



Australian Federation of AIDS Organisations

Comments regarding

**Electronic Health Records and
Healthcare Identifiers:
Legislation Discussion Paper
(Department of Health)**

24 June 2015

The Australian Federation of AIDS Organisations (AFAO) is pleased to provide comments on the *Electronic Health Records and Healthcare Identifiers Discussion Paper*. AFAO believes that an accessible, consumer-friendly electronic health record will be of great benefit to Australian consumers generally and particularly to people with chronic and/or multiple health conditions, including people living with HIV. We provide the following comments with a view to enhancing the benefits and utility of the e-health system for people living with HIV and for people among communities affected by HIV. Addressing these issues can only improve system fundamentals for all consumers and providers.

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 with HIV Australia (NAPWHA); the Australian Injecting & Illicit Drug Users League (AIVL); the Anwernekenhe National HIV Alliance; 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.

In this submission, we provide our views in relation to some of the commentary in the paper, in addition to responding to some of the specific questions posed. Whilst we appreciate that the scope of the consultation is limited to identifying and addressing issues that do not require legislative amendment, we have discussed some issues that may only be addressed with legislative support. AFAO notes that the Paper refers to an ongoing process to respond to recommendations made for improving the HI Service (at 2.4 and 2.5), including potential legislative changes.

2.1 Personally controlled electronic health record system

AFAO strongly supports the fundamental aims of the PCEHR system: overcoming fragmentation of health information; improving the quality and availability of health information; reducing adverse medical events; and improving healthcare coordination.

Each of these aims is highly relevant to the care of people living with HIV, and the prevention of HIV among other communities identified as 'priority populations' in the *Seventh National HIV Strategy 2014-2017* and the *Fourth Aboriginal and Torres Strait Islander Blood-borne Virus and Sexually Transmitted Infections Strategy 2014-2017*¹, which include: gay men and other men who have sex with men; Aboriginal and Torres Strait Islander people; people from high HIV prevalence countries; sex workers; and people who use drugs.

People among these communities can be reluctant to disclose certain stigmatised conditions (for example HIV-positive status), and criminalised or stigmatised behaviour that is highly relevant to their health – such as illicit drug use or condomless anal sex – yet this information is highly relevant to blood-borne virus prevention, diagnosis and early treatment. Once such behaviour is disclosed, they may have legitimate concerns regarding the sharing of that information with other healthcare

¹ Both strategies available at: <http://www.health.gov.au/internet/main/publishing.nsf/Content/ohp-national-strategies-2010> (accessed on 24 June 2015)

providers, especially providers for whom the information is irrelevant. If the system is to meet its stated aims for these groups, it is essential that well-targeted resources are developed outlining rights to privacy/confidentiality; how to use access controls; and complaints/appeals processes.

- ***For the PCEHR to meet its aims in respect of people living with HIV and communities affected by HIV, there is a need to ensure that rights to privacy and confidentiality, and processes for personal control of the PCEHR record, are not undermined by initiatives to enhance the completeness of information held on the PCEHR***
- ***There should be further development of the PECHR privacy framework with strong protections for consumers; and accessible, effective and speedy complaint and appeal processes.***

3.2.1 Establishment of ACeH

We note that under the governance arrangements to be established from July 2016, the Board of the new Australian Commission for Electronic Health (ACeH) will include a 'consumer of health services'. The proposed wording is ambiguous, and would seemingly allow for the appointment of individual who may have personal credentials but is in no way affiliated to a representative consumer organisation. Such an appointment would be inadequate; the Board position needs to be filled by a representative of a community health peak, ideally the Consumers Health Forum

- ***AFAO proposes that the ACeH Board include reserved positions for representative community organisations, including the Consumers Health Forum.***

Regarding additional consumer representatives, we propose that the National Association of People Living with HIV Australia (NAPWHA) be considered for inclusion on the Board. We understand that there have been high levels of engagement among people with HIV with the PCEHR to date, particularly among Medicare Local/Primary Health Network areas with a high population of gay men (e.g., Sydney inner-east). This uptake is not surprising given that the complexities of health management for people living long-term with HIV mean that many are expert in health self-management and co-ordination of health care services.

At the same time, people with HIV also often experience stigma and discrimination, including from within the health system. As the proverbial 'canary in the coal-mine' in terms of dealing with privacy/confidentiality issues as well as complex health management, we believe that including a NAPWHA representative on the Board would be useful, and would help ensure that PCEHR aims in respect of complex/chronic health management are met, and that the system is viable and attractive for consumers in terms of privacy and confidentiality considerations.

- ***AFAO proposes that any additional community representation on the ACeH Board include NAPWHA.***

AFAO understands that an independent chair is to head the ACeH Board. AFAO strongly supports this initiative.

3.3 An opt-out PCEHR system?

AFAO supports the trialling of an opt-out model; however, we are disappointed that providers will remain opt-in under the trial.

We understand from the recent community consultation (Sydney) regarding the Discussion Paper, that healthcare providers - particularly and significantly GPs - continue to have difficulties integrating the ehealth record with their own systems; and that the PCEHR is considered by many providers to be prohibitively time and resource-intensive.

AFAO appreciates that there are complex issues to be addressed for providers in terms of practicalities such as ensuring adequate computer software and systems for reliable and efficient ehealth record maintenance. The trialling of opt-out for providers as well as patients would have been of great assistance in identifying and understanding these issues and assuaging any misplaced concerns on the part of providers.

In the long-term, beyond the trials, AFAO's main concern in relation to providers remaining opt-in is the potential for incomplete patient ehealth records, with the potential ramifications of an incomplete record greatest for the people for whom the PCEHR would hold the most benefits. Incomplete records would be a particular issue for:

- People with a range of co-morbidities, multiple health care providers (some opting-in, some not) and multiple medications
- people with cognitive impairments that affect capacity to communicate with their provider
- people with psychiatric conditions
- people with drug and/or alcohol-related impairments
- people with poor English.

We are assured that the PCEHR will not replace patient history-taking, but there is bound to be some reliance on the PCEHR record for obtaining a snapshot of the patient's history, especially for short GP consultations – and particularly for people with poor or impaired communication capacity.

- ***Given that providers will remain opt-in under the trial, it is crucial that there is a strong and sustained information campaign targeting providers in trial areas, in the lead-up to and during the trials, to maximise provider engagement.***
- ***We propose that the trial evaluation include an examination of the impact of providers being opt-in while patients are opt-out, in terms of the completeness and integrity of PCEHR records for people with complex health needs.***

AFAO notes that at 3.3.1 “An Opt Out PCEHR system – Individual Consent”, it is stated that prior to the commencement of the trials, individuals in the affected regions will have two months to opt-out. Regarding individuals in these regions who do not opt-out by trial commencement, it states that:

Privacy concerns associated with registration of individuals who don't opt-out, and the uploading of documents to a registered individual's PCEHR, will be addressed by allowing individuals to:

- set access controls to control who can access what information in their PCEHR, including restricting access to their Medicare data and removing documents;

This measure, along with others noted in the Paper, is based on affected consumers knowing that their individual ehealth record already exists, and understanding what that means. This knowledge cannot be assumed; even if a patient is aware of the trial and the existence of their PCEHR record, their ability to understand and set controls or choose to opt-out, depends on the person's health and IT literacy.

The Paper does not detail how individuals in the trial regions will learn of the fact that ehealth records for people in the region have been created. A targeted communication education campaign regarding the trials needs to be developed, to ensure that all people in trial areas are given clear information regarding the trial and how to opt-out.

- ***A community education campaign regarding the trials should be developed, for all trial regions, with targeted materials developed for particular communities and health providers, so as to maximise engagement in the trial and ensure that people may make well-informed decisions whether to remain in or opt out of the trial.***

3.5.4 Penalties for misuse of information

- ***AFAO supports that serious misuses of PCEHR information should be subject to criminal penalties***
- ***AFAO also supports the proposed alignment of penalties for unauthorised disclosure of information under the HI Act and the PCEHR Act, with a graduated framework of penalties proportional to the severity of the breach.***
