



AASW

.....
**Australian Association
of Social Workers**

***Submission to Senate Community
Affairs Legislation Committee's Inquiry
into My Health Records Amendment
(Strengthening Privacy) Bill 2018***

September 2018

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Introduction

Who we are

The Australian Association of Social Workers (AASW) is the professional body representing more than 11,000 social workers throughout Australia. We set the benchmark for professional education and practice in social work, and advocate on matters of human rights, social inclusion, and discrimination.

The social work profession

Social work is a tertiary-qualified profession recognised nationally and internationally that supports individuals, families, groups and communities to improve their wellbeing. Principles of social justice, human rights, collective responsibility and respect for diversity are central to the profession and are underpinned by theories of social work, social sciences, humanities and Indigenous knowledges. Social workers consider the relationship between biological, psychological, social and cultural factors and how they impact on a person's health and development. Accordingly, social workers maintain a dual focus in both assisting with and improving human wellbeing and identifying and addressing any external issues (known as systemic or structural issues) that may have a negative impact, such as inequality, injustice and discrimination.

Our submission

Social work has been integral to health services since the profession's inception. A social worker's role in the health field is to enhance the person's social and emotional functioning through holistic assessments, targeted interventions and the mobilisation of services and supports. Social workers intervene in the context of a person's social environments and relationships, recognising the impact of the socioeconomic, cultural, psychological and political determinants on health and overall wellbeing.

Within the health sector, social workers operate in a number of roles across the continuum of support: early intervention services, hospitals, and services that interface with hospitals. Added to this are more than 2,000 Accredited Mental Health Social Workers who work in private practice and provide mental health therapies and supports through Better Access. In these diverse roles, Social workers will encounter My Health Record in three capacities:

- They will need to refer to material that is contained in the health records of their clients.
- They will also have a role in assisting clients to understand material that is in their record and to consider the differential levels of privacy and security that they should set for those documents.
- They have valuable insights to contribute to the health record of the people they are working with.

The AASW welcomes the My Health Records Amendment (Strengthening Privacy) Bill 2018 changes as an important measure towards assuring the confidentiality of Australians. While we welcome the changes, our submission raises key concerns and recommendations in relation to:

- The current timeframes for opt-out not being appropriate and should be extended, including a greater focus on public education for disenfranchised, vulnerable and alienated groups.
- Greater consideration needs to be given to victims and survivors of family violence, including safeguards to assure that the record is not used to further perpetuate abuse.
- Greater consultation and public awareness campaigns on how My Health Record affects the privacy of young people and 'mature minors'.
- Further research and consultation into how My Health Record may contribute to stigma and discrimination toward people living with HIV (PLHIV), sex workers, and people who use drugs (PWUD)/ people who inject drugs (PWID), and other disenfranchised/alienated groups

Response

The AASW supports the proposed amendments outlined in this Bill. Namely, that:

- The ability of the My Health Record System Operator to disclose health information in My Health Records to law enforcement agencies and government agencies without an order by a judicial officer or the healthcare recipient's consent will be removed; and
- The System Operator will be required to permanently delete health information stored in the National Repositories Service for a person if they have cancelled their registration with the My Health Record system – that is, they have cancelled their My Health Record.

The introduction of a centralised My Health Record system will be advantageous to some groups, and the AASW welcomes the additional safeguards afforded by the Strengthening Privacy amendments to the disenfranchised populations our members work alongside. However, we are not confident that these measures extend far enough for all people, and have continued concerns about a model which assumes consent, rather than gathering free and informed consent (as evidenced by the opt-out rather than opt-in standard).

Additionally, the AASW believes that not enough resources have been allocated to the provision of accessible, timely and tailored information to allow distinct groups to understand how the creation of a centralised health record will affect them and their privacy. As stated in our submission to the Senate Community Affairs References Committee's Inquiry into My Health Record, we do not believe that the opt-out period set has been long enough to allow people to make an informed decision about the creation of a personalised health record.

The AASW contends that the implementation of this model undermines best practice standards which value principles of informed consent, privacy and confidentiality, and self-determination. We recognise that where these principles are not promoted, the health and safety of people is compromised, and that this ultimately leads to unequal health outcomes.

Issues that require further attention

Based on the feedback of our members, we have significant concerns about how the implementation of the My Health Record system – even with the proposed privacy amendments – could negatively affect already disadvantaged groups. In our submission, we will discuss concerns for the privacy, safety, and/or rights of the following groups:

- The safety of people experiencing family violence
- Young people and 'mature minors'
- People who use drugs (PWUD)/ people who inject drugs (PWID), sex workers, people living HIV (PLHIV).
- Disenfranchised, vulnerable and alienated groups

a) The safety of people experiencing family violence

Social workers who are on the frontline of service provision have continuously raised significant concerns in relation to how the electronic My Health Record system poses unique challenges for victim/survivors of family violence. The current model – even with the proposed Strengthening Privacy amendments – underestimates the actions of perpetrators, who have the capacity to create and access a My Health Record on behalf of a child, without the knowledge of the child's other guardian/victim

survivor. By accessing a child's account, perpetrators can ascertain details of medical appointments attended, including their locations.

This places the safety of victim/survivors at great risk.

As Chief Executive of Women's Legal Service, Angela Lynch¹, notes, the only legal means of preventing such an occurrence is to apply for a Family Court order, which would grant sole parental responsibility to the victim/survivor. For many people experiencing family violence, this is simply not feasible, or appropriate.

Recommendation: The AASW strongly recommends that much greater consideration needs to be given to victims and survivors of family violence, including safeguards to assure that the record is not used to further perpetuate abuse.

b) The privacy of young people and 'mature minors'

The AASW supports the concerns of the Australian Association for Adolescent Health (AAAH)², which highlights the right to privacy of young people, and their right to quality healthcare outcomes. Although the My Health Record provides opportunities in this regard, it does not go far enough. As young people aged 14 years and above can change default settings to remove parent/guardian access as the authorised representative of the record, we agree, a system where those aged 14 to 17 years are automatically asked for consent, rather than the current model of assumed consent, is preferred.³

Of fundamental importance is educating all organisations providing training to current and future health professionals to ensure the right to confidential health care for young people is maintained.⁴ The AASW recommends increasing the understanding and literacy of health services about My Health Record privacy considerations for young people. In particular, how to avoid breaches to privacy for young people and how to provide better information about rights and responsibilities.

Recommendation: Increase awareness of young people about their rights - provide training to health professionals about having these conversations with young people.

c) Stigma and discrimination toward people who use drugs (PWUD)/ people who inject drugs (PWID), sex workers, and people living with HIV (PLHIV),

As Positive Life NSW⁵ explains, PLHIV, sex workers, and PWUD/PWID are heavily stigmatised groups which often experience discrimination, including in healthcare settings. Because of this, these groups are discerning about the disclosure of blood borne virus status, sex work status, drug use, sexual identity and risk behaviours. Because of this, the introduction of a centralised health record, which assumes consent, and has a notably short opt-out period, challenges the privacy, self-determination, and possibly even the health outcomes of these groups in particular ways.

My Health Record has capacity to undermine self-determination by enabling disclosure to individuals within the My Health Record system without the direct authorisation of the service user, including, for example, to medical centre reception staff. My Health Record may exacerbate stigma and discrimination in healthcare settings (particularly of sex workers) which may deter health service engagement, retention in care and discourage testing and treatment.

¹ (McCauley 2018)

² (Australian Association for Adolescent Health Ltd 2018)

³ Ibid

⁴ Ibid

⁵ (Positive Life NSW 2018)

d) Disenfranchised, vulnerable and alienated groups

As stated previously, the AASW believes that the opt out period needs to be extended and furthermore as the previous points highlight, there is an urgent need for a more targeted education campaign about the advantages and disadvantages of my health record for people with complex health and social circumstances.

The campaign, including material and content, needs to focus on providing appropriate information to possibly isolated and vulnerable groups based on their needs, this includes but is not limited to:

- People with mental health challenges
- People with disabilities
- Aboriginal and Torres Strait Islander peoples.
- People experiencing homelessness
- Newly arrived migrant and people from refugee backgrounds
- Trans and gender diverse people
- People with technological limitations
- People involved in the criminal justice system

Recommendation: The government engage in consultation to develop and implement targeted public education campaigns for disenfranchised, vulnerable and alienated groups.

Conclusion

For the whole of the social work profession's history, managing access to information and control over it have been integral to social work practice. In their commitment to self-determination, social workers ensure that individuals within the health care system can make informed decisions concerning their health and wellbeing. The implementation of My Health Record needs to be carefully managed to ensure that it does not inadvertently entrench current inequalities in health outcomes. The AASW believes that social workers have a key role to play in this area and we look forward to contributing to the successful implementation of My Health Record. We welcome the opportunity to further discuss any of the points raised in this submission.

Submitted for and on behalf of the Australian Association of Social Workers Ltd



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Australian Association for Adolescent Health Ltd 2018, *My health record and young people's rights to confidentiality*, Australian Association for Adolescent Health Ltd., viewed 11 Sept, <http://www.aaah.org.au/data/Position_Statements/AAAH_Position_Statement-MyHealth_Record_20July_2018.pdf>.

McCauley, D 2018, 'My health record a new battleground in family disputes', *Sydney Morning Herald*, 31 July 2018, <<https://www.smh.com.au/politics/federal/my-health-record-a-new-battleground-in-family-disputes-20180731-p4zunr.html>>.

Positive Life NSW, SWOP 2018, *My Health Record - briefing paper*, viewed 11 September <<http://www.positivelife.org.au/images/PDF/2018/MyHealthRecord-PLNSW-SWOP-2018.pdf>>.