

# **SUPPLEMENTARY SUBMISSION NO. 16.1**

*Joint Select Committee on Cyber-Safety: Inquiry into Cybersafety for Senior Australians*

## **DEPARTMENT OF HEALTH AND AGEING**

### **ADDITIONAL INFORMATION**

Further to the Department's submission dated 17 February 2012, additional information relating to the personally controlled electronic health record (eHealth record) system is provided to assist the Committee.

The national eHealth record system commenced on 1 July and take up is increasing in response to the careful and staged implementation approach. The staged implementation approach is consistent with industry best practice and learnings from international experience, and parallel strategies are being implemented to increase adoption by healthcare providers and consumers. The initial emphasis is on adoption by both consumers and healthcare providers within the lead eHealth sites, focusing on older Australians, mothers with young children, people with a chronic conditions and Aboriginal and Torres Strait Islander Peoples.

As the system develops over time, having an eHealth record will give doctors, nurses and other healthcare professionals involved in a consumer's care access to a summary of their key health information. This will include information such as medications, test results, hospital discharge summaries, allergies and immunisations. As people and healthcare organisations register for the eHealth record system, health care will become better connected which will result in better, faster and more efficient care for consumers.

#### **1. COLLECTION, USE AND DISCLOSURE OF CONSUMER HEALTH INFORMATION**

During the Committee's inquiry some concerns were raised about possible coercion of consumers to share their eHealth record.

The *Personally Controlled Electronic Health Records Act 2012* (PCEHR Act) limits when and how health information included in an eHealth record can be collected, used and disclosed. Unauthorised collection, use or disclosure of eHealth record information is both a contravention of the PCEHR Act and an interference with privacy.

A person or organisation can only access a consumer's eHealth record where they are authorised by law and/or the consumer consents to them having access. Generally, only consumers (including any authorised and/or nominated representatives of the consumer) as well as participants in the eHealth record system are authorised to access a consumer's eHealth record.

Consumers can choose to nominate individuals who can access their eHealth record (referred to as nominated representatives). Nominated representatives can access the consumer's eHealth record on either a read-only basis or the consumer can give them full access to be able to do almost everything the consumer themselves can do to access and manage their record. Usually a consumer would choose family members, friends or other people that they trust to be their nominated representative.

Should any individual or organisation, for example an employer or an insurer, request access to a consumer's eHealth record or request some or all of the health information contained in a consumer's eHealth record, the consumer would need to consent to this before such access or disclosure could be allowed.

If the consumer feels that they provided consent under coercion they can raise the matter with the Office of the Australia Information Commissioner (OAIC), which has privacy oversight regarding the eHealth system and its use. The OAIC can apply penalties if it finds a breach has been made (e.g. a breach under section 59 of the Act which prohibits unauthorised collection, use and disclosure of health information in a consumer's eHealth record).

Also, under the *Privacy Act 1988*, persons collecting information must ensure that they do not collect more information from an eHealth record than is necessary.

## **2. AUDIT LOG**

All access to a person's ehealth record is recorded in the audit log of the eHealth record system.

The audit log allows consumers to see when their eHealth record has been accessed, the nature of that access (e.g. a document was uploaded), and the organisation responsible.

Healthcare provider organisations participating in the system are required to uniquely identify each employee that has access to the eHealth record system. These organisations also have an audit log of their own activity on the eHealth record system.

In order to protect the privacy of healthcare organisation employees, a consumer will not be able to identify the individual responsible for accessing their record. However, if someone is concerned about an instance of access to their record they can report it to the System Operator.

The System Operator can investigate and identify the person responsible within an organisation for accessing a record or can seek advice from the healthcare provider organisation, which is required to provide this information.

If a privacy breach is suspected to have occurred the matter can be investigated by the OAIC.

## **3. COMMUNICATIONS AND EDUCATION**

In their supplementary submission, the Consumers Health Forum of Australia (CHF) raised concerns about consumer awareness of the eHealth record system and its benefits to those who wish to participate and whether there is sufficient education and guidance around this for consumers with low IT literacy. The CHF also advised that it is essential for consumers to be able to understand what information their eHealth record will contain and how they can control that information.

In recent months the Department has been focussed on implementing the functionality of the system and completion of the infrastructure. In August 2012 the build was completed with the delivery of the provider portal. There are now a number of planned promotional activities which will target key cohorts who will benefit most from the eHealth record system. Examples of consumer awareness activities include:

- the inclusion of eHealth promotional material that will go to all new parents from January 2013;

- an eHealth record consumer brochure is now included in all Medicare card issues up to June 2013; and
- the eHealth lead sites have also developed a range of promotional materials and letters to consumers in their local areas to promote uptake of the eHealth record system. By April 213 the eHealth lead sites are to have mailed out to 470,000 consumers.

Other identified co-promotion opportunities with the Department of Human Services (DHS) scheduled in the short-term are newsletter articles reaching a potential 2.8 million consumers and promotion via DHS facebook pages and emails.

In response to CHF's concerns regarding consumers' education regarding their control of information in an ehealth record, the Department can advise that:

- there is an interactive module on understanding privacy and security available at <[www.eHealth.gov.au](http://www.eHealth.gov.au)> as well as an accessible version that provides information in a clear and concise way; and
- consumers are able to contact the eHealth records helpline for assistance with the system by calling 1800 723 471 (1800 PCEHR1). For consumers that choose to register over the phone, a helpline operator will be able to provide assistance with setting access controls.

#### **4. NOTIFICATION OF BREACHES**

In its original submission to the Committee, CHF recommended that consumers be notified of all breaches of the eHealth record system affecting their record. In its supplementary submission, CHF acknowledged that this recommendation had been addressed in the PCEHR Act.

Subsection 75(4) of the PCEHR Act requires that the System Operator notify all affected consumers of data breaches that have occurred. Where a significant number of consumers are affected the System Operator must notify the general public.

The requirement to notify data breaches or potential data breaches affecting a repository, portal or the System Operator is intended to allow the System Operator and the OAIC to investigate, take corrective actions and help mitigate any loss or damage that may result from the breach. The steps required under subsection 75(4) are critical to the ongoing security and integrity of the eHealth record system and maintaining consumer and provider confidence in the eHealth record system.

#### **5. PROVIDER PARTICIPATION**

During the Committee hearing on 19 September 2012, the CHF expressed concern that some healthcare providers may choose not to use the eHealth record system for consumers who exercise greater control over access to their eHealth record.

Healthcare providers are subject to professional obligations in providing healthcare services to consumers. Healthcare providers will need to consider information available to them and use it as they see fit in the interests of the best treatment for the patient. Whether or not healthcare providers use the eHealth record system is a professional decision of the provider.

However, a healthcare provider cannot decide to not treat a consumer based on whether the consumer has an eHealth record or has set certain access controls for it.

An anti-discriminatory clause is included in the PCEHR Act to address the matter of where a healthcare provider may not want to treat a patient who has an eHealth record. Section 46 of the PCEHR Act imposes conditions on registered healthcare provider organisations in relation to circumstances where a consumer does not have an eHealth record or has an eHealth record and has chosen to set particular access controls over it. In either case, a registered healthcare provider organisation cannot refuse to provide healthcare to the consumer or otherwise discriminate against the consumer in relation to providing healthcare.

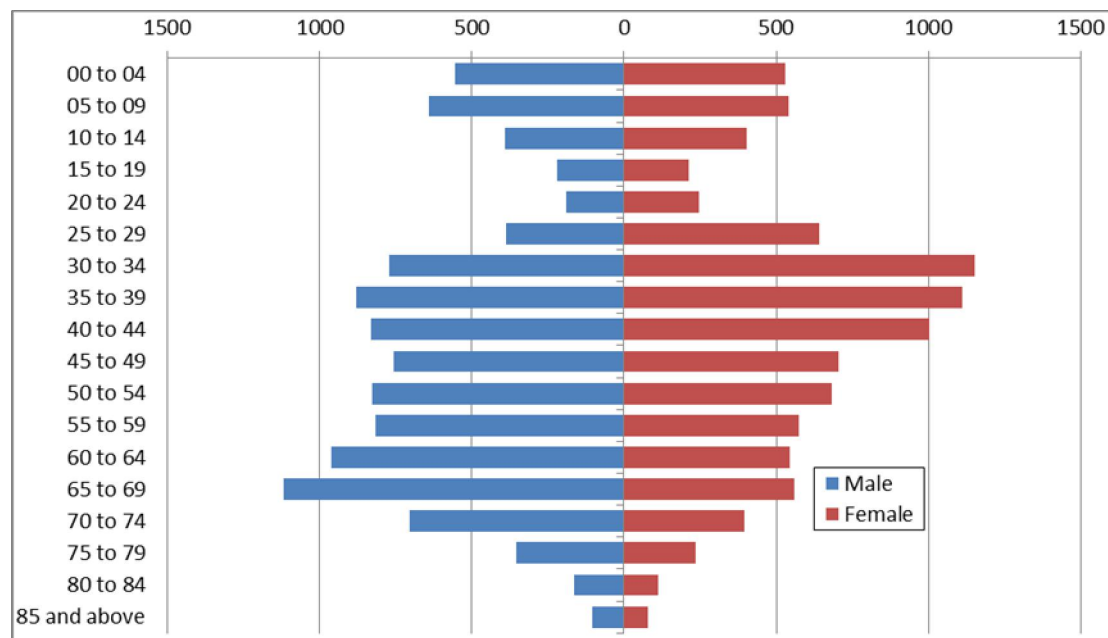
If a healthcare provider organisation contravenes these conditions, their registration to participate in the eHealth record system may be suspended or cancelled. They may also be subject to penalties under their professional code of conduct.

## 6. REGISTRATION SINCE 1 JULY 2012

On 19 September 2012 the Committee requested information about the number of consumers registered since the system commenced and a breakdown of registrations by age groups.

The total number of consumers that have registered since 1 July 2012 is 22,212 (as of 5 December 2012). The breakdown of active eHealth records by gender and age group (as of 26 November 2012) is shown below.

**Figure 1: eHealth Records by Gender and Age Group**



The demographic breakdown is as follows:

- 48% Female; 52% Male.
- 17% are for consumers under 20 years of age;
- 26% are for consumers between 20 and 39 years of age;
- 38% are for consumers between 40 and 64 years of age;
- 19% are for consumers aged 65 years or above.

## **7. GOVERNANCE (INCLUDING COMPLAINTS)**

Individuals and healthcare providers can raise complaints about the operation of the eHealth record system with the System Operator or with the OAIC.

The OAIC regulates the handling of personal information under the eHealth record system by individuals, Commonwealth government agencies and private sector organisations.

Their role includes investigating the mishandling of health information in an individual's eHealth record, and the OAIC can initiate its own investigations.

The OAIC has the power to impose penalties, seek injunctions and undertake conciliation. The OAIC will issue Enforcement Guidelines that will outline the Commissioner's approach to enforcement for the purposes of the eHealth record system.

The System Operator is required to notify the Australian Information Commissioner as soon as practicable after becoming aware of a data breach relating to the eHealth record system.