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Committee Secretary
Senate Standing Committees on Community Affairs
Parliament House
Canberra ACT 2600

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

The National LGBTI Health Alliance welcomes the opportunity to provide a submission to the Senate Community Affairs Reference Committee providing feedback on the *My Health Records Amendment (Strengthening Privacy) Bill 2018*. Our submission:

- highlights the benefits of the My Health Record system
- 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
- outlines key recommendations for amendments to the Bill

About the National LGBTI Health Alliance

The National LGBTI Health Alliance (the Alliance) is the national peak health organisation in Australia for organisations and individuals that provide health-related programs, services and research focused on lesbian, gay, bisexual, transgender, and intersex people (LGBTI) and other sexuality, gender, and bodily diverse people and communities. We recognise that people's genders, bodies, relationships, and sexualities affect their health and wellbeing in every domain of their life.

Intended benefits of My Health Record System

The Alliance recognises the inherent benefits of moving towards a digitised health system. There are clear advantages to consolidating all of one's health information in one place. It ensures doctors, specialists or hospital staff have access to all the appropriate health information to provide the best possible treatment and care. Additionally, a digitised health system will enable people to access their health information online without having to visit a healthcare provider. As a result, a digitised health system has the potential to increase health literacy among individuals and enable them to be more

active in making decisions relating to their treatment and care, and support self-management of ongoing health needs.

The Alliance understands that My Health Record, the digitised health system that has been introduced by the Government will also be able to over time enable patients to organise their medication and prescriptions repeats online and have them sent to their local pharmacist without the extra time or cost of attending a medical appointment. Therefore, My Health Record will improve coordination of care for people with chronic and complex physical and mental health conditions, and who are highly mobile for example, fly-in/flyout workers. It also has the potential to reduce hospital admissions and save money by reducing the duplication of tests, and help prevent harmful drug interactions.

Key Points

The Alliance welcomes and supports the following changes in the Bill that are responding to the concerns that have been raised by many:

- removing the ability of the My Health Record System Operator to disclose health information in My Health Records to law enforcement agencies and government agencies on grounds of suspected unlawful activity without an order from a magistrate or judge
- the insertion of 69A(4) in the Bill, which requires the System Operator to make a written note of any use or disclosure of personal health information arising from an order from a magistrate or judge
- the addition of subsection 17(3) and (4), which requires the destruction of health records after an individual has made a cancellation request

Recommendations

In addition to supporting the recommendations, the Alliance would like to make the following recommendations:

- section 64 of the Act be amended to prohibit the System Operator from disclosing an individual's personal health records without judicial oversight in the event that it "is necessary to lessen or prevent a serious threat to an individual's life, health or safety..., [or to] public health or public safety"
- all security and privacy controls be activated, when a My Health Record is created. Individuals should be provided with a temporary PIN, via text message or email, which prompts the individual to set a permanent pin code, review their privacy settings and self-determine the health information they wish to disclose to health practitioners
- when a My Health 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 an option allowing the individual to change this to 'participate' at a later date

- the Australian Digital Health Agency (ADHA) fund a public education campaign to support the community to understand My Health Record including system security and privacy safeguards. A particular emphasis be provided in public education to marginalised communities, people that experience reduced access to health care and poorer health literacy. The Alliance has expertise in developing and delivering LGBTI awareness training and initiatives, particularly within the aged care and mental health and suicide prevention sectors. Therefore, we are well positioned in taking a broader role in educating LGBTI communities in relation to My Health Record
- health care practitioners including doctors and clinicians be adequately trained in the diverse health issues affecting LGBTI people

The Alliance would like to thank the Senate Committee for the opportunity to provide feedback on the *My Health Records Amendment (Strengthening Privacy) Bill 2018*. If you require any further information, please do not hesitate to contact myself [REDACTED], or the Policy and Research team on policyandresearch@lgbtihealth.org.au, to discuss this submission further.

Yours Sincerely,

Nicky Bath

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EXECUTIVE DIRECTOR
NATIONAL LGBTI HEALTH ALLIANCE