



# **Australian Federation of AIDS Organisations (AFAO)**

## **Personally Controlled Electronic Health Record System: Exposure Draft Legislation**

### **Comments**

**28 October 2011**

## **About AFAO**

The Australian Federation of AIDS Organisations (AFAO) is the national federation for the HIV community response. AFAO's members are the AIDS Councils in each state and territory; the National Association of People Living with HIV/AIDS (NAPWA); the Australian Injecting & Illicit Drug Users League (AIVL); the Anwernekenhe Aboriginal and Torres Strait Islander HIV/AIDS Alliance (ANA); and Scarlet Alliance, Australian Sex Workers Association. AFAO advocates for its member organisations, promotes medical and social research into HIV and its effects, develops and formulates policy on HIV issues, and provides HIV policy advice to Commonwealth, state and territory governments.

## **Our perspective on this Inquiry**

AFAO is pleased to provide comments on the Department of Health and Ageing's Personally Controlled Electronic Health Record System: Exposure Draft Legislation (Companion Document) ("Companion Document") and the Exposure Draft PCEHR Bill 2011 (PCEHR Draft Bill).

AFAO welcomes the provision of substantial penalties for the mishandling and/or misuse of consumers' PCEHR information. However, we remain concerned about: the lack of provision of rights regarding removing or barring access to PCEHR information; the absence of provisions detailing consumers' rights of access to the audit trail; and the lack of consistent privacy protections for individuals' information held in different state and territory PCEHR repositories.

## **Access removal and barring**

We understand it was previously proposed that consumers have the ability to mark parts of their PCEHR record "no access" but it was decided not to pursue this. Instead, so we understand, information/documents may be marked or tagged for "effective removal".

Given that we cannot find reference to either of these terms in the draft legislation it is difficult to comment on the decision not to allow for "no access" to be ascribed by a consumer in respect of information on their PCEHR record that they no longer want providers to have access to. That being said, the consumer's right to remove or bar access to information should be included in the legislation. (AFAO understands that the Consumer Health Forum's submission will cover this issue, reflecting concerns raised at the consultation held on 26 October 2011 in Canberra.)

## **Audit**

As stated in our August submission to the *Personally Controlled Electronic Health Record System: Legislation Issues Paper*, AFAO believes that providing clear measures of accountability is pivotal to ensuring public confidence, and thus participation, in the PCEHR. These measures include ensuring consumer rights of access to the audit trail of their own PCEHR.

The Companion Document states "the Draft Bill contains some key privacy protections, including...the ability to view an audit trail of all access to consumer's PCEHR". The only reference to audit in the PCEHR Draft Bill is in section 11(g) - Functions of the System Operator, which states that

the System Operator is “to establish and maintain an audit service that tracks flows of information in relation to the PCEHR system”.

This provision does not ensure consumers a right of access. Although the Concept of Operations does contain detail of consumers’ rights to access the audit trail, AFAO believes that such crucial rights should be enshrined in legislation and thereby guaranteed.

On a related note, the legislation should require that regular audit and system reviews be conducted at defined intervals. This reporting should be referred to the Commonwealth Ombudsman and Information Commissioner for consideration and report. The legislation should require that these reports be tabled in Parliament and/or referred to an appropriate Senate or House of Representatives committee.

### ***Re relationship between Privacy Act 1988 (Cth) and PCEHR Draft bill***

We welcome the position expressed in the Companion Document that “an act or practice that contravenes the Draft Bill in connection with a consumer’s health information included in a consumer’s PCEHR would be taken to be an interference with privacy for the purpose of the Commonwealth Privacy Act”. This would allow for complaints to be lodged under the Commonwealth Privacy Act, with corresponding remedies thus available, including compensation or an apology. We note that as the Commonwealth Privacy Act is currently being redrafted, the exact nature of remedies may change.

The Companion Document also states that “In the Draft Bill the Information Commissioner will have standing to seek from a court or accept a voluntary enforceable undertaking in respect of the contravention.” The Information Commissioner must be adequately resourced to pursue enforceable undertakings as well as acquit its complaints investigation responsibilities. We note that under-resourcing of the Office of the Privacy Commissioner after the introduction of the private sector provisions 10 years ago caused unacceptably long delays in dealing with complaints.

### ***Re relationship between Privacy Act 1988 (Cth) and PCEHR Draft bill and State/territory privacy laws***

A key driver behind current privacy reforms is the harmonisation of privacy laws so that people can easily understand their rights and navigate appeal and complaint mechanisms regardless of location. From a practical consumer perspective, having one set of laws to follow/understand/administer will help create confidence in the system.

According to the Companion Paper 3.8.6.:

*Section 98 of the Draft Bill will permit the Minister to designate that state or territory privacy and health information laws are designated privacy laws. At this stage it is anticipated that a designation can be made in relation to privacy and health information laws in all states and territories other than Western Australia and South Australia (this is because Western Australia and South Australia rely on administrative schemes, common law duties of*

*confidentiality associated with confidential health records and health-specific legislation restrictions on the disclosure of health information).*

It appears that designated privacy laws will apply to the regulation of a majority of state/territory repository operators. As a result, a single complaint lodged in a jurisdiction in which designated state/territory privacy laws operate, will be subject to differing privacy protections, depending on whether the behaviour of a repository, a health provider or third-party provider is at issue. This inconsistency is undesirable.

Multiple legal regimes applying to the same privacy complaint will likely cause confusion for the average consumer. Consumers with cognitive impairments and/or mental health conditions may face particular difficulty in following up a privacy complaint in such a complex environment. Optimally, all state-territory repository operators should be subject to Commonwealth Privacy Act, thus minimising confusion for consumers.

### ***Long-term governance of PCEHR***

According to s10 of the Draft Bill, the System Operator may be the Secretary of the Department or if a body established by a law of the Commonwealth is prescribed by the regulations to be the System Operator—that body.

AFAO understands that the Department of Health and Ageing is planning to contract out this role to Medicare as an interim measure, pending the creation of an appropriate statutory authority. While AFAO appreciates that such an interim arrangement is now necessary if the July 2012 deadline for roll-out is to be met, establishing a statutory body as System Operator prior to implementation would have been preferable.

There is potential for actual or perceived conflicts of interest between Medicare and insurers regarding consumers' health records - in compensation claims for personal injury, for example - and it would be unfortunate if such issues affected consumers' and other stakeholders' confidence in the system. The contractual relationship between DoHA and Medicare as the System Operator should be subject to public scrutiny; and an independent statutory authority should be finalised as soon as possible.

### ***Consumer Representation***

AFAO welcomes the creation of the Independent Advisory Council. The Companion Document at 3.2.3. states that in addition to the Chairperson and the Deputy Chair, there will be between four and seven other members who should have experience in at least one of several fields, including "receiving healthcare as a consumer". Consumer membership of the Independent Advisory council is essential, however, the current structure does not assure this. The legislation should require that the Independent Advisory Council include at least two dedicated professional consumer representative positions nominated by relevant peak community organisations. This will ensure that a member who is a healthcare provider or a technical expert, would not be expected to provide the consumer healthcare input just because they have healthcare experience in their personal life.

## ***PCEHR Rules***

AFAO supports the provision that the Minister for Health and Ageing make rules, via the tabling of Disallowable Instruments, to support the PCEHR system, as stated in the Companion Guide at 3.8.6. The creation of any such rules should be subject to a requirement for public consultation.

## ***Conclusion***

AFAO is pleased that PCEHR draft bill contains significant penalties for breaches of PCEHR legislation. Such an approach will hopefully provide great incentive to organisations to appropriately handle individuals' PCEHR information. We would like to see legislative provision for consumer rights of access to the audit trail and for a "no access" tag to bar access to specified information. We also propose that provision be made in the legislation for at least two dedicated consumer representatives on the Independent Advisory Council.

AFAO's most fundamental concern is the Government's intention that engagement with the PCEHR system will be voluntary for providers. While this is so, neither a consumer nor a healthcare provider can be confident that a PCEHR record being accessed is complete; it may appear to be complete but critical diagnostic and/or treatment information may be missing where a provider has chosen not to register. This is a basic flaw and AFAO's view is that the PCEHR system must be compulsory for providers.