



Australian Federation of AIDS Organisations (AFAO)

*The adequacy of protections for the privacy of
Australians online*

**Submission to
Senate Standing Committee on Environment,
Communications and the Arts**

1 October 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 Australian Government for initiating this Inquiry. AFAO's concerns regarding the Inquiry's Terms of Reference cut across all its Terms of Reference, but specifically relate to:

- the storage, sharing and transfer of information held by government agencies regarding individuals' HIV status, particularly in the light of the government's e-health initiatives;
- emerging privacy issues regarding the use of social networking sites by government and community agencies, where individuals using those sites have disclosed their HIV-positive status.

AFAO has had the opportunity to read the submission to the Inquiry prepared by the Office of the Privacy Commissioner. The submission provides an excellent overview of the complexity of the issues involved. We concur with the points made in the submission, especially regarding the need for principle-based privacy protection legislation, and its proposals regarding de-identification of personal information. .

AFAO seeks to highlight issues of particular relevance to the Australian HIV response, and outline the privacy concerns faced by people living with HIV. Given our perspective, below we discuss term of reference(c) first, followed by (a).

Term of reference (c): data collection activities of government agencies

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

These issues are particularly important for people with HIV. 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-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-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 - including those relating to information collated and disseminated via the internet - 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 the government’s roll out of e-health initiatives needs to take into account detailed modelling of the proposed new system, with modelling to test the efficacy of proposed privacy protections for people with particular privacy issues, such as people living with HIV.

The modelling should include scenarios to show how the new 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

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).

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 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 around information stored and transmitted via the internet. 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 – with further complexities arising from the imminent structural reform of the health system. It is of course in the interests of public health that people at risk of HIV, particularly sexually active gay men and members of the priority populations identified in the *Sixth National HIV Strategy*, be encouraged to attend such services for confidential testing and treatment. 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, or that members of their family may be able to gain access to summary Pharmaceutical Benefit and/or Medicare records. Such considerations would apply to 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 Antiretroviral 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 National HIV Strategies implemented over the years, 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.

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%20%20Report.pdf>

Issues for healthcare providers

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.⁴

Term of reference (a): privacy protections and data collection on social networking sites

Use of social networking sites by government agencies and the community sector for consultations, research, community development and education is new but progressing rapidly. Recent controversy regarding privacy issues for Facebook users point to the plethora of issues for government agencies and non-government community agencies utilising such sites. Use of these sites by organisations such as

⁴ 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/>

AFAO and its member organisations represents a case in point, it being inevitable that information regarding users' HIV-status will be disclosed or inferred.

It is crucial that clear guidelines be developed to ensure that organisations understand their obligations regarding users' privacy rights, and that users' privacy rights are respected and protected. In terms of intentional and non-intentional gathering of information that a person would wish not to be stored or divulged to third parties, clear opt-in rules regarding site use and strong, enforceable restrictions on storage, sharing and transfer of information must be developed especially in respect of information that is subject to *particular* privacy protections, such as a person's HIV status.⁵

Privacy protections should include requirements that government and community organisations must have privacy/confidentiality policies in place for utilising social networking sites, including ethical codes of conduct.⁶

Recommendations

AFAO recommends:

- that information products regarding the Commonwealth's e-health initiatives be developed for healthcare providers and community organisations, which target 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 privacy protections should include requirements that Government and community organisations must have in place privacy/confidentiality policies, including ethical codes of conduct, regarding use of social media;
- that community organisation funding arrangements require the development of social media policies and guidelines to ensure that organisations understand their obligations regarding users' privacy rights, and that users' privacy rights are respected and protected; and
- that in terms of intentional and non-intentional gathering of information that a person would wish not to be stored or divulged to third parties, clear opt-in rules regarding site use and strong, enforceable restrictions on storage, sharing and transfer of information must be developed - especially in respect

⁵ Concerns around lack of transparent privacy controls available on social networking sites have already prompted development of one alternative. Diaspora promotes itself as: 'The privacy aware, personally controlled, do-it-all, open source social network.' <http://www.joindiaspora.com/> While still in early implementation phase, this and similar sites could offer viable alternatives in the future.

⁶ For examples of currently operating social media policies, see:

a) Telstra's *3Rs of Social Media Engagement*, which the company has made available for reuse online at: <http://www.telstra.com.au/abouttelstra/download/document/social-media-company-policy-final-150409.pdf?red=/at/m/d/smcpf150409pdf>

b) The Powerhouse Museum's communications policy for the operation of publicly accessed web-logs ('blogs') implemented in 2007 and available at: http://www.powerhousemuseum.com/dmsblog/wp-content/powerhouse_museum_blog_policy_2007.pdf

of information that is subject to specific privacy protections, such as a person's HIV status.
