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Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

12 January 2011

Dear Sir/Madam,

Re Personally Controlled Electronic Health Records Bill 2011

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.

We are pleased to provide comments on the *Personally Controlled Electronic Health Records Bill 2011* (the Bill). AFAO has been engaged in the PCEHR consultation process from the outset. We believe that the PCEHR potentially offers significant benefits to people living with HIV, especially given that HIV-positive people can have complex health conditions requiring frequent use of the health system, with frequently changing medication regimens. Chronic disease management is particularly challenging for people who have lived long-term with HIV, as well as for their health providers.

AFAO has read the submission to this Inquiry made by the Consumers Health Forum (CHF) and took part in the consultations referred to in its submission. The comments and additional recommendations below are made further to the CHF submission, having particular regard to HIV-related issues that may affect the take-up of the PCEHR among Australian populations affected by HIV.

AFAO fully endorses CHF's recommendations, except that we hold reservations regarding its comment that an opt-out model may ultimately be required in order to achieve active participation by consumers and health providers. As outlined below, given the stigmatisation of people living with HIV and of people among communities most affected by HIV, AFAO and its members' main concerns regarding the PCEHR relate to privacy and confidentiality issues. AFAO appreciates that an opt-out approach would be pragmatic in terms of maximising participation in PCEHR but we would be hesitant to support such an approach without a proven privacy framework in place with strong protections for consumers, and demonstrably effective complaint/appeal processes.

Information and engagement strategy

Australian populations most affected by HIV include: people living with HIV; gay and other men who have sex with men; Aboriginal and Torres Strait Islander peoples; people from or who frequently visit countries with high HIV prevalence; sex workers; people in custodial settings; and injecting drug users (*Sixth National HIV Strategy 2010-2013*). People among these populations are by definition subject to stigma and discrimination - within affected communities, in the broader community and also within parts of the health system. The stigma associated with HIV compounds these issues and creates barriers to accessing HIV prevention, care and support services.

Improving testing rates among people at risk of HIV and enhancing affected communities' equitable access to the health system are core priority actions of the *Sixth National HIV Strategy 2010-2013* and fundamental drivers of the recent review of the *National HIV Testing Policy 2011*. As acknowledged in the *National HIV Testing Policy 2011*, for people among these populations confidence in the confidentiality of records regarding HIV testing and pre- and post-test discussions/counselling is crucial. Any lack of confidence in the confidentiality of patient/provider relationships and the privacy of HIV-related medical records would undermine engagement with the PCEHR among these populations, and potentially undermine the engagement of people from target priority populations with the health system per se.

AFAO is concerned that those with most to gain from linked health records may choose not to engage with the PCEHR due to privacy concerns. If initial PCEHR opt-in rates are poor among key populations affected by HIV, the rigor, accuracy and completeness of individual records and the utility of the system for providers whose clientele includes people with complex needs will be undermined significantly. While the range of records accessible through a person's PCEHR will initially be limited, the fact of a person's HIV-positive status may be apparent – either explicitly (e.g., as part of a Shared Health Summary), or by implication (e.g., where HIV antiretrovirals are listed as part of a discharge summary). It is essential that the extent to which a patient's HIV-positive status and/or information about their sexual practices, sexuality or injecting drug use would be shared under PCEHR is clearly explained to individual patients, so that the decision whether to opt-in is genuinely an informed one, that privacy rights are understood and that any undue concerns are allayed.

The potential sharing of PCEHR information regarding sexual health issues can pose particular issues for people among Aboriginal and Torres Strait Islander communities, and among communities of people from countries where HIV prevalence and associated stigma is high.

Implementation of a staged communication and engagement strategy, as flagged in the May *Draft Concept of Operations - Relating to the introduction of the personally controlled electronic health record (PCEHR) system*, would go some way to comprehensively engendering trust in the PCEHR among key populations and thereby enhancing opt-in rates, provided that information is carefully targeted to communities. It will be essential that this strategy includes providing information regarding PCEHR privacy and confidentiality controls, with information targeted to key populations.

Particularly for consumers with potentially stigmatising conditions such as HIV or psychiatric conditions/mental illness, it will be important to involve peak community organisations in developing strategies to target consumer populations. Given that the system is going live on 1 July 2012, we trust that development of such a communication and engagement strategy is well underway.

- *In order to enhance engagement with the PCEHR, peak community organisations should be consulted with toward developing strategies to target consumer populations – prior to and during roll-out of the staged communication and engagement strategy.*

Authorised collection, use and disclosure of health information

The CHF has recommended (page 8 of its submission to this Inquiry), that the legislation should explicitly provide that third parties, such as employers or insurers, may not use PCEHR information and that restrictions apply to courts and tribunals access.

Clause 70 of the Bill provides that the System Operator may disclose health information to law enforcement agencies for prescribed purposes set out in sub-clause 70(1). AFAO believes that this discretion is too broad and that this may result in law enforcement authorities “fishing” for evidence possibly contained in a person’s PCEHR.

Issues regarding the investigation and conduct of criminal prosecutions of people living with HIV in relation to the sexual transmission of HIV, or exposing others to HIV, represent a case in point. Providing access to health/medical information for the purpose of prosecuting criminal matters or resolving civil legal disputes should continue to be subject to subpoena rather than the System Operator’s discretion, and should relate to particular information rather than to general information contained on their PCEHR.

- ➢ *AFAO proposes Clause 70 of the Bill be amended so as to preclude disclosure/provision of information on an individual’s PCEHR to the police/Directors of Public Prosecution and other law enforcement agencies in respect of criminal matters other than under subpoena.*

Governance arrangements

While appointing an interim System Operator is necessary given the 1 July 2012 start-date, establishing an independent statutory body as the System Operator prior to implementation would have been preferable. It appears that Medicare will be the interim System Operator. AFAO is concerned that there is potential for actual or perceived conflict of interest between Medicare and insurers regarding consumers’ health records. In compensation claims for personal injury, for example, 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 established as soon as possible.

- ➢ *AFAO proposes that the long-term governance arrangements set out in the Bill be subject to an extensive public consultation process, commencing within a year of the introduction of the PCEHR so that the proposed two year review of the legislation is properly informed by community input.*

- ➢ *AFAO proposes that the two year review of the PCEHR implementation consider collection, use and disclosure issues relating to the interaction of the PCEHR and other e-repositories containing information regarding individuals, particularly health information – e.g., Medicare, the PBS.*

The Independent Advisory Council

AFAO commends the fact that the Bill provides for the appointment of consumer representatives to the Independent Advisory Council. We are pleased that a member with experience/knowledge regarding provision of care to people from Indigenous communities will be included, particularly given the sensitivities associated with the possible disclosure of sensitive information to health providers from a persons’ community.

For the reasons outlined above AFAO also believes that the Independent Advisory Council should also include members with experience/knowledge of providing care for people with people with mental health conditions and/or cognitive disability, and people with blood-borne viruses.

- ➢ *AFAO proposes that sub-clause 27(1) and sub-paragraph 27(b)(ii) of the Bill be amended such that the Independent Advisory Council includes five community members (rather than three), with the additional two members having experience or knowledge in providing healthcare for: people with mental health conditions and/or cognitive disability; and people from communities affected by blood-borne viruses.*

Thank you for the opportunity to provide comments to the Inquiry.

Yours faithfully,

Rob Lake
Executive Director