Phone – 02 9517 2577
Fax – 02 9517 2488
Post – PO Box 854,
Newtown NSW 2042
Street – Suite 203, 1 Erskineville Road, Newtown NSW 2042
Email – info@scarletalliance.org.au
Web – www.scarletalliance.org.au

Australian Sex Workers Association

29 August 2018

To: Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

Thank you for the opportunity to comment on the Senate Community Affairs Reference Committee inquiry on the My Health Records.

Scarlet Alliance is the Australian Sex Workers Association. Through our objectives, policies and programs, Scarlet Alliance aims to achieve equality, social, legal, political, cultural and economic justice for past and present workers in the sex industry. Formed in 1989, Scarlet Alliance is the national peak body representing a membership of individual sex workers, and sex worker networks, groups, projects and organisations from around Australia.

Scarlet Alliance is a leader when it comes to advocating for the health, safety and welfare of workers in Australia's sex industry. Our member organisations and projects have the highest level of contact with sex workers in Australia of any agency, government or non-government. Through our projects and the work of our membership we have a high level of access to sex industry workplaces throughout Australia. Scarlet Alliance represents sex workers on a number of committees and Ministerial advisory mechanisms.

Please find our submission attached. If you have any questions relating to our submission please do not hesitate to contact, CEO Jules Kim

Regards,

Jules Kim

Recommendations

Scarlet Alliance welcome the changes proposed in the My Health Records Amendment (Strengthening Privacy) Bill 2018. However these changes do not go far enough in ensuring the community privacy concerns about MHR are addressed. We recommend that further measures are implemented to fully address these issues and enable actual informed consent in relation to the creation, collection and use of MHR.

1. Ideally My Health Records should return to an opt-in system. The promotion around MHR and of the opt-out system has been extremely limited. By changing to an opt out system, it will necessitate Australian Digital Health Agency (ADHA) to actively promote and justify the benefits of MHR. At a minimum, ADHA should resource an education campaign to assist communities to understand and effectively utilise MHR. This must be done in partnership with communities that require greater consideration of the risks to their participation of MHR, such as sex workers who are subject to inconsistent laws around sex work which vary state by state, including legislative barriers around their health and experience pervasive stigma and discrimination, including in healthcare.

2. Privacy controls in MHR should be set by default to the highest privacy and security settings and the healthcare recipient can adjust and reduce those privacy controls and grant access to specified healthcare providers. When a MHR is created, the MHR settings are by default, set on the lowest privacy settings for the widest sharing of the healthcare recipient's information. Although the healthcare recipient can restrict who can view their information, changing the privacy settings requires an understanding of how the system works, understanding the content of each document uploaded into the MHR system which may include complex scientific and medical information, making an assessment of the 'sensitivity' of the information, and who the healthcare recipient wants to share that information with. For those who have chronic or complex needs, there will likely be a lot of medical documentation that will require the healthcare recipient to assess whether they want that information uploaded, 'deactivated' and/or shared. There is a risk that sex workers with time constraints or limited IT skills will be unable to effectively operate the privacy controls and their information will be unnecessarily shared without their consent, undermining their right to privacy. Making MHR accounts by default in the highest restrictive privacy settings will ensure sex workers are able to actively consent to what information is uploaded and shared amongst selected healthcare providers.

3. The healthcare recipient should be notified each time their data will be used for a secondary purpose, be informed of how the information will be used and agree to participate. As with any research project outside of MHR, informed consent must be obtained in order to collect information. Healthcare recipients must be informed about how their information will be used and for what purpose and provide consent to participate in the research. Scarlet Alliance asserts that the healthcare recipient should have the opportunity to opt-out of secondary use while still having a record that can be used for primary purposes. At a minimum, MHR holders must, on each occasion, be informed on and actively provide consent for their data to be used for secondary purposes as well as being provided with

comprehensive information on the risks of re-identification when sharing their data for secondary purposes.

4. In addition to the destruction of records following a cancellation request, healthcare recipients should have the ability to permanently delete individual records without the necessity of cancelling their registration in order to do so. Provisions in the bill must allow for the destruction of documents and records after they have been uploaded to MHR upon request by the healthcare recipient and irrespective of whether they are opting to retain a MHR. Currently the bill proposes in the new subsections 17(3) and (4) that the System Operator permanently destroy any record uploaded to the National Repositories Service, which includes health information that is included in a healthcare recipient's My Health Record, ***if that healthcare recipient has requested that the System Operator cancel their My Health Record.*** While the ability to permanently destroy records on request is a very welcome change, these subsections should apply to individual records, even if the recipient is not cancelling their MHR.

5. Scarlet Alliance supports the changes in the new sections 69A and 69B of the bill that requires no My Health Record information be released to law enforcement agencies or government bodies without a court order. Further we support the requirements in 69A(9) that the order must identify the healthcare recipient, specify the information sought and for what purpose, and specify a date for when the order is to cease having effect. These, rightly, mirror requirements for a court order by a judge or magistrate in order for law enforcement or government agencies to access medical records held outside of MHR.

6. However in cases where there is a warrant, subpoena, or court order requiring the doctor to produce a patient's medical record, some doctors may wish to oppose disclosure of clinically sensitive or potentially harmful information. The records are still supplied but under seal, but the court is asked not to release the records to the parties until it has heard argument against disclosure. Additionally in the context of psychiatric or counselling records, the mental health professional may object to the court order, and a court may find that the disclosure of confidentially obtained records in court may have significant adverse consequences for the person concerned and for the therapeutic relationship. Courts may decide that the risk of harm to persons named in the records, and the risk of harm to the public interest by breaching the confidentiality of psychiatric or counselling records may outweigh the potential value of the information to the legal proceedings.

   A doctor, social worker, counsellor or therapist (or anyone who provides confidential professional services to clients) may claim professional confidential relationship privilege and request the Judge or Magistrate to protect documents or evidence in any court case. The Judge has discretion to maintain confidentiality if the harms of disclosure outweigh the desirability of the evidence being given. Otherwise, the requested information will be disclosed and treated like any other document. A number of the states have provisions to protect information communicated confidentially to a clinician by a victim of a sexual offence.

The MHR has no such protections and information is being provided by the "Systems Operator" and not a healthcare provider, who has understanding of the sensitivity of the materials being sought, has professional confidentiality obligations and a relationship to the healthcare recipient to who the information relates. There is no requirement to notify the healthcare provider in order to access the information from MHR. This removes the additional protections afforded by the requirement, outside of MHR, for a court order to require the healthcare provider to handover their patient records. Scarlet Alliance recommends that the court order for health records must be made to the healthcare provider and not through the System Operator of MHR.

7. Scarlet Alliance supports the changing of section 70 from "Disclosure for law enforcement purposes, etc." to "Disclosure in relation to unlawful conduct". This removes the ability of disclosure for the purposes of prevention, detection, investigation by an enforcement body and replaces this with disclosure of this information in relation to unlawful activity and with the requirement of an order from a magistrate or judge. However there should be no circumstances when MHR are accessible without active consent by the healthcare recipient or their nominated representative or the presence of an order by a magistrate or judge. We recommend the additional requirement for court order in relation to disclosure and use of MHR as permitted in section 64 of the *My Health Records Act 2012.*

Sex workers in Australia have maintained world renowned low rates of BBV and STI. This is largely attributed Australia's long-standing partnership approach with sex workers in which sex workers are actively engaged with the public health response in delivering exceptional health outcomes for the community at large. Scarlet Alliance strongly believes that these recommendations are a necessary requirement for sex workers to be able to benefit from and access My Health Records.