
**Submission to the Senate Community Affairs
Reference Committee on the *My Health
Records Amendment (Strengthening Privacy)
Bill 2018***

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Australian Federation of AIDS Organisations

The Australian Federation of AIDS Organisations (AFAO) is the national federation for the HIV community response in Australia. AFAO works to end HIV transmission and reduce its impact on communities in Australia, Asia and the Pacific. 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 (ANA); and Scarlet Alliance, Australian Sex Workers Association. AFAO's affiliate member organisations – spanning community, research, public health and clinical workforce – share AFAO's values and support the work we do.

Introduction

The Australian Federation of AIDS Organisations (AFAO) welcomes the opportunity to provide a submission to the Senate Community Affairs Reference Committee on the *My Health Records Amendment (Strengthening Privacy) Bill 2018* (“the Bill”). Our submission:

- highlights the benefits of My Health Record
- reviews amendments to the privacy and security settings regarding third party access by law enforcement and government agencies to personal records and default privacy settings
- makes recommendations for amendments to the Bill.

AFAO’s network of 29 member and affiliate member organisations represent a diverse range of constituents and communities across Australia. This includes LGBTI communities, people with HIV, sex workers, people who use drugs, Aboriginal and Torres Strait Islander communities, and culturally and linguistically diverse communities. Some of these communities are subject to criminalisation and all experience stigma and discrimination in access to healthcare.

AFAO notes that health issues are socially embedded and some health information is particularly sensitive. By sensitive, we mean that it is given by consumers to healthcare professionals with trust, sometimes courage, and that consumers rightly expect the information to be handled with respect and care. It is also generally provided in the confines of private discussion between a consumer and their trusted healthcare provider. My Health Record transfers this sensitive information to a much larger audience. Health issues such as HIV and sexually transmitted infections (STIs) are also sensitive because of continuing stigma in healthcare settings and the wider community.

We welcome the amendments proposed in the Bill but note continuing unease among our members and affiliates and within communities regarding the profound expansion of access to health information that My Health Record entails. These concerns are sufficient that some members and affiliates are recommending to their communities that individuals opt out or recommending to the Inquiry that My Health Record once again be made an opt in system.

We propose a number of recommendations to further strengthen the Act, provide information to consumers and build community confidence in My Health Record.

Key points

AFAO supports changes in the Bill that require:

- an order from a magistrate or judge before disclosing health information in a My Health Record to law enforcement agencies on grounds of suspected unlawful activity by an individual with a My Health Record
- the My Health Record system to note any use or disclosure arising from an order from a magistrate or judge (section 69A(4))
- My Health Record to permanently destroy any health information on My Health Record, if an individual has made a cancellation request (sections 17(3) and (4)).

Recommendations

AFAO recommends that:

- disclosure of personal records under section 64 of the Act on the grounds that disclosure “is necessary to lessen or prevent a serious threat to an individual’s life, health or safety..., [or to] public health or public safety” be amended to prohibit a My Health Record System Operator from disclosing an individual’s personal health records without an order from a magistrate or judge
- section 15(h) of the Act be amended to mandate a minimum proportion of records to be audited for inappropriate access in a given period to build consumer confidence in My Health Record and deter misuse

- amendments proposed by the Bill requiring an order from a magistrate or judge before disclosing health information in a My Health Record be restricted to law enforcement agencies and exclude other government agencies.
- when a My Health Record is created, all security and privacy controls be activated. Individuals should be provided with a temporary pin number, via text message or email, which prompts the individual to set a permanent pin code, review their privacy settings and self-determine the information they wish to share with relevant healthcare providers or nominated representatives
- when a record is created, an individual's default setting for sharing data for research and other secondary purposes should be set to 'do not participate' with a prompt for the individual to change this to 'participate' at a later date, if they wish
- the Australian Digital Health Agency (ADHA) resource a national program to support the community to understand My Health Record and utilise privacy settings and that particular emphasis be provided in public education to individuals and communities that experience reduced access to health care, poorer health literacy and greater risks or complexity in considering their participation in the My Health Record.

My Health Record: Policy Context

Australia now has the technology and know-how to reduce HIV transmission to low levels and support people with HIV to live long and healthy lives. The capacity for information to be shared across healthcare providers will enable a more integrated and comprehensive response to people's healthcare needs, avoid unnecessary costs associated with duplication and improve individuals' safety at the point of care.

In relation to HIV, My Health Record can improve the quality of service delivery across the primary, secondary and tertiary healthcare continuum allowing for rapid and more informed healthcare decision making. For individuals and communities at increased risk of HIV, My Health Record will provide healthcare workers with increased information to initiate conversations about prevention and testing for HIV and STIs.

To achieve these outcomes, our communities need to be confident that they can control their records through privacy and security settings to reduce the risk of unintended disclosure of health information. This includes sensitive information relating to risk factors and history of HIV and STI testing, diagnosis and treatment.

Issues

Privacy and security: Disclosure of health information

Section 70 of the *My Health Record Act 2012* ("the Act") authorises the My Health Record System Operator to disclose an individual's My Health Record to an enforcement body for certain enforcement related activities. This allows for the disclosure of sensitive information between the My Health Record System Operator and law enforcement agencies without judicial oversight, such as a court order or subpoena.

Court orders and subpoena mechanisms support an individual's privacy by ensuring judicial oversight of the disclosure process. This approach protects individuals from unreasonable or unnecessary disclosures based on outdated, inaccurate and uninformed understandings of HIV. In effect, this prevents an original decision maker making an arbitrary and unreviewed decision to disclose sensitive information that might have long-term implications for the individual concerned. Fear of unintended disclosure of health records could encourage individuals to opt out of My Health Record and compromise the anticipated benefits of this reform.

AFAO supports changes in the Bill that require:

- an order from a magistrate or judge before disclosing health information in a My Health Record to law enforcement agencies on grounds of suspected unlawful activity by an individual with a My Health Record
- the My Health Record system to note any use or disclosure arising from an order from a magistrate or judge (section 69A(4)).

AFAO notes however that the Bill does not provide equivalent protections in circumstances where a “serious threat to an individual’s life, health or safety..., [or to] public health or public safety” is perceived. This language is vague and open to considerable interpretation, particularly in relation to HIV, where outdated beliefs about the transmissibility and impact of HIV persist.

AFAO also notes that the amendments proposed by the Bill will allow government agencies in addition to law enforcement to access personal records held in the My Health Record through an order from a magistrate or judge. AFAO considers information shared by consumers with health professionals in the context of healthcare to be a highly protected category of information. A strong public interest exists in protecting to the greatest possible extent the confidentiality, safety and appropriate use of information shared by consumers in the healthcare context. AFAO does not support health-related information being accessible by non-health agencies such as the Australian Tax Office or Department of Home Affairs.

Recommendations

- Disclosure of personal records under section 64 of the Act on the grounds that disclosure “is necessary to lessen or prevent a serious threat to an individual’s life, health or safety..., [or to] public health or public safety” be amended to prohibit a My Health Record System Operator from disclosing an individual’s personal health records without an order from a magistrate or judge.
- Section 15(h) of the Act be amended to mandate a minimum proportion of records to be audited for inappropriate access in a given period to build consumer confidence in My Health Record and deter misuse
- Amendments proposed by the Bill requiring an order from a magistrate or judge before disclosing health information in a My Health Record be restricted to law enforcement agencies and exclude other government agencies.

Permanently Deleting My Health Record

Under the Act a person can cancel their My Health Record registration. In the event of a cancellation, section 17 of the Act requires the My Health Record System Operator to retain health information for 30 years after the individual dies, or if the date of death is unknown, 130 years after the individual’s date of birth. For communities subject to criminalisation, stigma and discrimination, including people with and at risk of HIV, this provision could increase concern around confidential medical information being used for prosecution or discrimination purposes at a later date.

AFAO supports subsection 17(3) and (4) of the Bill which require the My Health Record System Operator to permanently destroy any health information on My Health Record if an individual makes a cancellation request.

Default Privacy Settings

When a record is created, the default privacy settings on a My Health Record is set to ‘open’. It is then up to individuals to limit access to how health information should be shared. This situation potentially exposes a person living with HIV to unnecessary or unwanted disclosure of HIV status.

To restrict the access settings, individuals need to understand the content of each document in their record (which will often include complex information). Individuals also need to make an assessment of how sensitive the information is and decide who they want, or need, to share it with.

In the case of people with HIV, My Health Record is likely to host a considerable number of documents for each individual. Those individuals without sufficient time to learn the system and log on and assess large numbers of health documents, will be unable to utilise My Health Record’s privacy features to protect unintended disclosure of their HIV status.

Recommendations

- When a My Health Record is created, all security and privacy controls should be activated. Individuals should be provided with a temporary pin number, via text message or email, which prompts the individual to establish a permanent pin code, review

their privacy settings and self-determine the information they wish to share with relevant healthcare providers or nominated representatives.

- When a record is created, an individual's default setting for sharing data for research and other secondary purposes should be set to 'do not participate' with a prompt for the individual to change this to 'participate' at a later date, if they wish.

My Health Record: A public Information program support roll-out

My Health Record has the potential to have a transformative effect on the provision of healthcare in Australia. To capitalise on this opportunity there is a need to ensure that individuals can make informed decisions about their participation in My Health Record. This includes supporting our communities to understand privacy and security, and to have the technical knowledge to activate access controls over their record.

Recommendation

- The ADHA resource a national program to support the community to understand My Health Record and utilise privacy settings and that particular emphasis be provided in public education to individuals and communities that experience reduced access to health care, poorer health literacy and greater risks or complexity in considering their participation in the My Health Record.