Electronic Health Records and Healthcare Identifiers: Legislation Discussion Paper

AIIA response

July 2015

Introduction

About AIIA

The Australian Information Industry Association (AIIA) is the peak national body representing Australia's information and communications technology (ICT) industry.   Since establishing 35 years ago, the AIIA has pursued activities aimed to stimulate and grow the ICT industry, to create a favourable business environment for our members and to contribute to the economic imperatives of our nation. *Our goal is to "create a world class information, communications and technology industry delivering productivity, innovation and leadership for Australia".*

We represent over 400 member organisations nationally including hardware, software, telecommunications, ICT service and professional services companies.   Our membership includes global brands such as Apple, EMC, Google, HP, IBM, Intel, Microsoft, PWC, Deloitte, EY and Oracle; international companies including Telstra, Optus; national companies including Data#3, SMS Management and Technology, TechnologyOne and Oakton Limited; and a large number of ICT SME's.

Comments

The AIIA welcomes the opportunity to comment on this important issue.

AIIA supports the Electronic Health Records and Healthcare Identifiers initiative. Electronic health records can provide many benefits and improvements to traditional means of patient information management. Benefits include potential to improve patient safety, increased continuity of care, evidence based decision making, and greater patient engagement to name a few.

However, AIIA has a number of concerns around implementation of the initiative. We outline these concerns below and propose a number of mitigating actions.

1.1 Governance

AIIA supports a strong governance arrangement to ensure the effectiveness of MyHealthRecord, the re-branded personally controlled eHealth Record system (PCEHR).

Although the discussion paper provides a high-level framework for governance, more detail is required particularly around the qualifications and expertise of ACeH's Board and Advisory Committee members.

AIIA strongly recommends that members appointed to the Board and Advisory Committees are independent and do not represent the views of any particular group, but rather, selected based on expertise, skills and experiences in relevant fields.

To achieve this, AIIA proposes a list of criteria for selecting members of the Board and Advisory Committees (based on the fields listed in the discussion paper).

A) **Health care provision:** individuals who are actively involved in healthcare provision that come from primary care, acute care, secondary care, tertiary care and community care facilities.

   I.   These practitioners could be allied health, dentistry, midwifery (obstetrics), medicine, nursing, optometry, pharmacy, psychology and other health professions such as Health Information Managers.

B) **Consumer of health services:** these individuals should be in a position to represent the needs of consumers at all stages of life. This recognises that different generations prefer to consume healthcare goods and services in different ways. Their experience might include working closely with a wide range of health consumers, likely GPs, pharmacist, or consumer group representatives.

C) **IT systems and innovation including health informatics:** the three areas represented here are distinct areas of expertise and should be considered as such. At the very least, innovation and informatics should be separated, as they require specific experience and capability.

   I.   Innovation should be represented by an individual who is actively involved in research and development for ICT in Healthcare. This could come from government (e.g. CSIRO), innovators in the industry such as R&D in larger ICT companies, or a person who has demonstrated success in developing new solutions for the industry. The person should be able to bring to the group a far sighted view of what is possible in the future as well as being familiar with current developments in the industry.

   II. Informatics is a key capability and would require a person actively working as a Health Informatician with broad understanding of data & analytics in healthcare. Having certification from a recognised credentialing program for health informatics, such as Certified Health Informatician Australasia (CHIA), should also be a criteria.

III. AIIA is well placed to advise the government on any further technical requirements in this area if needed.

D) **Governance:** This should not be someone who simply holds a senior management role in the healthcare sector but someone with specific expertise and experience in developing or implementing governance guidelines for large or complex schemes. Experience using a best practice approach to governance, such as COBIT (Framework for IT Governance and Control) would also be desirable.

E) **Clinical safety:** someone with extensive experience developing or implementing OH&S guidelines in the healthcare sector. Ideally someone who has worked directly in client care and has conducted reviews of clinical safety policies, particularly around analysing effectiveness of those policies.

F) **Privacy and security:** these are two distinct areas and should be separated.

I. Privacy should be focused on laws and regulations and information management processes. Someone with this experience might be a lawyer or management consultant.

II. Security should be someone who understands ICT security and has an extensive technical background in ICT information management systems.

AIIA is disappointed that the Government has yet to release a terms of reference or a charter for the board. Providing an opportunity for industry comments on these important documents must be a priority. In the meantime, AIIA notes the need for clarification around:

- the decision making framework of the board and advisory committees, particularly whether or not the advisory committee will have decision making powers; and

- the tenure of the board.

Finally, any TOR or Charter should be based on best practice governance guidelines.

1.2 Participation

AIIA supports the trial of an opt-out approach. We think this will increase participation and overall efficiencies of the system.

While we agree that the majority of the opt-out trials be geographically determined, we recommend a trial based on specific cohorts, such as disability. A cohort based approach poses some challenges, such as reliance on the cooperation of medical practitioners of cohort members, which means a smaller sample size than a geographical trial. However, AIIA understands that Government already intends to conduct such a trial with the indigenous community in the Northern Territory. We support extending this approach to other cohorts and think it would provide more targeted insights into groups that may have unique needs.

Importantly, the criteria for success of the new MyHealthRecord system should be clearly outlined from the start. Ultimately, success of the new system will largely depend on the number of people using it based on the value it provides.

To this end, AIIA recommends at a minimum, the following principles based criteria for determining success:

1. **User centric**: An online e-health records and healthcare identifier system must be user centric. It must be based on technology that is easy to understand and use; provide convenience and accessibility for individuals; and offer choice so individuals can choose the types of services valuable to them. Solutions must, by design, ensure a positive user experience.

2. **User-owned identity:** The system must ensure users can own and control their identity in an online environment.

3. **Awareness:** the system must be taken up by all stakeholders – not only consumers, but also health care providers and suppliers. In this regard, the AIIA notes the lack of awareness in the GP community. Consumers must also be aware they can opt-out.

4. **Technology literacy:** The Government must ensure technology literacy of the user population, including consumers, healthcare providers and suppliers. This is a common challenge in adopting new ICT. Not only must the system be user friendly and accessible by design, training and IT support should also be available and timely.

5. **Privacy enhancing:** The system must use privacy enhancing technology, policy and processes to ensure the integrity of individual privacy and civil liberties.

6. **Secure and Resilient:** The system must be secure and resilient. This requires technical robustness in the form of platform, network and software security and a commitment to driving awareness across individuals and organisations of their respective security obligations to support the integrity of the system.

7. **Data & analytics:** the system must maintain robust data sets within clear governance requirements.

8. **Whole of Economy:** The system must be architectured to support potential transactions across the whole economy, including transactions that range from anonymous to fully authenticated and from low to high value.

9. **Future-proofing framework:** The system must be appropriately adaptable to ensure it can evolve in alignment with changing technology trends and government policies. For example, it should comply with the Australian Government Architecture Framework (as produced by AGIMO) to support interoperability with other government systems.

1.3 Standardisation

AIIA recommends the Government work closely with Standards Australia in developing the system to ensure it meets the criteria of success outlined above.

In the increasingly complex environment of integrated patient health care, it is essential that information in the electronic heath records (EHR) can be shared between members of a multi-specialty and multi-disciplinary healthcare team. Individuals should also be able to view their own records.

This can only be achieved through standardisation of those aspects of the EHR and EHR systems necessary for interoperability – particularly, the structure and broad content of the record but, also, the processes and technologies used to manage and exchange EHR content.

Standards to ensure the unique identification of subjects and providers and the privacy and security of the subject's personal health information are also essential for the integrity and trust of EHR systems.

Standards Australia is currently developing work to facilitate the effective sharing of EHR information through its IT-014-09 EHR Interoperability Subcommittee. It promotes the harmonisation and, where possible, convergence of EHR and related standards, including those now being developed internationally for the Personal Health Record (PHR) and PHR systems.