Oracle; international companies including Telstra; national companies including Data#3, SMS Management and Technology, Technology One and Oakton Limited; and a large number of ICT SME's.

A number of our members are actively involved in supporting a range of eHealth activities, and specifically the development and implementation of the Personally Controlled Electronic Health Record (PCEHR).

AIIA welcomes the opportunity to submit a response to the Government's Review of the PCEHR.

OVERVIEW

AIIA strongly supports the advancement of Australia's ehealth agenda. In this context we support the development of an electronic health record that consumers can use to share their health related information with relevant clinicians across the health sector.

Noting the considerable investment that has already been committed to building the PCEHR the AIIA supports this important asset to drive achievement of Australia's ehealth objectives and quality healthcare outcomes.

AIIA strongly encourages the Government to leverage this critical infrastructure in the pursuit of a more efficient, effective and patient centric healthcare system. We do not support any consideration that investment into PCEHR be abandoned. Rather we strongly believe there is scope to open the system to innovation and mainstream third party applications (products and services) of value to clinicians and patients. In this regard we believe the ICT industry has a key role in realizing the return on the PCEHR investment.

RESPONSE TO TERMS OF REFERENCE

Level of consultation with stakeholders during the development phase

AIIA members have mixed views regarding stakeholder engagement during PCEHR development phases. While members acknowledge that various mechanisms for engagement have been in place through the lifecycle of the project, there is much less enthusiasm for the quality of engagement and the subsequent take-up of constructive stakeholder feedback.

After providing many hours of time to various engagement meetings, members express concern that industry feedback has on many occasions apparently been ignored with original positions continued to be adopted. This is notwithstanding that in many instances feedback provided by the AIIA was closely aligned with that of the jurisdictions.

Specific examples provided by our members include:

- Industry has had to modify applications (at considerable cost) because the centralised HI service cannot enforce reasonable search algorithms – while this is specific to the Individual Health Identifier issue, it is central to the operation of the PCEHR
- The PCEHR does not check the hash (security identifier) of the documents as they are submitted
- The PCEHR uses only one identifier to identify a person – again requiring industry to bear the cost to enforce this.

The implication of issues such as these is more cost and risk to industry.

There was also mixed feedback from our members on the quality and extent of clinician engagement on the PCEHR. From our perspective, engagement is critical at all levels to support quality of outcomes and the necessary governance to ensure that all stakeholders (not just the Commonwealth government) is involved in making appropriate design decisions.

The lack of engagement with industry in change management processes is also of particular concern. This has resulted in industry being unaware of changes to the system that potentially impact their products. Current arrangements have already result in problems with backward compatibility of changes that could have been avoided through appropriate (and industry practice) change management procedures. Industry change management processes ensure that any change in software is tested against every system it interacts with prior to release. This has not been the case in the PCEHR and again increases cost and risk, including for patients.

Finally, in our view much closer engagement with jurisdictions is imperative and necessary to support implementation at scale and similarly be reviewed.

Level of use of the PCEHR by health care professionals in clinical settings

Clinical use of the PCEHR is low. To some extent this is to be expected given the relatively embryonic stage of PCEHR development and the consequent lack to date of high quality systems and information that clinicians can access and use. It also reflects the fact that the PCEHR is essentially a summary record – with practices still maintaining their own deeper clinical records and the reality that an ecosystem of eHealth needs to be built up (including Electronic Medications Management, eDischarge summaries, and specialist letters). Until this ecosystem develops, the PCEHR on its own offers only limited benefits.

While a key priority going forward must be addressing the quality, usefulness and ease of access to information in the PCEHR, we acknowledge that complex electronic record systems, particularly those of scale, take many years to evolve and mature into solutions that are content rich, seamlessly integrated into health care workflows and supported by appropriate education and training by all relevant parties. Nevertheless members working directly with clinicians advise that the overwhelming priority for clinical staff is access to existing core documents such as referrals, discharge summaries and specialist letters and to communicate these across organisational boundaries. These are primary documents in most acute and primary care settings – frequently used and immediately relevant to current and future patient management. To the extent that these are not available, the value of the PCEHR is limited.

Barriers to increasing usage in clinical settings

The following summarises the key barriers identified by AIIA members.

- The lack of consumers enrolled in the system to date, driven by a clumsy registration process and deficit of content. Because the current system is opt-in, there is limited motivation for most consumers to ‘sign-up’ for the system.
 - Clinicians must be confident that the patient sitting in front of them has a record that is ready to use. AIIA members have advised that current enrolment issues are, amongst other things, impacted by the delay in permitting vendors to implement the Web service calls for 9 months - and providing in the meantime a very labour intensive tool (taking some 30 minutes to register patients).
- The inability of GP desktop software to search and flag that a patient has a PCEHR and upload, view, download and print from the PCEHR.
- The lack of useful (reliable, complete, high quality, timely) information in the PCEHR system
 - This is a major barrier to clinician take-up and requires a concerted effort to improve the flow of high value data (e.g. GP care plans, PBS medications, pathology, radiology, hospital discharge summaries, care summaries from allied health care professionals) into consumers’ health records.
- Lack of easy to use and useful IT solutions/applications that connect to the PCEHR and which drive value for clinicians and patients.

- The introduction of new processes (e.g. the shared health summary) rather than simply supporting existing process (discharge summaries, referrals, and specialist letters etc).
- The significant additional costs of complying with the ongoing testing regimes required of technology providers, over and above developing the new functionality.
- Change management processes that do not include product vendor stakeholders to ensure systems can be integrated seamlessly and do not present any potential clinical risk.
- The lack of appropriate financial or compliance (e.g. accreditation) levers to drive clinical adoption and use.
- Lack of compelling and timely communications on the relevance and value of the PCEHR to the clinicians and their businesses.

Responses to these issues are included in our recommended actions outlined below.

Comments on standards for terminology, language and technology

We preface our comments by making the point that it is imperative to maintain and continually enhance core information exchange foundations (e.g. information standards, identifier / authentication services, CCA regimes). Without these key foundations there is no national ehealth agenda.

We would specifically point out that not all hospitals, medical practices, specialist centres and health practices are computerised. This is a fundamental issue that needs to be addressed as a first step.

Second, implementing the “plumbing” and utilising standardised secure electronic messaging and health identifiers to communicate with other software systems in the health care sector is a key foundation step before effective technical integration between systems and utilisation of the PCEHR infrastructure across all software in the health care sector can be achieved. While good work is underway in the area of standards development, there is an argument for increasing the focus on software systems actually implementing and adopting initial standards and ensuring these are tried and tested in the field before moving forward with additional standards development initiatives. In other words, get the fundamentals - the basic standards right in the first instance.

Members also express concern that, in general, the PCEHR system has been designed by teams of people who have experience principally in dealing with Medicare data models and processes and more broadly, commonwealth privacy requirements. This has, at least to some extent, meant that those designing the system are not those who are deeply familiar with how the underlying business works. Involving the primary and acute care technology experts would help to mitigate this issue.

In regards to current arrangements we would also express concern regarding lack of transparency, particularly where clinical safety issues have emerged. Members are aware of instances where significant issues have not been managed through a formal transparent reporting process.

Current testing requirements by NEHTA and NATA, at least after the first round of validation, need to be reviewed as a matter of priority. Arrangements are very expensive, especially for smaller vendors. Members have also questioned the rigour and consistency of some test cases developed by NEHTA.

Key clinician utility and usability issues

Comments above also apply in response to this question.

Clinicians need easy to access and use ehealth solutions that can be seamlessly incorporated into their care workflows. They need access to information they can trust and use to deliver higher quality care. At the moment the solutions available are clunky and, arguably, do not contain clinical content that is of priority to clinicians.

Key patient usability issues

Similar to clinicians patients need easy to access and use registration processes, health record content that is meaningful to the current management of their health and ideally, access to additional products and services that add value to the core PCEHR infrastructure. Similarly they need confidence that the system is available wherever they access health services and assurance that their privacy is appropriately protected.

To support patient value it is also important that the system support maximum mobility enablement for PCEHR with the ability for consumer data entry to be combined with clinical data. For example in the case of medications, to give a complete picture of medications that the consumer is taking when they combine complementary medicines with prescribed medicines (as just one example).

Additional comments

We would also make the following additional comments.

Concerns have also been raised in relation to:

- Inadequate project management disciplines to support execution of the project.
- The complexity of relationships between DOHA, NEHTA and conformance and compliance arrangements (e.g the CCAGG) has also resulted in a lack of transparency and clear accountability. This also needs to be addressed.
- The role and authority of the Independent Advisory Committee (IAC) has been ambiguous and while industry has been pleased to be involved, it has been unclear how the IAC has contributed to the PCEHR implementation process.

Suggested improvements to accelerate adoption of the platform

As noted in the Overview to this submission, AIIA strongly supports the need to advance a digitally driven ehealth agenda, including the implementation of an electronic health record. This is imperative to keep pace with global ehealth developments and essential to ensuring the competitiveness and sustainability of the Australian health system against the imperative of our demographics. **On this basis AIIA supports the ongoing development of the PCEHR but makes the following suggestions to drive the content and usability necessary to make it a valued product/service for clinicians and patients.**

1. Improve the value of information in the PCEHR. This will require a health care industry wide focus on tackling high priority information domains such as medications management, shared health summaries, pathology, diagnostic imaging, specialist letters and discharge summaries.
2. To drive consumer take-up transition the PCEHR to an opt-out scheme. This needs to be done at an appropriate time when the underlying PCEHR solutions and information content are at a reasonable level of maturity. In the meantime continued effort is necessary to target take up by key and high use cohorts (e.g. aged, chronically diseased, newborns, indigenous). Simplification of the registration process is also strongly advised.
3. Drive increased clinical use of the PCEHR, through a combination of improved system usability and content and by adjusting other longer term levers such as linking clinical accreditation to the use of electronic health records.
4. Improve the quality, usability and scope of clinical and consumer technology applications. This requires
 - Addressing the cost and red tape associated with external developers linking applications to the PCEHR infrastructure
 - Opening up repository based solutions
 - Development of consumer portals to facilitate streamlined integration with PCEHR compliant solutions.
5. Implement a properly considered and sustainable commercial model for key stakeholders involved in the scheme (including government, clinicians and the IT industry). This is necessary to stimulate innovation and drive sustainable IT investment in the national ehealth agenda.
 - Opening up the PCEHR platform will allow third parties to create many different provider and consumer portals across different platforms (smartphones, Tablets, smart TVs' T-Box, X-Box etc). The official PCEHR provider and consumer portals are obstacles to wider adoption because there cannot be a one size fits all approach to a user interface. Enabling mobile based front-end solutions that are distributed through traditional app stores also offers a mechanism for software developers to be remunerated for their innovation. Opening up the presentation layer and allowing innovative new front end and specialised interfaces to

be created will drive innovation, improve usability and increase adoption by clinicians and consumers.

6. Implement more representative and transparent governance of the PCEHR (and national ehealth) program, including greater industry, clinical and consumer representation on key governance forums and more effective engagement of jurisdictions to support implementation of the program at scale.
7. Implement a formal, transparent and authoritative change management process that is developed and executed with industry involvement.
8. Clarify the role and authority of the Independent Advisory Committee (IAC) specifically in terms of how it contributes to the PCEHR roll out and future development.
9. Strengthen key project management and communication disciplines

In addition to the above suggestions we reiterate the need to maintain and enhance PCEHR information exchange foundations (as noted in the body of this submission).