

E-health will greatly enhance both the quality and timeliness of healthcare information, delivering substantial benefits to healthcare consumers, healthcare providers and the Australian health sector as a whole. Australian governments are committed to implementing e-health around existing electronic health initiatives to transform the way information is used to plan, manage and deliver healthcare services.

Australian governments are equally committed to the principles that reflect the strong value Australians place on controlling who has access to their health and other personal information and the circumstances in which that information can be used.

One of the key foundations for a national approach to e-health will be a standard process across the health sector to accurately identify everybody involved in a healthcare transaction. The Healthcare Identifiers (HI) Service is a system that provides a consistent set of identifiers for people receiving healthcare and for those providing it, enabling:

- Healthcare providers to associate health information about a person accurately and consistently within a healthcare context, including electronic communications such as discharge summaries, prescriptions and referrals; and
- A means of managing the relationship between health care provider individuals and healthcare organisations for access to a potential future individual electronic health record (IEHR).

Healthcare identifiers are a critical building block in establishing the foundations for e-health which could include an IEHR. However, it is important to differentiate between healthcare identifiers and any future system of electronic health records. Having the HI Service in place will provide immediate benefits for more accurate recording and communication of health information. This will ensure the right information can be linked to the right person at the right time and place.

It is important to note that any potential future IEHR system would be subject to further consultation and would be underpinned by additional privacy safeguards for consumers and healthcare providers, so that health information can be securely viewed by patients and their healthcare providers with patient authorisation.

As the organisation leading the progression of e-health in Australia, NEHTA adopts best practice processes to address the potential impact of e-health on the privacy of Australians. To ensure that privacy principles are built into every stage of Australia's e-health transition, we embed privacy analysis into the technology, governance and legislation phases of our planning, design and delivery.

As a result, NEHTA will deliver a service that enhances privacy and protection of health information. For example, the Healthcare Identifier Service will strengthen the prevention of unauthorised information access or modification, or detection of instances where this may have occurred, in way that current systems may not.

One example of NEHTA's consideration of privacy issues is our use of Privacy Impact Assessments (PIAs). On three occasions since 2006, we have engaged experts to undertake a comprehensive assessment on the impact our work on the Healthcare Identifiers Service could have on privacy.

In 2006, a preliminary PIA was conducted by Galexia to inform us and test the degree to which initial concepts under consideration might impact people's privacy. At this time, much of the detail around individual healthcare identifiers was still under development. However, we considered it prudent to obtain early feedback on privacy so that we could address these issues from the outset.

Galexia raised issues concerning information collection, maintaining data quality over time, governance and the future potential for secondary uses of data.

By 2007, more detail was available and key policies had been developed and we commissioned Clayton Utz to undertake another PIA. This allowed us to assess the design changes we had made since the preliminary assessment, including changes we made in response to recommendations in the first report.

In their PIA Clayton Utz notes that,

"NEHTA is to be commended for its proactive approach to building privacy issues into the design and development of all its work including the Unique Health Identifier Program from the outset."

This PIA raised issues around authentication and access rights, practical issues around information collection and opting out, and operational challenges presented by inconsistent privacy regimes in different parts of the country.

Late in 2008, the Council of Australian Governments (COAG) agreed a key policy around the creation of individual healthcare identifiers. Ministers decided that a more appropriate balance could be struck between the benefits of e-health and the importance of protecting people's privacy by underpinning e-health with a universal individual healthcare identifier.

In January 2009, NEHTA commissioned a third PIA from Mallesons Stephen Jaques which specifically considered the impact of this change. This third PIA was provided to NEHTA in late August 2009.

In their PIA, Mallesons acknowledged that “NEHTA has publicly and consistently endorsed a proactive approach to privacy”. They identified the need to clarify governance arrangements and ensure protections are in place to limit the use of identifiers for healthcare related purposes. They also recommended that details be refined relating to the impact of healthcare identifiers on how individuals access healthcare (such as when claiming benefits or when choosing to remain anonymous).

Coupled with the outcomes of public consultation on the legislative proposals for the HI Service that took place in July-August 2009, the recommendations from the PIAs will inform policy makers and legislators on areas such as governance required to supplement technology and provide important privacy protections.

The design of the HI Service and the enabling legislation will be a culmination of many years’ work and will consider a range of inputs, including recommendations from the PIAs, public consultations, representations from stakeholders, and the health reform agenda of Australian governments.

What was the purpose of the PIAs commissioned by NEHTA?

The PIAs obtained by NEHTA were assessment tools that described the information flows in the healthcare identifier project, and analysed the possible privacy impacts that those flows, and the project as a whole, may have on the privacy of individuals. This analysis helped NEHTA identify and recommend options for managing, minimising or removing privacy impacts.

While privacy legislation does not require NEHTA to undertake PIAs, the success of the healthcare identifier project will depend in part on how well it meets broader community expectations about privacy. Together with stakeholder consultation, PIAs help us understand and appropriately address privacy issues which could have an impact on perceptions of privacy and notions of trust that are critical to the successful adoption of e-health in Australia.

By obtaining PIAs at each phase of development, we are in a better position to embed privacy principles into system design. We will continue to use this methodology and obtain further PIAs in the future as we move further towards implementing e-health initiatives.

Have all the recommendations in the PIAs been implemented?

As the lead organisation supporting the national vision for e-health in Australia, NEHTA aims to ensure the anticipated benefits of e-health are realised in a way that meets community expectations around privacy protection. However, some recommendations in the PIAs would have significantly impacted the effectiveness of the reform program to achieve the anticipated benefits of e-health. In these instances, the recommendations in the PIAs are considered by governments as one input in finalising policy positions.

The earlier approach was to allocate healthcare identifiers only to individuals who requested one. When this was discussed with consumers, clinicians and other health professionals, they advised us that a fragmented adoption of healthcare identifiers would prevent many clinical benefits of consistent adoption and jeopardise the capacity of healthcare providers to streamline business processes and realise cost savings. COAG subsequently decided that a more appropriate balance of privacy protection and other benefits would be achieved by a universal healthcare identifier issued to everyone.

Individuals will retain the right to receive anonymous healthcare in the circumstances where they are already able to do so now.

Why is NEHTA releasing the PIAs now?

While the three privacy impact assessments were commissioned by NEHTA to inform our design work while government policy was still being developed, we consider it important to now make these documents available to the broader community.

The purpose of the PIAs has been to assist us in managing privacy issues in the healthcare identifier project at various points in time and to ensure an appropriate balance between the benefits of healthcare service delivery and privacy protections needed to support the implementation of healthcare identifiers. These documents will also provide historical context to some of the policy positions proposed in draft healthcare identifier legislation. As such, they form a relevant part of the suite of publicly released documents that support the implementation of the HI Service that is expected to commence in mid-2010.

Next steps

Input received during public consultation in July and August 2009 has been taken into consideration in developing regulatory proposals, and further public consultation will occur on the regulatory proposals and protections to underpin healthcare identifiers.

Both NEHTA and Australian governments continue to refine the development of the HI Service and remain interested in community input into the technology and regulatory frameworks that ensure Australians are able to maintain privacy protections when they receive healthcare.