

Hon Greg Hunt MP
Minister for Health
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House of Representatives
Parliament House
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3rd August 2018

Call to Suspend My Health Record Roll Out

Dear Minister Hunt,

We, the undersigned organisations, are deeply concerned about serious risks that My Health Record pose to a range of constituencies and that have not been satisfactorily responded to by the Australian Digital Health Agency.

Our attached policy brief highlights the poor design of My Health Record for a range of Australians who have particular privacy and safety concerns. Those at greatest risk of serious harm from My Health Record's current implementation approach include:

- People who cannot access the online system to manage their privacy due to technological literacy barriers, costs of internet and poor internet coverage in rural and remote regions;
- Young people between the ages of 14 and 18 whose health record information will be available to their parents/guardians by default unless they take immediate action to safeguard their privacy. For those of diverse sexuality and/or gender or from an environment with stigma around mental health care, this parental access poses serious risk of abuse and harm;
- People with mental illness who risk having the privacy of their mental health diagnosis breached, with increased stigma, discrimination and reduced life expectancy due to diagnostic overshadowing;
- The misuse of My Health Record by abusers to control and harm people in situations of domestic and family violence, including young people and seniors who are particularly vulnerable to abuse; and
- The misuse of My Health Record by abusers to control or harm people in situations of institutional violence and abuse, including people with disabilities in residential care, people under guardianship and administration, young people in foster care, youth in detention, and people in psychiatric hospitals;

These risks are exacerbated by:

- Lack of clear capacity tests to protect people's right to control their My Health Record;
- Powers granted to third party individuals, such as family members, to take control of a person's records where a person has permitted them access;
- Contradictory (dual) management options of My Health Record by young people under 18 and their parents/guardians;

- Default settings permitting unrestricted, broad and non-selective provider access to all personal health records;
- A provider-biased system in which documents can be uploaded without a person's knowledge or consent, and can be downloaded and retained by providers without a person's knowledge or consent once used for emergency purposes;
- An emergency access system that enables a person's record to be made available to any registered provider, not just emergency or medical personnel;
- Powers of the individual's self-appointed representative to override the individual's control of My Health Record;
- Powers of health professionals under the My Health Record system to share sensitive information in contradiction to the Australian Privacy Principles;
- Misleading communications by ADHA in which the benefits, not the risks, of My Health Record, are communicated;
- The absence of robust awareness raising and education initiatives on the realities and impacts of My Health Record, including a lack of targeted information for populations at increased risk of harm. This includes young people under 18 years of age, people with mental health issues, Aboriginal and Torres Strait community members, people with experience of alcohol and other drug harm, older Australians, members of culturally and linguistically diverse communities, and members of the LGBTQI+ community.
- Potential conflicts of interest through ADHA funding of the OAIC, as the 'independent' investigatory body for ADHA issues;
- Extensive powers of the ADHA to disclose information to other government agencies without individual knowledge or consent.

From these issues there is a real and serious risk of harm if My Health Record continues with its current design and approach to implementation. The safety of individuals who could be affected by My Health Record's current design cannot and must not be ignored to realise other benefits of this system.

We urgently call on you to exercise your powers as Minister for Health to address the sweeping and significant risks of harms from privacy breach of My Health Record by committing to Suspension of the national roll out until the following strategies have been fully implemented.

Urgent My Health Record System Changes

1. Implement strategies to ensure people who do not access or effectively use the internet can gain access and manage their My Health Record.
2. Ensure people who do not have control of their My Health Record are aware of who will be controlling their My Health Record and how they could gain control of their own My Health Record.
3. Set default settings of the My Health Record scheme to restrict access so that consumers must permit access prior to information being uploaded and shared by providers.

Urgent Protective Measures to Safeguard Choice and Control and Prevent Data Misuse

4. Commit funding for the provision of transparent and effective community-wide information to enable all Australians to have informed choice and control of their My Health Record before they are forced to decide whether to opt out.
5. Commission an urgent independent review to identify, address and report on privacy, choice and control and conflict of interest issues associated with national rollout. This process must be accessible for community members to report complaints, include thorough consultation with a diverse range of community groups and organisations, consider legal reforms to the My Health Record Act 2012 and report its findings and recommendations to Parliament.

It is essential to the future success of the My Health Record system that the balance is achieved between the rights and interests of consumers, and the rights and interests of health providers and the Commonwealth government. This can only be achieved by suspending roll out until these additional consumer rights protections have been adopted.

Sincerely,

CoMHWA



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