INQUIRY INTO THE HEALTHCARE IDENTIFIERS BILL 2010

AllA Response

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Australian Senate Community Affairs Legislation Committee

AUSTRALIAN INFORMATION INDUSTRY ASSOCIATION LEADING THE ICT BUSINESS COMMUNITY

## INTRODUCTION

AIIA supports the introduction of a unique health identifier because it may enable advanced technological systems to be used to save lives and cut costs; the business case is compelling, as the Minister and expert commentary have pointed out. This is not a debate about technology however; the potential solutions are neither novel nor complex, they are currently available and there is very little challenge or risk. The concepts are mature and the solutions overseas demonstrate this. Policy settings and operational systems must support patient confidence and trust in the final identifier platform, or risk unnecessary fragmentation and piecemeal implementation.

If Australia is to address the ongoing challenges of international competitiveness and the need to maintain standards of living as the population ages, it must find new sources of productivity and economic growth. One sector largely missing in action from previous microeconomic reforms but essential to underpinning future productivity growth is health. Unless decisive and timely reform action is taken it will still be missing from the next wave of microeconomic reform and productivity improvement.<sup>1</sup>

The Prime Minister recognised this during his recent announcement on 3<sup>rd</sup> March 2010 relating to the establishment of the National Health and Hospitals Network when he noted that the reform of health is "one of the greatest challenges facing Australia."

AIIA believes reform of this sector is both essential and inevitable. Essential, because as the Intergenerational Report has acknowledged, without effective intervention the rise in chronic diseases and ageing population demographics will undermine social and economic prosperity through lower workforce participation and productivity. In addition,

<sup>&</sup>lt;sup>1</sup> BCA E-health Plan

by between 2035 and 2045, total states' revenue will be consumed by health care and maintenance, unless fundamental, not incremental, reform is commenced now.

Inevitable, because interoperability needs are driving pockets of e-health initiatives already – at state level there already exist identifiers for different levels of health system entry – pharmacy, hospital, doctor. In NSW alone there are twenty different identifiers now; efficiency dictates that building on these developments by reducing that duplication would be beneficial.

The health sector accounts for 9% of GDP, expected to increase to 12 or 15% over the next twenty years. While it is exposed to international labour markets and imported technologies, it has not been driven by the same international competition that other sectors have faced - the Business Council has estimated the health sector to have one of the lowest rates of productivity growth of all economic sectors in Australia. Whereas other sectors which have invested in General Purpose Technologies have seen productivity gains as a consequence, this sector has underinvested in tools that would facilitate leverage of information gleaned from already advanced patient administration systems and clinical technologies. It is widely acknowledged that the flow-on impacts of ICT diffusion throughout the economy are profound, but long in arriving. The Secretary of the Treasury Dr Henry recognised this in his 2009 address to the QUT Business Leaders' Forum, where he noted the continuing impact of ICT and its potential to have "profound implications for the way in which government services are provided to a rapidly growing aged population..." He also noted that the productivity gains of General Purpose Technologies characteristically take a long time to have their full effect, with much of it occurring some decades after the initial breakthroughs. Both these observations are clearly correct. They have implications for the success or otherwise of this health identifier initiative.

Although Australia has been experimenting with e-health initiatives for some time, other health systems internationally have managed to achieve greater levels of functionality

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and coverage, albeit not without some angst. The benefit for us is that whereas the positive outcomes of health sector reform were once only speculative, international experience now shows clear evidence of the scale of benefits available if we were to implement a national e-health reform program. Brief summary notes of international jurisdictions and their various systems are attached as Appendix A.

#### Information Safeguards

There is a noticeable lack of detail in the Bill about the consent of individuals who may wish to choose to share (or not) their identifier. Regulations to clarify this issue may be required to ensure robustness of the scheme and thus, trust and confidence in the IHI.

AIIA acknowledges the apparent safeguard in the Bill via linkages to the Privacy Act 1988; sections 27, 29 (1) and section 9 (6), making a health identifier an identifier for the purposes of the Privacy Act. We note that while National Privacy Principles apply to private sector organisations (ensuring a private sector company would not be able to use the new health identifier as a way of identifying individuals), Federal public sector organisations are not bound by the NPPs. They must comply with the Information Privacy Principles in section 14 of the Privacy Act. Medicare thus does not have to comply with the NPPs and so it could technically use the health identifier as a way of identifying individuals without breaching the Privacy Act.

We also note that there is no requirement for healthcare providers to use an individual's health identifier when providing health care, so the eventual robustness of the system may require support through regulation (section 25 of the Bill *authorises* the provider to use the IHI but does not *require* it).

Operation of the IHI Service, including access to the identifier

AIIA notes that to a large extent the Bill is 'bare-bones' drafting, because the regulations which will set out the detailed implementation of the concepts in the Bill, are not yet public. An appropriate access rights management process should be detailed in those regulations. We welcome however, the establishment of a Ministerial Council under the National Partnership Agreement on e-Health. The Ministerial Council has oversight of the Healthcare Identifier Service operator's performance and functions, regulations under the HI Act and the operation of the HI Act (including undertaking and presenting to Parliament a review of the Act and performance of the HI Service Operator within three years).

All healthcare providers operating in Australia are licensed, and have a unique number associated with that licence. The number of individuals who need to receive IHIs in Australia is relatively small so the allocation of numbers and the subsequent management of the process should not require a huge level of administration. <u>Relationship to EHRs and the overall e-health agenda</u>

Electronic Health Records, and the mechanisms required to support them, are an important aspect of providing both safety and quality in healthcare. Ultimately, EHRs are safer, provide a greater level of security of information than is provided by paper records and will have a significant and beneficial impact on the overall costs of healthcare delivery by ensuring money is well spent, reducing increasing costs.

The Government has indicated that Healthcare Identifiers will eventually support a system of Individual Electronic Health Records. At this stage however, individual electronic health records do not form part of the Healthcare Identifier Service and are not established under the IHI Schedule.

In the National Partnership Agreement on e-health agreed to by the members of COAG, it was suggested that, in order to support national electronic health initiatives, uniform national health privacy arrangements would have to be established. It is proposed that

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these arrangements be formed within a national privacy network that provides a high level of protection for health information. The main concerns surrounding the implementation of the HI Bill relate to secure access, and without details surrounding the proposed implantation of the EHR scheme, these concerns are difficult to address.

The IHI system will hopefully form the foundation of a national electronic health system by removing any technological and organisational impediments that presently exist with respect to the effective sharing of health information.

AIIA supports the introduction of IHIs to combat the demands of 21<sup>st</sup> century healthcare, such as the ageing population, technological change and an increase in customer expectations. EHRs and IHIs present an opportunity to create a system that supports better coordinated healthcare and ensures that the right information is available to the right people so that care can be provided. EHRs should provide better access to an individual's own health information, enable them to participate more in their own healthcare and to make more informed decisions with respect to their health.

## **APPENDIX A**

## **ELECTRONIC HEALTH IN GLOBAL JURISDICTIONS**

## SUMMARY OUTLINE

### Sweden

Began the "national patient summary" in July 2009 in one county council. Aim was to "improve diagnosis, treatment and follow-up and to ensure that patients have greater access and control over their medical records and security controls".

What is stored on the NPS:

- Personal identification information
- Next of kin
- Medication received from pharmacies (if consented)
- Previous Diagnosis
- Allergies
- Care documents
- Test results (including image diagnostics)
- Scheduled and effected contacts
- Plan options for care
- Referral results

There is an access log that is for the patient's eyes only. The patient is able to say no to a particular record being included if they want to. This is done through the patient's GP.

#### **RE: SECURITY**

- To prevent any breaches or unregistered staff accessing files, the NPO developed a national level security solution called BIF (basic services in information maintenance).
- In order to access information, all healthcare providers need an electronic ID card and every visit to a patient's record is logged.

- "Patient relation" → in order to access information, a healthcare provider needs a "patient relation", which is where a patient gives consent for the healthcare provider to look at their record. This requirement is waived in the event of an emergency.
- Created the Patient Data Act of 2008, which establishes clear rules designed to ensure secure and efficient handling of personal data while improving patient safety and strengthening personal privacy.
- Further, all healthcare providers are subject to the Secrecy Act and are subject to the professional activities in the Health and Medical Care Field Act.

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# Denmark

Has a national public health portal  $\rightarrow$  sundhed.dk

Citizens have access to general and personal information, while professionals have access to more services such as reading electronic records etc.

Danish citizens have been given a unique personal identifier at birth for the last 40 years and this is used in the health care system.

Citizens can log on and perform the following functions:

- Book GP appts
- Renew prescriptions
- Review medication data
- Communicate with healthcare authorities

Doctors can view/upload:

- Discharge letters
- Out patient notes
- Casualty letters
- Doctor on call notes
- Specialist notes
- GP letters
- X rays
- Physio notes
- Bookings
- Clinical emails

Prescriptions (eprescriptions have now all but replaced non-electronic prescriptions).

Denmark has tried to avoid specific regulation of ehealth – it is seen and implemented as a natural extension of health care in general. However, the latest eHealth strategy suggests that regulating data security and patient privacy in eHealth scenarios specifically is a necessity, so there may be more targeted regulation in the future.

# The Netherlands

One of the EU's frontrunners regarding eHealth and the use of computers in health care. Lab results are systematically transferred electronically and data transfer between GPs (while not an established practice) is much more common than in other EU countries.

- Eprescription is used in 75% of all GP practices.
- One of the main assets of the Dutch healthcare system is AORTA (national communication infrastructure for healthcare), which contains eID authentication systems and allows safe, controlled transfer of health data across the Netherlands through a central hub.
- Electronic exchange of info is strictly regulated.
- AORTA hub contains systems that guarantee the privacy of each user and has a comprehensive access rights management framework so the legislation relating to the exchange of health info mostly contains provisions that force users to go through the hub for all transactions. Also, only relevant info can be made available in a secure manner and on a need to know basis.

# Hong Kong

Has an existing scheme "public-private interface for e-patient record" where doctors employed by the Hospital Authority are able to place patient records (with patient consent) on to a system. Records can currently be accessed by doctors in Hospital Authority + private medical practitioners. Records have been online since 2006. Under the current scheme, doctors from private hospitals are not able to upload records, so they are attempting to include private hospitals into the system.

Doctor needs user ID, password and RSA token to be able to log on. When a patient record is viewed, an SMS is sent to the patient to advise them.

## Canada

Will have a unique code for each individual linked to an "electronic health record". The data on the records will include lab results, discharge summaries and diagnostic imaging reports. This system was rolled out in some Canadian provinces in December 2009.

## Scotland

- Has an "emergency care summary" system. This provides information for out of hours centres/ A&Es. Not all medical details are included, only things such as allergies/adverse reactions to drugs and any prescribed medications.
- Almost all of the 5.2 million population now has an ECS record. Only 1400 people have opted out on privacy grounds.
- Privacy for patients → all patients are asked for their explicit consent before any doctor looks at the record. Staff cannot browse records, as they need several pieces of data to get access to each patient.

# Specific Examples of where online health records have provided beneficial outcomes for patient care or where the lack of health records has impeded it.

- Jonathan Cameron, the ECS programme manager cites one example whereby a mentally ill patient was distressed and presented to A&E. Usually, the patient would have to be admitted and observed and be subjected to tests while they attempt to contact the GP. With the ECS, the staff were able to look up the medication prescribed to the patient and establish that they had failed to take a dose. They could then administer the medication and send the patient home, rather than having to admit them.
- 2. Libby Morris, GP who chairs the ECS board cites some examples where electronic records have saved lives: a 62 year old patient who had not mentioned on admission to hospital that she needed insulin and an unconscious 17 year old who was a victim of an overdose. The staff found the drug he had used through his father's record, after his father had given permission for access. Also particularly beneficial for elderly people in psychiatric care allows access to the medication that they're on and increases the safety of medicine reconciliation.
- 3. "Health's black hole" → SMH July 18<sup>th</sup>, 2009. This article describes the experience of a doctor who was admitted to intensive care following a near-fatal bashing. He spent 6 days at a public hospital in intensive care and was then transferred to a nearby private hospital. The GP was shocked to learn how much the inaccessibility of updated medical records affected his care. After returning home,

he suffered from persistent fatigue and eventually discovered anaemia as the cause. Despite numerous blood tests in both hospitals, the condition was missed as a result of the lack of continuing record-keeping and the severity of the decline in his red blood cells went unnoticed. Further, when he had a scan at another hospital to review his condition, it was not possible to compare it to the scan taken immediately after the attack as the two systems did not communicate. This is a potentially dangerous situation.

http://www.smh.com.au/national/healths-black-hole-20090717-do8p.html

#### <u>About AIIA</u>

The Australian Information Industry Association (AIIA) is Australia's peak technology industry body. AIIA's role is to lead and represent the ICT industry in Australia to maximise the potential of the Australian economy and society. AIIA's membership encompasses all sectors of the ICT sector including hardware, software, services and telecommunications. It has almost 500 member companies, from individual consultants, small to medium enterprises to the world's leading multinational corporations.

AIIA member companies employ over 100,000 Australians, generate combined annual revenues of more than \$40 billion (approximately 5% of GDP) and export more than \$2 billion in goods and services each year.