



Australian Council of Social Service

14 September 2018

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

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To whom it may concern,

Re: My Health Records Amendment (Strengthening Privacy) Bill 2018

The Australian Council of Social Service (ACOSS) is a national advocate for action to reduce poverty and inequality and the peak body for the community services sector in Australia. Our vision is for a fair, inclusive and sustainable Australia where all individuals and communities can participate in and benefit from social and economic life.

The My Health Records Amendment (Strengthening Privacy) Bill 2018 (the Bill) will amend the *My Health Records Act 2012* to:

- remove 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; and
- require the System Operator to permanently delete health information stored in the National Repositories Service for a person if they have cancelled their My Health Record.

ACOSS supports these changes to the Act as an important first step, and a significant improvement. That said, there are important privacy concerns that the Department, and the Australian Digital Health Agency have yet to grapple with. In particular, ACOSS is concerned about the potential for My Health Record information to be used for non-health related purposes, including court proceedings eg family law, criminal prosecutions and other forms of litigation. These concerns are heightened in the context of the system being an "opt out" system, rather than the current "opt in approach".

ACOSS was concerned that the My Health Record legislation permitted the System Operator (The Australian Digital Health Agency) "... to 'use or disclose health information' contained in an individual's My Health Record if they 'reasonably believe that the use or disclosure is reasonably necessary' to, among other things, prevent, detect, investigate or prosecute any criminal offence, breaches of a law imposing a penalty or sanction or breaches of a prescribed law; protect the public revenue; or prevent, detect, investigate or remedy 'seriously improper conduct'." This provision could have resulted in the release of My Health Record data to government agencies in a range of circumstances unrelated to a person's health, including social security, tax and the criminal justice system without consent or a judicial order.

The changes proposed to the Act ensure that My Health Record information can only be used for certain enforcement-related activities by an order of a judicial officer. In making such an order the



judicial officer is required to be satisfied that the disclosure of the information would not unreasonably interfere with the privacy of the individual.

ACOSS remains concerned about the potential for My Health Record information to be used for non-health related purposes. While the protection of requiring a judicial order to access the information is an important first step in protecting patients from inappropriate access to their confidential health information, there is still a risk that this information is released from a My Health Record for reasons that are completely unrelated to the delivery of healthcare, and doesn't address the design of the system that invites interest from third parties. These reasons include court proceedings (such as family law proceedings), criminal prosecutions or other litigation. The Committee should be particularly seek expert evidence on the legal, privacy and technical issues associated with ensuring that the system does not enable greater access by third parties to a person's health record than would otherwise be the case.

ACOSS supports the changes to the Act to require the System Operator to permanently delete health information stored in the National Repositories Service for a person if they have cancelled their My Health Record. The ability to permanently delete a My Health Record provides health consumers with an important control over their health information. ACOSS recommends that the right to permanently delete your My Health Record should be notified to a person when that record is created.

ACOSS believes that My Health Record has the potential to deliver better coordinated care and allow people more control over their health information. These changes to the legislation will improve the system, and better protect the privacy of health consumers.

That said, ACOSS notes that some of our members remain concerned about the privacy protections of the My Health Record system for the people that they work for and with. ACOSS recommends that the Department of Health and the Australian Digital Health Agency continue to work with representatives of health consumers to ensure that the architecture of the system protects the rights and interests of all health consumers.

ACOSS has received financial support from the Australian Digital Health Agency to assist with communication to the community sector about the introduction of My Health Records and we will continue to provide the community with accurate information about implementation while continuing to engage in dialogue with Government to ensure appropriate legislative and policy frameworks are in place.

We would be happy to provide the Committee with further information upon request.

Yours sincerely,

Dr. Cassandra Goldie, ACOSS CEO