

5 March 2010

Ms Naomi Bleeser
Committee Secretary
Community Affairs Legislation Committee
PO Box 6100
Parliament House
CANBERRA ACT 2600

Dear Ms Bleeser

Thank you for the invitation to provide a submission to the Community Affairs Legislation Committee's Inquiry into the *Healthcare Identifiers Bill 2010* (the Bill).

NEHTA is the lead organisation supporting the national vision for e-health in Australia; working openly, constructively and collaboratively with consumers, providers, funders, policy makers and the broader healthcare industry to enable safer, higher quality, accessible, equitable, efficient and sustainable healthcare.

Our key priority is to urgently develop the essential foundations required for e-health and the enablement of health reform. The development of the Healthcare Identifier system was an initiative of the previous Government, announced by Council of Australian Governments (COAG) in February 2006 to provide this vital building block for e-health.

The following submission outlines how:

- Australian healthcare will be improved by a national, uniform method for reliably identifying individuals, providers and organisations;
- A key way of enhancing healthcare is through good clinical information transfer enabled by reliable identification of individuals, providers and organisations;
- Providing valid, trusted, accurate and timely clinical information and being able to share this information is critical for safety, quality and continuity of care;
- The healthcare identifiers will be protected at every stage of their journey through the healthcare system with a combination of regulatory and technical means;
- NEHTA and Australian governments consulted with stakeholders on business requirements for the HI service and consensus emerged around a model for the universal allocation of health identifiers for individuals;
- Some time in the future this critical infrastructure may allow Australia to achieve an electronic health record system, and
- E-health will improve patient care through improvements to clinical safety and quality by enabling timely access to better and more accurate clinical information.

1. Introduction

Over the past four years, NEHTA has worked nationally with a wide range of clinical, consumer and industry stakeholders, the States and Territories and the Commonwealth Department of Health and Ageing to develop requirements for the Healthcare Identifier Service (HI Service). The HI Service will be operated by Medicare Australia who will be responsible for assigning and maintaining healthcare identifiers to healthcare recipients, providers and organisations.

The Bill being considered by this Committee provides the legislative basis to establish the HI Service to move into production and plays a crucial part in progressing e-health in Australia.

Internationally, it is recognised that the introduction of broad-based identifier systems can improve healthcare:

- New Zealand's patient identification system, the National Health Index, was introduced in 1992 and covers about 95% of the population. A 2006 review found the National Health Index made it possible to minimise the risk of medical mishaps¹
- The absence of unique patient identifiers in the US has been acknowledged as a hindrance to using data from electronic health records². A 2008 study found that approximately 8% of records are filed into the wrong record. The study concluded that giving a health identifier to every patient in the US health system would reduce medical errors, increase efficiency, improve patient confidence and protect patient privacy³.

The critical role of identifiers was also highlighted in the proposals from the National Hospital and Health Reform Commission and the National E-Health Strategy:

There is a need to implement an identification and authentication regime for health information as soon as possible as this work will be absolutely fundamental to the nation's ability to securely and reliably access and share health information. Australia should seek, as far as possible, to make the allocation of consumer and care provider national identifiers universal and automatic.⁴

Some time in the future this critical infrastructure may allow Australia to achieve an electronic health record system, where consumers can opt-in to make electronic records of their health information available to their authorised health providers. While we note that an electronic health record system is currently beyond government plans and may require new legislation, one thing is clear – accurate identification of individuals and treating clinicians is a mandatory requirement for ever achieving such a system.

2. About the Healthcare Identifiers (HI) Service

The **Healthcare Identifiers (HI) Service** will manage a national system for uniquely identifying healthcare providers and individuals. The Service will assign three types of healthcare identifiers which will identify everyone involved in a healthcare event:

Individual Healthcare Identifier (IHI)

For individuals receiving healthcare services

Healthcare Provider Identifier - Individual (HPI-I)

For healthcare professionals and other health personnel involved in providing patient care

Healthcare Provider Identifier - Organisation (HPI-O)

For organisations (such as the hospital or health clinic) where healthcare is provided

The HI Service will operate in conjunction with a standardised authentication technology to protect individual privacy through technical and non-technical means, and legislation.

- Information security has been the primary consideration in the design and development of the HI service;
- Access to the HI Service is secured through the use of recognised world-class security and encryption technology; and

- The HI Service will not contain any clinical information. The Service will return only the IHI number.

3. Better management of health information is required across the sector

Our healthcare system is of high quality and excellent in international comparisons but strategies are vital to address its sustainability into the future and to address current inequities documented today (NHHRC: Better care for All Australians).

There are complexities around **where** the health services are delivered: in many ways and many places (public hospitals, private hospitals, community and aged care facilities, medical centres, pharmacies) and by **whom**: (Clinicians – General Practitioners, Specialists (Medical & non-Medical), Nurses, Pharmacists, and Dentists for instance). Providing valid, trusted, accurate and timely clinical information and to be able to share this information is critical for safety, quality and continuity of care. This all must be underpinned with appropriate security and privacy protections of both the data and those to whom it pertains.

The use of modern technologies to enhance connectivity in the health sector lags behind many other industries, such as banking and finance. Healthcare communication relies heavily on the memories of patients about their health – often numerous and complex interactions with a number of services, providers, investigations and medications over many years.

These can be confounded by age, illness, mental state and cognitive function such as dementia. Healthcare providers record this information in multiple formats, but even the 98% of GPs in Australia who store their records electronically can not consistently share this information with other GPs through electronic means. The multiple episodes of care they manage involve manually labelling forms and specimens, transcribing demographic data between providers and laboratories, manually filing records, and transcribing information from faxes, letters and forms into IT systems.

The manual and error prone nature of these activities is not acceptable when technology is available to improve systems and support safe and accurate data management. Up to one in six (18%) medical errors were due to inadequate patient information⁵. In 2007, 187 procedures involving the wrong patient or body part occurred in Australian hospitals due to failures to properly identify patients and match them to intended procedures⁶.

A key way of enhancing healthcare is through good clinical information transfer enabled by reliable identification of individuals, providers and organisations. The National Health and Hospitals Reform Commission's recommendations 13 & 115-123 signalled that E-health was a key enabler for health reform and should be used by all in the health sector:

Recommendation 120

- hospitals be able to accept and send data such as referral and discharge information
- pathology providers and diagnostic imaging providers be able to provide key data, such as reports of investigations and supplementary information
- other health service providers – including general practitioners, medical and non-medical specialists, pharmacists and other health and aged care providers – be able to transmit key data, such as referral and discharge information, prescribed and dispensed medications and synopses of diagnosis and treatment
- all healthcare providers be able to accept and send data from other providers⁷.

E-health presents significant benefits for patients

Jim is a 67-year-old man with multiple chronic and complex health care needs including diabetes and its complications (eye disease, kidney failure) and heart disease who recently had an acute episode requiring surgery. He is a keen self-carer, noting and charting his blood pressure and glucose reading amongst other pro-active interventions. Currently, he needs to keep a raft of scans, scripts and spreadsheets he compiles himself to carry to the dozen specialists he needs to see on a regular basis.

On his recent episodes in hospital, he was astounded when he found himself giving the doctors more information than they could find on their own systems even though he was well known to the hospital only recently having been discharged from there. "When I was admitted they couldn't even find the file from three days earlier. I even had to give them the list of medications which they gave me when I left the hospital, they couldn't even give me the list they had given me three days earlier from the pharmacy".

Jim's GP Dr Mukesh Haikerwal, like 98 per cent of GPs, uses computers and software for his records. But connection and compatibility between medical providers doesn't yet exist. "Today I can do a lot of things electronically, but I can't send it to anybody."

4. Healthcare identifiers are an essential foundation for e-health

Australia currently has no single method of reliably identifying individuals, providers and organisations. Today, healthcare providers create and maintain their own records, often electronically, about their patients and the care that has been delivered to them. They all create their own identifiers which are different within and between provider organisations.

Today, with the consent of individuals, information is exchanged when GPs make referrals, pathology results are transmitted to the requesting physician, and hospitals send discharge summaries. When sharing this information across organisational boundaries, it is difficult to reliably confirm the right patient to whom the information relates and the right clinician who authored the information. For example, large pathology laboratories can process tests for around 2000 patients an hour during their peak times. Relying on a name and date of birth to locate a patient's previous test results in their electronic system not only creates inefficiencies for the pathology lab, but also affects clinical safety by increasing the risk that the results are recorded in the wrong patient file. Members of the pathology industry quote a large number of instances where patients have many numbers in their systems and so are mis-identified. This is replicated in other labs and diagnostic facilities.

The HI Service, and the Bill which supports its operation, will create a set of healthcare identifiers which are an essential component for e-health systems to reliably share information between one another. The identifiers will ensure that information is correctly attributed to the right individual, the right provider and the right organisation.

5. Robust protections for the Healthcare Identifier Service

The introduction of new healthcare identifiers needs to be accompanied by an additional set of safety nets. The healthcare identifiers will be protected at every stage of their journey through the healthcare system through a combination of regulatory and technical means.

Only authorised healthcare providers can request a patient's identifier. The HI Service will return the healthcare identifier using Public Key Infrastructure (PKI) and widely accepted secure messaging standards.

The HI Service will be able to keep track of everyone who asks for a healthcare identifier by keeping an audit log of who has accessed it and when they accessed it. This effectively leaves a "fingerprint" of those who have accessed the HI Service, which is an additional security

measure. Individuals will be able to access the audit log online, by phoning Medicare Australia or by visiting a Medicare office.

The HI Service will not hold any clinical health information on individuals. It will only hold a person's name, sex, birth information and addressⁱ. The HI Service is designed so that healthcare providers cannot browse information about people. The only information a healthcare provider will receive is the identifier that matches the personal information a person has already given to their healthcare provider.

6. Consideration for consumers to 'opt-out' from having an individual healthcare identifier (IHI)

While the Bill supports the broad-based or universal allocation of IHIs, this was not always part of the HI Service design. Before 2009, the HI Service was based on a model where an individual could choose to have an IHI and later deactivate it if they no longer wished to have one.

Through stakeholder consultation and the commission of independent privacy impact assessments⁸ during 2008 it became clear that people may not be easily able to opt-out. This was partly due to Australia's State-based health system, as attempts to enforce a person's decision to no longer have an identifier would render the system un-implementable.

In addition with insufficient uptake, hospitals would continue to rely on local identifiers as the main identifier, and the benefits of a national system would be lost.

For example, one privacy impact assessment noted that if an individual opted-out from having an IHI, the IHI should be deactivated in both the HI Service and also in every healthcare provider's local patient administration system. Clearly, this would have significant repercussions across the entire healthcare sector and the burden on hospitals and practices to maintain this information would make the system unsustainable.

NEHTA sought advice from stakeholders on ways to address this issue and it was determined that a model for the universal allocation of health identifiers would be the most appropriate. In November 2008, COAG agreed to the universal allocation of identifiers and advised NEHTA to change the design of the HI Service to reflect this.

To offset any increased impacts on privacy, NEHTA changed several other aspects of the system design. For example, the HI Service would no longer return any personal information to a healthcare provider (such as address). Also, if a healthcare provider entered a name and date of birth which matched two people the HI Service would no longer display both people for the provider to choose from, but would require the provider to also enter the address as a 'tie-breaker' to achieve an exact match before the HI Service would ever return the IHI. NEHTA also sought an additional independent privacy impact assessment on these design changes, and implemented the recommendations made in that assessment.

7. The need for a staged approach to implementation

The introduction of the Healthcare Identification Service will be incremental. There would be risks in attempting rapid implementations and therefore a staged approach is recommended, working closely with the healthcare sector and industry vendors to gradually implement healthcare identifiers.

While the HI Service is intended to commence operation on 1 July 2010 subject to the successful passage of legislation, the uptake and adoption of healthcare identifiers across the healthcare sector will occur over a number of years.

We expect the early stages of our implementation plan to take up to 18 months, as software vendors work with their customers and NEHTA to undertake the necessary software changes. There will be "early adopters" of the healthcare identifier and "fast followers" as the learnings

ⁱ The address information is not shared with end users of the HI Service. It is only maintained to improve the quality of matching.

are shared across the health sector. Early implementation work can not proceed without the legislative support for the HI Service being in place.

8. Consumer comments

NEHTA's stakeholders, engaged through formal consultation processes, have assisted in the development of a healthcare identification service that they believe meets their clinical, safety and quality needs. In addition, to inform stakeholders about the HI Service in detail, NEHTA has developed a Model Healthcare Community in the Canberra premises of Medicare Australia. This demonstration of the proposed Service through clinical scenarios has been well received as the following quotations from Consumer organisation representatives on Friday March 26 indicate:

- *"The unique identifier is out and about in many countries – it's about time we had it here."*
- *"It's obviously the direction we have to go to reduce the number of errors and speed things up for everybody."*
- *"This is an enormous step forward to have unique identifiers for all participants – its got to improve things."*
- *"IHIs are a necessary pre-cursor for the massive changes that are needed in the transfer of health information."*

9. Conclusion

Australia's healthcare system is ready to be connected in a generational shift away from the current system. The current fragmented health network will not be able to exploit 21st century technology until all organisations in the sector are able to securely share information.

NEHTA has sought the support and guidance of the health sector, through multiple clinical, safety, privacy, quality, consumer and industry organisations to develop the proposed HI Service as it is represented in the Healthcare Identifiers Bill 2010.

We believe the HI Service is a critical building block to e-health and the enablement of health reform. The Parliament of Australia is now being asked to consider the *Healthcare Identifiers Bill 2010* and the *Healthcare Identifiers (Consequential Amendments) Bill 2010* which will provide the necessary approval for us to move to the next stage in delivering the national vision for e-health in Australia. We appreciate the opportunity to present our views to this Committee and would be pleased to provide any additional information to support its recommendations.

Yours sincerely

Peter Fleming
Chief Executive Officer

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- ¹ A Review of the National Health Index in New Zealand, Health Informatics New Zealand (2006)
<http://www.hinz.org.nz/journal/2006/06/Fourteen-Years-Young-A-Review-of-the-National-Health-Index-in-New-Zealand/936>
- ² Catherine Quantin et al. (2007) "Unique Patient Concept: A key choice for European epidemiology" in *International Journal of Medical Informatics*, 76: 419-426.
- ³ RAND Corporation (2008) *Identity Crisis, An Examination of the Costs and Benefits of a Unique Patient Identifier for the U.S. Health Care System*, xvii.
- ⁴ Australian Health Ministers' Conference (2008) *National e-Health strategy summary*, p10.
- ⁵ Australian Institute of Health and Welfare (2002) *Australia's Health 2002*.
- ⁶ Australian Commission on Safety and Quality in Healthcare report, *Window into Safety and Welfare in Healthcare 2008*, www.safetyandquality.gov.au/internet/safety/publishing.nsf/Content/windows-into-safety-and-quality-in-health-care-2008. NEHTA is also working with the Royal Australasian College of Surgeons to enable the WHO Surgical Check-list to be available in an electronic format
- ⁷ National Health and Hospitals Reform Commission (2009) *A healthier future for all Australians - Final Report June 2009*
<http://www.health.gov.au/internet/nhhrc/publishing.nsf/Content/nhhrc-report>
- ⁸ Clayton Utz (2008) *National E-Health Transition Authority unique healthcare identifier program privacy impact assessment*.
<http://www.nehta.gov.au/connecting-australia/privacy/pias>