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

The AIDS Action Council of the ACT (the Council) welcomes the opportunity to respond to the call for submissions Senate Community Affairs Reference Committee on the My Health Records Amendment (Strengthening Privacy) Bill 2018 (“the Bill”)

The Council was formed in 1983 and incorporated in 1986 as part of the community response to the impact of the HIV/AIDS in Australia. Today, we are Canberra’s leading community-based organisation for people living with HIV/AIDS, sex workers and sex and gender diverse people. We provide a range of services to our communities, including counselling, support, information and advocacy. As a leading community based organisation within the ACT we are well placed to make the following comments to the Senate Community Affairs Reference Committee on the Bill.

My Health Record has the potential to support increased health outcomes for many Australians and be transformative in the way that individuals interact with health care providers. To allow this potential to be realised, individuals need to have the capacity and understanding of the control that they have to access their records, but to do this they must have basic computer skills and be willing to engage and understand privacy and security settings, and to have the technical knowledge to activate access controls over their records.

In the case of people living with HIV or other Chronic and complex conditions the records will likely hold a considerable amount of information and the ability of most individuals to fully understand the inbuilt privacy settings and apply them in such a way that their privacy is protected will lead to unintended disclosure of HIV or other Chronic and complex conditions to unintended parties.

Recommendation around Default Privacy Settings for individuals

- That a national program is resourced by the Australian Digital Health Agency to ensure that the community, in particular to those communities and individuals who have poorer health outcomes due to reduced access to health care, understand the control and the ability to utilise privacy settings in considering their participation in the My Health Record.
- That the default setting for when a record is created 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.
- 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.

Further issues that we would like to comment on are:

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. An unreviewed decision to disclose sensitive information that might have long-term implications for the individual that may not be evident to the decision maker at the time of making the decision. 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.

Recommendation

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

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.

Recommendation

- 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.

Permanently Deleting My Health Record

The Council 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.

This would ensure that communities subject to criminalisation, stigma and discrimination, including people with, and at risk of, HIV, can have their confidentially maintained. Without it, this provision could increase concern around confidential medical information being used for prosecution or discrimination purposes at a later date.

The Council is a member of the Australian Federation of AIDS Organisations (AFAO). AFAO has also made a submission to this process which the Council endorses.

Yours sincerely

Philippa Moss
Executive Director

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