



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

**Comments on Exposure Draft
Healthcare Identifiers Bill 2009**

7 January 2010

About AFAO

The Australian Federation of AIDS Organisations (AFAO) is the peak body for Australia's community sector response to the HIV/AIDS epidemic. AFAO is charged with representing the views of our members: the AIDS Councils in each state and territory, the National Association of People Living with HIV/AIDS, the Australian Illicit and Injecting Drug Users League, 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/AIDS and its effects, develops and formulates policy on HIV/AIDS issues, and provides HIV policy advice to Commonwealth, state and territory Governments.

AFAO's perspective on this Inquiry

We commend the Government for its commitment to ensuring that e-health initiatives form part of each of the national health Strategies currently under development. AFAO supports e-health reform, not only because of its capacity to improve the quality of healthcare but also because of its potential for improving health monitoring and facilitating medical and social research.

AFAO has had the opportunity to read the submission on the exposure draft of the Bill prepared by the Council of Social Service of NSW (NCOSS) on behalf of the COSS Network. We concur with the points made in the submission and strongly endorse the recommendations made by NCOSS.

In this submission we highlight issues of particular relevance to the Australian HIV response, and outline the privacy concerns faced by people living with HIV. We note the stated commitment of the Commonwealth, state and territory governments to ensuring that the confidentiality and privacy of medical records and personal data is not compromised by e-health reform. AFAO believes that introducing the Healthcare Identifier legislation prior to the harmonisation of Commonwealth and state/territory privacy legislation, and before the construction of a national privacy framework, runs counter to that commitment. This view was strongly argued in many of the submissions made in response to the Health Ministers Advisory Council's discussion paper, *Healthcare identifiers and privacy*, and it is disappointing that these submissions appear not to have been given due consideration.

Ambiguity regarding purpose of the Bill

In addition to the broad concerns raised by NCOSS in its submission regarding the exposure draft, we note that while the draft legislation is certainly primarily concerned with covering the fundamentals of assigning healthcare identifiers to healthcare recipients and providers, and placing limits on disclosure of identifiers to third parties, Part 4 of the Bill, entitled 'Healthcare Provider's use or disclosure' seems to go further than this.

Sub-section 15(1) of the Bill sets out the situations in which a healthcare provider is authorised to use an identifier, or disclose an identifier to an "entity" (defined in section 5 as "a person or an unincorporated body"). Use or disclosure of an identifier

must be,

“ ..., for the purposes of communicating or managing information, as part of:

- a) the provision of healthcare to a healthcare recipient; or
- b) the management, funding, monitoring or evaluation of healthcare; or
- c) the conduct of health or medical research that has been approved by a Human Research Ethics Committee.”

(underlining added.)

Sub-section 15(2) of the Bill would provide that the entity to whom/which the identifier has been disclosed is authorised:

- a) to collect the information; and
- b) to use the information for the purpose to which it was disclosed to the person.”

(underlining added.)

Although this may be a misconstruction, section 15 could be interpreted to mean that a healthcare provider would be authorised to disclose a person’s identifier *and* “information” about them, to researchers (given that the research project has been approved by the Human Research Ethics Committee). This interpretation is contrary to the explanation in the Release Note regarding Part 4 of the Bill, which indicates that Part 4 only provides for disclosure of identifiers, not for disclosure of “health information”.

We are concerned that either the Release Note fails to fully explain section 15 of the Bill, or that section 15 unintentionally covers health or medical ‘information’, when it was intended to cover ‘identifying information’ (as defined in Section 5). We propose that this provision is ambiguous and needs to be clarified, and that when the Bill is introduced, the accompanying Explanatory Memorandum should clearly explain each of the Bill’s provisions.

Privacy and the HIV response

In its submission in 2005 to the Parliamentary Inquiry into Privacy, the Australian Medical Association (AMA) reflected on the need to be mindful of the privacy risks associated with using technology to create readily accessible medical profiles of healthcare recipients, together with their healthcare providers’ clinical notes:

“... new technology permits access to a wide range of information that can contribute to improvements in the delivery of healthcare and health outcomes for patients. The ultimate development of a national electronic health record has the potential to provide the means to share an individual’s health information for the purposes of their health care needs throughout their lifetime. Access to a reliable, historical record of an individual’s encounters with the health system throughout their lifetime can contribute to safety and quality in the delivery of health care, particularly as the patient moves in and out of different parts of the health system.

“However, such systems also provide a source of data on individuals that has never before been available in a form that can be interrogated and linked so easily and so widely. This new environment, while creating the potential for significant positives in improving health care, has at the same time created significant potential risks to the privacy of individual health information and the independence of a medical practitioners’ clinical decision making.

“It is the AMA’s view that the development in information and communications technology has created a significantly greater potential for privacy intrusion through data linking.”¹

AFAO considers that these issues are particularly important for people with HIV and their healthcare providers. Australia’s partnership response to HIV has been highly successful, and this success is substantially attributable to the active engagement of people living with HIV, healthcare providers, community organisations and researchers in consultative processes and policy formulation. Development of effective HIV surveillance and contact tracing policies would not have been possible without community confidence in the Commonwealth’s commitment to developing and maintaining strong privacy principles with regard to HIV status. As a result, measures to protect the confidentiality of HIV/AIDS related information in the possession of an organisation or individual were introduced in Australia early in its response to HIV. Guidelines on the protection of HIV/AIDS related information on individuals were first issued by the Federal Privacy Commissioner in 1992, for use by Commonwealth public sector agencies, and most states and territories have introduced legislation requiring service providers to protect the confidentiality of a person’s HIV positive status.

Where health sector privacy safeguards are perceived to be weak, people at risk of acquiring HIV may be deterred from discussing sexual health issues with health providers, and from presenting for testing. They may therefore fail to be diagnosed or to receive counselling related to behaviour change or referral to treatment. This clearly may have repercussions in terms of broader prevention efforts for HIV and also for other sexually transmitted infections (STIs).

We propose that whatever the timing of the introduction of Healthcare Identifier legislation into Parliament, the Explanatory Memorandum accompanying the Bill should provide detailed modelling of the new system. The modelling should include scenarios to show how the Healthcare Identifier system will inter-relate with Commonwealth and state/territory privacy legislation, including legislation specifically dealing with HIV. As acknowledged in the Government’s response to the ALRC’s Recommendations, this interplay is complex. The HIV surveillance system is a case in point.² Without modelling, it is difficult to envisage how the healthcare identifier system will operate along-side (or together with) HIV surveillance, and the task of explaining privacy protections to people with HIV will be impossible.

Privacy for people living with HIV

The *HIV Futures* studies conducted by the Australian Research Centre in Sex, Health and Society have consistently found that about a third of the people living with HIV

¹ The Australian Medical Association’s submission to the Senate Standing Committee on Legal and Constitutional Affairs’ Inquiry into the Privacy Act 1988, p. 5
http://www.aph.gov.au/SENATE/committee/legcon_ctte/completed_inquiries/2004-07/privacy/submissions/sub09.pdf

² Cases of newly diagnosed HIV infection have been reported nationally since July 1990. In January 1993, to facilitate identification and removal of duplicate diagnoses, report name codes were introduced, consisting of the first two letters of the family name and the first two letters of the given name. Researchers may access surveillance data, subject to approval by the National Blood Borne Viruses and Sexually Transmissible Infections Surveillance Committee. Submissions for access must meet strict requirements, including relevant ethics committee approval, and access requirements differ according to data sought. Upon approval, requested data is only provided from states/territories that have approved release. Data released does not contain individuals’ name codes and dates of birth, except when this information is required for studies that involve record linkage (e.g. linkage of National Death Index data with NCHECR data), and then data including name codes and dates of birth are only provided to the organisation conducting the linkage (i.e., not directly to the researchers).

surveyed had experienced discrimination from health care services. Confidentiality of patient information has been among the most common problems reported.³

People with HIV are intensive users of the healthcare system and have much to gain from the introduction of e-health identifiers and electronic storage of health records, especially in terms of ensuring that treating health professionals are fully aware of co-morbidities and treatment histories. However, people living with HIV also have reason to fear such initiatives, given the potential to expand access to comprehensive health records indicating their HIV positive status - both within and beyond the healthcare system.

People living with HIV may be deterred from regularly attending treatment services if they are concerned about privacy breaches. HIV treatments require regular prescription and clinical monitoring. There may be serious health consequences for a person living with HIV who fails to attend for regular health monitoring tests that assess the effectiveness of drug combinations, treating co-morbidities and managing side-effects of medications.

Another area of sensitivity is attendance at sexual health services. Fears about privacy breaches are likely to be exacerbated by the introduction of electronic record keeping and sharing. It is of course in the interests of public health that people at risk of STIs, particularly sexually active youth, be encouraged to attend such services for confidential testing and treatment. Young people may be deterred from accessing sexual health services, however, if they fear that their sexual health histories will be made electronically available to other providers (for example their family's local GP), or that members of their family may be able to gain access to summary Pharmaceutical Benefit and/or Medicare records. Similar considerations apply to young people who may be discouraged from consulting a health service in relation to drug use, for fear that their health records may be accessed by third parties.

The nature of the Australian HIV epidemic has evolved considerably since the 1980's, particularly with the advent of Highly Active Anti-Retroviral Therapy (HAART). While transmission of HIV has been largely contained to homosexually active men, there is considerable cultural, social and economic diversity among people living with HIV, and within Australian populations at high risk of acquiring HIV. As acknowledged in the various National HIV/AIDS Strategies, this clinical diversity and complexity needs to be accommodated in effective programmatic responses to HIV, including those which would potentially utilise e-health data for developing education, prevention and treatment strategies.

Issues for healthcare providers

The Release Note accompanying the exposure draft emphasises that passage of the Bill would result in no changes to the storage of information and health records regarding individuals, nor to the release, transfer and sharing of such information between healthcare providers, government health policy analysts and researchers. This may be so, but establishing the identifier system is essential to the implementation of the whole of the national e-health strategies, which will ultimately mean that more health information is stored electronically, by identifier number. As

³ J Grierson, R Thorpe, and M Pitts (2006). *HIV Futures 5: Life as we know it*, monograph series no. 60, The Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Australia, p. 68 <http://www.latrobe.edu.au/hiv-futures/HIV%20Futures%205%20Report.pdf>

outlined in the National E-Health Transition Authority's explanatory materials⁴, this will ultimately facilitate the collation and efficient exchange of accurate and complete health information.

Some of those who have most to fear from their doctor compiling an actual or imagined medical profile are the people whose interests will be particularly well served by e-health. This group includes people with limited or no capacity to provide new doctors or hospitals with information regarding past and present medical and psychiatric conditions, treatments, medications and care histories. This may be due to the cognitive issues themselves, and/or because of deliberate concealment because of a rational or irrational desire to keep this information private.

Obtaining informed consent from people with such conditions and disabilities will be challenging. Some of the people who now seek to be selective in disclosing health conditions and treatments to individual doctors and other health practitioners do so to protect their privacy and avoid the stigmatisation that mental illness and cognitive disability can attract.

A person living with HIV may quite rationally be of the view that the fact that they are HIV positive they are a sex worker, or that they are being treated for depression is none of their physiotherapist's business, and none of the business of a doctor engaged by Centrelink to assess their work capacity. Similarly, an injecting drug user with hepatitis C may only wish to disclose their drug use to particular healthcare providers.

Healthcare providers will inevitably be called upon to try to persuade people with such privacy concerns of the usefulness of the e-health identifier, and to explain the role of the identifier in e-health initiatives. Healthcare providers will have a particular responsibility to explain the initiative very carefully to patients who are mentally ill (or have had a mental illness in the past), and to people with dementia, and people with an acquired brain injury, or who have any condition affecting cognition or intellectual capacity, in order to obtain informed consent to opt in to the system. If issuing a Healthcare Identifier means that their physiotherapist or a doctor contracted by Centrelink is no more likely to be privy to the fact that they live with HIV or hepatitis C, or that they have been treated for a mental illness, or that they have been an injecting drug user, this needs to be clearly stated. If it is the case (as would appear to be so) that such providers will ultimately be able to access the full range of their health information once further e-health initiatives are firmly in place, this also needs to be made clear.⁵

Legislation premature

AFAO is concerned that establishing the identifier system prior to initiating legislative and inter-governmental regulatory reforms developed in response to recommendations made by the Australian Law Reform Commission (ALRC)^{6,7}, is premature. We propose that the

⁴ e.g., National E-Health Transition Authority press release (regarding COAG's decision to accelerate NEHTA initiatives), *Cornerstones of e-health given the green light*, 10 February 2006

⁵ Australian Law Reform Commission. *For Your Information: Australian Privacy Law and Practice*. ALRC 108 (Final Report). <http://www.austlii.edu.au/au/other/alrc/publications/reports/108/>

⁶ Australian Law Reform Commission. *For Your Information: Australian Privacy Law and Practice*. ALRC 108 (Final Report). <http://www.austlii.edu.au/au/other/alrc/publications/reports/108/>

identifier legislation should be introduced after the proposed amendments to the Privacy Act 1988, not before. AFAO strongly believes that e-health reforms should be rolled out in such a way that people living with HIV, healthcare providers, and the community sector organisations involved in HIV health promotion, prevention, and policy development, can be assured that rights to privacy and confidentiality are preserved (or enhanced) by e-health initiatives. In the absence of that assurance, the successful implementation of e-health initiatives that would potentially be of great benefit in responding to HIV would be undermined. As argued by the Public Interest Advocacy Centre (PIAC) in its response to the Health Ministers Advisory Council's discussion paper, *Healthcare identifiers and privacy*, e-health strategy implementation should be deferred until a new comprehensive national privacy framework is in place, with appropriate governance systems. AFAO agrees with PIAC that,

“... although ... there are strong arguments that a national e-health system will improve patient safety, there are stronger arguments that unless there is consumer confidence in the system, then patient safety will not be strengthened but threatened. If consumers are not confident in the confidentiality and security aspects of any e-health regime, they will not participate, or worse, not disclose vital information or simply not tell the truth to protect their privacy.”⁸

Recommendations

AFAO recommends:

- that the introduction of Healthcare Identifiers Bill into Parliament be deferred, and that it not be introduced until amendments to the Privacy Act 1988 have been introduced and a new privacy framework is in place;
- that the Explanatory Memoranda accompanying the Healthcare Identifiers Bill and the legislation amending the Privacy Act 1988 be comprehensive, and that they include detailed modelling and scenarios illustrating the operation of privacy protections for people with sensitive health information, such as information regarding mental illness or HIV;
- that information products regarding the Commonwealth's e-health initiatives be developed for healthcare providers and community organisations, which targets people with significant privacy issues and/or issues affecting consent, for example, people with HIV, people with mental illness, and people with intellectual disability or acquired brain injury;
- that the Bill be amended in the light of concerns raised in the NCOS submission; and that
- sub-section 15(1) of the exposure draft of the Bill be re-drafted so as to remove any ambiguity.

⁷ Australian Government First Stage Response to the Australian Law Reform Commission Report 108 *For Your Information: Australian Privacy Law and Practice*. October 2009

⁸ Public Interest Advocacy Centre (PIAC), submission in response to the discussion paper, *Healthcare identifiers and privacy* [http://www.health.gov.au/internet/main/publishing.nsf/Content/eHealth-017/\\$FILE/017_Public%20Interest%20Advocacy%20Centre_13-08-09.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/eHealth-017/$FILE/017_Public%20Interest%20Advocacy%20Centre_13-08-09.pdf)