

**Personally Controlled Electronic Health Record (PCEHR) System:
Legislation Issues Paper**

SUBMISSION TEMPLATE

Thank you for taking the time to consider the PCEHR System Legislation Issues Paper. We value and appreciate your constructive comments on Australia's PCEHR system, so the department can further refine the design and improve the quality of the information we provide.

Individual responses to submissions will not be provided.

Submissions will be made public and shared with relevant Commonwealth, state and territory government agencies to inform consideration of the PCEHR legislative framework. Submissions that are intended to remain confidential should be clearly marked as such and submitters should be aware that confidential submissions may still be subject to access under Freedom of Information law.

The closing date for comments and submissions is 5 p.m. (Australian Eastern Standard Time), Wednesday, 3 August 2011.

**Mandatory fields*

***Name**

Australian Federation of AIDS Organisations

(First name is mandatory and will be displayed if submission is published.)

***Postcode**

***Indicate the theme(s) of your submission**

Participation	<input checked="" type="checkbox"/>	Security	<input type="checkbox"/>
Access	<input type="checkbox"/>	Governance	<input checked="" type="checkbox"/>
Privacy	<input checked="" type="checkbox"/>	General comments	<input checked="" type="checkbox"/>

***Indicate the stakeholder group(s) you represent**

Member of public	<input type="checkbox"/>	Hospital care	<input type="checkbox"/>
Research and academic	<input type="checkbox"/>	Healthcare providers	<input type="checkbox"/>
General practice	<input type="checkbox"/>	Aged and community care	<input type="checkbox"/>
Peak body representative	<input checked="" type="checkbox"/>	Union and community care	<input type="checkbox"/>
Allied health	<input type="checkbox"/>	Union representative	<input type="checkbox"/>
Indigenous representative	<input type="checkbox"/>	ICT/Software industry	<input type="checkbox"/>
Government	<input type="checkbox"/>	Other	<input type="checkbox"/>

*Do you agree to your submission being published and made public (including on the www.yourhealth.gov.au website)?	X Yes	<input type="checkbox"/> No
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*I agree to the submission terms of use (read terms of use on www.yourhealth.gov.au website).	X Yes
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Your submission/comments:

PCEHR Legislation Issues Feedback
Department of Health and Ageing
GPO Box 9848
Canberra, ACT 2606

Via e-mail: ehealth.legislation@health.gov.au

3 August 2011

Dear Sir or Madam,

Following please find the Australian Federation of AIDS Organisations' (AFAO) submission to the Department of Health and Ageing's Personally Controlled Electronic Health Record System: Legislation Issues Paper.

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 and 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/AIDS issues, and provides HIV policy advice to Commonwealth, State and Territory Governments.

If you wish to discuss this matter, please contact Linda Forbes, Manager, Policy and Communications on 02 8568 1109 or by e-mail at lforbes@afao.org.au

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Rob Lake', with a stylized flourish at the end.

Rob Lake
Executive Director
Australian Federation of AIDS Organisations

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: Legislation Issues Paper ("Legislation Issues Paper").

The Legislation Issues Paper provides some detail about what mechanisms may be available for consumer complaints. However, the paper provides inadequate information regarding governance arrangements. Further, key features of the PCEHR identified in the *Draft Concept of Operations: Relating to the introduction of the personally controlled electronic health record (PCEHR) system* ("Concept of Operations") document, such as access controls, are not discussed in detail in this paper. Providing the framework to enable these features and explaining its structures are essential to establishing consumer confidence.

Governance Framework

As we stated in our submission to NEHTA on the Draft Concept of Operations, it is crucial that a comprehensive governance framework be established well in advance of the start date for use of the PCEHR – 1 July 2012. There must be adequate time for community input and public scrutiny of any governance proposals. It is disappointing to see that the only reference to governance in the Legislation Issues Paper is of a general nature, solely naming high-level principles; strategic, operation and regulatory arrangements.

We are yet to learn:

- who is proposed to be the body responsible for the overall oversight of the system from 1 July 2012. We presume that this may be NEHTA, but this is yet to be made clear;
- of the legislative framework under which the system would operate;
- what expectations/responsibilities such a body will have;
- how such a broadly based body would interact with different participants of the PCEHR system; and
- the nature of the relationship between the PCEHR system and state health complaints bodies, for example the Health Care Complaints Commission in NSW.

AFAO believes that governance arrangements must address the following issues:

- **the need for consumer representation in governance structures.** This could be through a dedicated consumer position in an advisory body and/or on a governing board.

- **regular and transparent accountability measures.** This should include audit and system review at regular intervals. This reporting should be made publicly available, for example through the tabling of reports in Parliament or referral to an appropriate Senate or House of Representatives committee.
- **regular review of data management practices.** A key driver for community/AFAO support for the PCEHR has been the highlighting of its potential to prevent healthcare and record-keeping errors. To ensure that PCEHR realises its full potential, and that it garners and maintains public confidence, establishing a requirement for system-wide regular reviews of data-management practices is essential.

Legislative Privacy Protections

We note that healthcare providers' handling of consumers/individuals health information is and will continue to remain subject to the *Privacy Act 1988* (Cth). As the national privacy legislation, AFAO considers that the *Privacy Act 1988* is the most appropriate legislative regulation for privacy complaints. To this end, we support the proposal to extend coverage of the *Privacy Act 1988* to cover system and portal operators.¹ It is essential that all participants in the PCEHR system be subject to binding privacy requirements. We note the discussion about the lack of privacy legislation in Western Australia (WA) and South Australia (SA).² To ensure that individuals/consumers in those jurisdictions are afforded adequate protection of their information in the PCEHR, public health bodies in WA and SA should be encouraged to opt in to the *Privacy Act 1988*.

In response to question 23, where a repository operator is a state/territory body they should be subject to the *Privacy Act 1988*. A key driver behind current privacy reforms is the harmonisation of privacy laws so that Australians 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 will help create confidence in the system. 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 complaints environment.

Use and Disclosure Provisions/protections

The Legislation Issues paper proposes that secondary use and disclosures already permitted under the *Privacy Act 1988* continue to be allowed to operate in the PCEHR system. It states that those secondary uses and disclosures include³:

- use or disclosure authorised required by or under law (including a subpoena issued by a court, and public health and child welfare reporting obligations in states and territory legislation);
- use or disclosure to prevent or lessen a serious and imminent threat to life and health; and
- use or disclosure for law enforcement purposes.

¹ DoHA (2011). *Personally Controlled Electronic Health Record System: Legislation Issues Paper*. Australian Government, Canberra, 29

² DoHA (2011). *Personally Controlled Electronic Health Record System: Legislation Issues Paper*. Australian Government, Canberra, 30

³ DoHA (2011). *Personally Controlled Electronic Health Record System: Legislation Issues Paper*. Australian Government, Canberra, 31

People living with HIV can be subject to criminal prosecutions relating to sexual transmission of HIV, or exposing sexual partners to HIV. AFAO believes such criminal prosecutions are ineffective in preventing the spread of HIV, that they undermine public health strategies and have a general effect of stigmatising people living with HIV. It is possible to conceive of circumstances in which the authorities/police may be doing background investigation into an allegation of HIV exposure/transmission and may wish to access information in an individual's PCEHR – see the scenario below. Such access would likely be permissible under these provisions. While such use and disclosures are currently permitted under the *Privacy Act 1988*, in the context of a linked electronic record such as the PCEHR, these provisions are of concern. A linked electronic record provides an obvious honeypot of information for easy reference which the equivalent dispersed records currently held by individual healthcare providers do not.

We are concerned that when people living with HIV understand the implications of these provisions, some may choose to avoid the PCEHR system altogether, or even more seriously, may avoid completely important health care. We therefore do not support the proposal allowing for secondary uses and disclosures of personal information in the PCEHR system.

Penalties and other redress for inappropriate handling

We note the penalties provided for under the Healthcare Identifiers Act. We do not believe that these are adequate, with the maximum penalty under section 26 of the Healthcare Identifiers Act being 120 penalty units, currently equivalent to \$13,200, and a maximum of 50 penalty units for other offences – equivalent to \$5500.⁴ To provide a serious deterrent to unauthorised access, the maximum penalty should be significantly higher. Where the circumstances of the offence are less egregious, a lesser penalty would likely be appropriate.

As the *Privacy Act 1988* is currently being reformed it is difficult to comment on the adequacy of future privacy provisions, including the adequacy of penalties for privacy breaches. We support the proposal by the Department of Prime Minister and Cabinet to give a new power for the Privacy Commissioner to seek (through a court) a civil penalty for serious or repeated offences⁵. However, as we understand it, the review of privacy provisions in relating to the powers of the privacy powers of the Australian Information Commissioner has yet to begin.

In the absence of this detail, we would reiterate our view for the need for substantial penalties to apply to individuals and organisations who mishandle consumers' health information. We support the continuation of the current provisions in the current *Privacy Act 1988*, which allows for individuals to be compensated for any loss or damage suffered due to a breach of their privacy, including for emotional/psychological loss or damage.

Complaints path

AFAO welcomes the development of a single entry point for PCEHR privacy complaints, with the proposal for the complaint to be forwarded to the appropriate regulator. However, we note that while this may simplify the process for lodging a complaint, consumers will in fact be entitled to

⁴ DoHA (2011). *Personally Controlled Electronic Health Record System: Legislation Issues Paper*. Australian Government, Canberra, 32

⁵ Office of the Privacy Commissioner (2009), *Privacy Commissioner welcomes response to privacy inquiry 14 October 2009*, Australian Government, available at <http://www.privacy.gov.au/materials/types/media/view/6955>

varying types of redress, depending on which legislation applies. Under the *Privacy Act 1988* for example, a consumer may be entitled to compensation for any loss suffered, while under the privacy arrangements in a particular state they may have no such right. This inconsistency of outcomes is undesirable and potentially confusing to consumers.

As noted above under “Legislation Privacy Protections”, all participants in the PCEHR system should be subject to the same legislative requirements. AFAO would like consumers to be able to access the same redress, regardless of which participant in the PCEHR system is the subject of the complaint, i.e. healthcare providers, repository operator, state health body etc.

As mentioned above in relation to penalties, it is difficult to assess the adequacy of future complaints mechanisms. It is essential that the complaints process is clear and user-friendly, and that appeals against decisions are easy to make and low/no cost. Complaints and appeals processes must also be timely and with the predictable increase in complaints once the PCEHR starts, it is essential that the Office of the Privacy Commissioner be adequately resourced to process complaints. 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.

Scenario:

Max is a gay man who has recently been diagnosed with HIV. A hospital he attends records the diagnosis, and upon discussion with Max, the hospital employee links the record of the HIV diagnosis to Max’s PCEHR. The record also notes that Max believes he has had sex with a number of men since his incident of risk.

After some background investigation, the police approach the PCEHR operator, explaining that they believe that Max may have exposed someone to/transmitted HIV. The police then request access to Max’s PCEHR. They assure the PCEHR operator that this information may be legally passed on due to the use/disclosure provisions that govern handling of PCEHR information.

Significant questions arise about how the PCEHR operator should respond to such a request, including at what level a decision regarding releasing information about an HIV diagnosis should be made. Currently, under public health laws in some jurisdictions, the delegation to act is reserved to the chief health/medical officer. For decisions on such serious matters, the delegation to act should remain at least at this level of authority.

If the proposed secondary uses and disclosures provision are adopted, an approach which may allow people living with HIV to use the PCEHR with confidence may be to encourage them to use the ‘no access’ access control option. This would be contingent on data designated ‘no-access’ not being made available under the above disclosure provisions.

Use of ‘no access’ or any other of the access controls outlined in the Concept of Operations are predicated on these access controls being provided for in the overall framework, presumably

through legislation or regulation. AFAO had expected that such key features would have been addressed in this Legislation Issues Paper. Access controls, along with other key concepts raised in the Concept of Operations, are crucial to creating consumer confidence in the PCEHR. Consumer comment and scrutiny of the regulation providing for this and other important features is essential.

Conclusion

AFAO is pleased that the proposed privacy framework for the PCEHR builds on the current privacy regime, underpinned by the *Privacy Act 1988*. We believe that the optimal approach for dealing with PCEHR privacy complaints is for all complaints to be subject to the same laws and remedies. We thus support extending the coverage of the *Privacy Act 1988* to system and portal operators. We also believe that states where no privacy laws exists, as well as repository operators, should be subject to the *Privacy Act 1988*.

We are concerned that there is scant detail about general governance arrangements other than in relation to privacy complaints. It is crucial that among other key governance issues, the Government/DoHA must address the following: which body is proposed to be responsible for the overall system from 1 July 2011; details of the legislative framework under which this body would operate and how such a body would relate to the various participants in the PCEHR system; and, details of how consumers would be included in the governance structures. It is also essential to detail the mechanisms for review of the PCEHR system, including audit and public reporting, as well as methods for implementing system-wide feedback in relation to data accuracy and security. Further, these details must be provided with plenty of time for scrutiny and public comment, well in advance of the commencement of the PCEHR.

AFAO also has significant concerns about the broad provisions for secondary use and disclosure, particularly the potential for information relating to an individual's HIV status being disclosed in order to pursue criminal prosecutions regarding HIV transmission/exposure. These provisions may cause people living with HIV and people in at-risk communities to avoid the PCEHR system – or avoid accessing the health system altogether. Such a circumstance would be of grave concern to AFAO, as it would also seriously undermine the positive public health response to HIV achieved so far.

The advent of a comprehensive e-health system promises great benefits for individuals and communities affected by HIV, given that people living with HIV (PLHIV) who have complex health conditions are frequent users of the health system, often managing a range of medical conditions along with psycho-social issues, including HIV-related stigma and discrimination. It would be unfortunate if the benefits of the PCEHR system were undermined by inadequate governance arrangements, and by inadequate protections regarding disclosure of sensitive information.
