



14 September 2018

Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600
By email: community.affairs.sen@aph.gov.au

Dear Committee Secretary,

My Health Records Amendment (Strengthening Privacy) Bill 2018

1. Women's Legal Service NSW (WLS NSW) thanks the Senate Community Affairs Legislation Committee for the opportunity to comment on the My Health Records Amendment (Strengthening Privacy) Bill 2018.
2. WLS NSW is a community legal centre that aims to achieve access to justice and a just legal system for women in NSW. We seek to promote women's human rights, redress inequalities experienced by women and to foster legal and social change through strategic legal services, community development, community legal education and law and policy reform work. We prioritise women who are disadvantaged by their cultural, social and economic circumstances. We provide specialist legal services relating to domestic and family violence, sexual assault, family law, discrimination, victims support, care and protection, human rights and access to justice.
3. In summary, WLS NSW opposes an opt out option in the My Health Records system. It is of vital importance that people are aware of what is involved with My Health Records and that they make an informed decision about whether or not this is appropriate for them. We also continue to have reservations about an alternative of opting in as we feel safety concerns and privacy concerns are still not adequately addressed.
4. This submission will focus on the following aspects of concern in relation to My Health Records:
 - 4.1 Safety concerns, including the possible tracking of domestic violence victims-survivors through the adult or children's records;
 - 4.2 Given the nature of an online system, there is no guarantee information is dependably safeguarded;
 - 4.3 The deletion of personal information from databases is a difficult process;
 - 4.4 Consumer fears about privacy could lead to the reduction in disclosure of medical issues to health care professionals.
5. This submission highlights that the introduction of My Health Records could have serious ramifications on the grounds of safety, privacy and security possibly leading to poor outcomes for the most vulnerable, including women and children.



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Children's records and other means as a tool to track domestic violence victims

6. WLS NSW is concerned that My Health Records can be used to track the location of medical practitioners and pharmacies visited by the child with their primary caregiver, possibly narrowing down the locations of victims in hiding. This places victims of domestic violence at risk.
7. In our experience, many violent relationships also have controlling behaviours. Thus it is likely that a perpetrator of domestic violence will have access to *My Gov* and other passwords and control of accounts. In this situation, access to My Health records by the perpetrator may constitute a risk of further harm to the victim.
8. Consequently, victims of domestic violence are at risk of abuse in the form perpetrators controlling login details.

No guarantee health records are secured

9. WLS NSW is concerned with the extent to which health care records and information could be protected under My Health Records.¹ There are instances which highlight the Government's inability to secure data. This is apparent in the case where the Department of Human Services used personal data seemingly for political reasons, providing private Centrelink information to a journalist.²
10. As outlined by Ben Grubb, up to 900,000 health professionals will be granted access to an individual's health records and there is no guarantee that the security of their computers will be up-to-date.³

¹ See, for example, Katharine Kemp, Bruce Baer Arnold and David Vaile, My Health Record still isn't safe enough to proceed. It needs more than a band-aid fix', *ABC News*, 1 August 2018 at: <http://www.abc.net.au/news/2018-08-02/my-health-record-still-not-safe/10063026>

² Henry Belot, 'Privacy Commissioner 'making inquiries' after Centrelink leaked personal information to journalist', *ABC News*, 28 February 2017 at: <http://www.abc.net.au/news/2017-02-28/watchdog-inquiries-after-centrelink-leaked-personal-information/8310034>

³ Ben Grubb, 'Why I'm opting out of the government's digital health record and you should too', *SMH*, 16 July 2018 at: <https://www.smh.com.au/technology/why-i-m-opting-out-of-the-government-s-digital-health-record-and-you-should-too-20180715-p4zrna.html>

The deletion of personal information in My Health Records presents many difficulties

11. WLS NSW acknowledges that the legislation provides for a mechanism to permanently delete records from the My Health Records system. Whilst, this may sound promising, the deletion of records is a complex problem. The My Health Record database is designed for retention not deletion. Consequently, even if data is deleted from the database, there is a possibility that it may still be present in the backup 'snapshots'.⁴ Some of these backups may be retained for extended periods and accessible to a small group of IT administrators.⁵ This radically weakens the effectiveness of the mechanism afforded in the legislation to delete health records, consequently putting private health information at risk of exposure.

Privacy concerns could lead to a reduction in disclosure of medical issues to health care professionals

12. Consumer fears about privacy and security may lead to members of the community disclosing less about their health-related issues.
13. This may particularly be an issue for those who are marginalised, including Aboriginal or Torres Strait Islander people, mental health consumers, sex workers, drug users, or people living with HIV.

If you would like to discuss any aspect of this submission, please contact me or Liz Snell, Law Reform and Policy Coordinator on 02 8745 6900.

Yours faithfully,

Women's Legal Service NSW

Helen Campbell
Executive Officer

⁴ Robert Merkel, 'My Health Record: Deleting personal information from databases is harder than it sounds', *The Conversation* (online), 3 August 2018 at <https://theconversation.com/my-health-record-deleting-personal-information-from-databases-is-harder-than-it-sounds-100962>

⁵ Ibid.