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September 11th, 2018

Submission to:
**The Senate Community Affairs Reference Committee on the
My Health Records Amendment (Strengthening Privacy) Bill 2018**

Letter of Support – Hepatitis Queensland

Brief introduction of Hepatitis Queensland

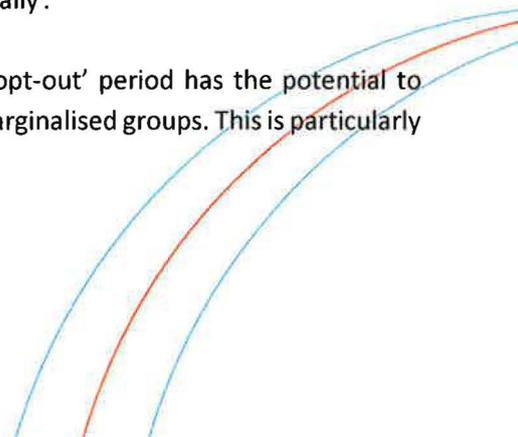
Hepatitis Queensland (HQ) is a not for profit community-based organisation whose mission is to provide a holistic, innovative and pro-active response to the challenges confronting those affected directly and indirectly by viral hepatitis and liver disease. Liver cancer is the fastest increasing cause of cancer death in Australia, and overall the sixth most common cause of cancer death. Chronic hepatitis B and C and non-alcoholic fatty liver disease (NAFLD) cause 80% of liver cancers globally and 90% of all cases of liver disease. At HQ we deliver projects that drive change in our communities, advocate for awareness and reduce stigma and discrimination, create powerful, engaging digital content and health resources and empower and educate the health workforce. The HQ team are encouraged to adopt a think outside the box mentality and embrace a partnership approach in developing broad reaching initiatives that address emerging issues, concerns or provide positive support for viral hepatitis and liver health.

Statement of Support

The Australian Government and all jurisdictions have developed and adopted National Strategies to support the treatment and management of patients living with, or at risk of, viral hepatitis. The suite of strategies encompasses viral hepatitis, HIV, sexually transmissible infections (STI) and Aboriginal and Torres Strait Islander health.

In the development of these strategies, ***stigma and discrimination*** were identified as leading causes for missed diagnoses of viral hepatitis and for the failure of people living with viral hepatitis to engage with the health system and seek timely care. Additionally, a large proportion of the affected cohort experience difficulties with health literacy or literacy in general and whilst the My Health Record is intended to assist these people there are published research studies that assert significant concerns with usability related elements of the My Health Record which create barriers to its effectiveness as identified in similar initiatives internationally¹.

Further, a failure to provide adequate information and support during the 'opt-out' period has the potential to negatively impact affected populations removing choice in some of our most marginalised groups. This is particularly





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so within our remote Aboriginal and Torres Strait Islander communities who currently report limited to no awareness or support despite the 'opt-out' period nearing closure.

Under the Human Rights Act of 2004 everyone has the right to *not have his or her privacy, family, home or correspondence interfered with unlawfully or arbitrarily*. The absence of informed consent or understanding in the management of personal health information could be seen as an arbitrary removal of privacy. It is for these reasons that Hepatitis Queensland offers its full support to the submission by Hepatitis Australia which recommends the continuation of the 'opt-in' model.

Hepatitis Queensland also supports the recommendation for additional enhancements to improve the My Health Record's suitability for our communities of interest. Specifically, Hepatitis Queensland supports the review of section 64 (2) and section 70 of the My Health Records Act 2012. Section 64 is intended to cover responses to a critical incident where the health care recipient may be unable to provide consent and where timely response may be of critical importance to patient survival. In these instances, access to patient history is essential in the provision of effective treatment and/or response. However, section 64 (2) – where the Act references a "perceived" threat to public health/safety would not require a time critical response and Hepatitis Queensland supports an amendment to section 64(2) and section 70 which would prohibit a My Health Records Systems Operator disclosing an individual's personal health records without an order by a judicial officer or the healthcare recipient's consent.

Yours sincerely

Michelle Kudell
Chief Executive Officer
Hepatitis Queensland

ⁱ Walsh L, Hemsley B, Allan M, et al. The E-health Literacy Demands of Australia's My Health Record: A Heuristic Evaluation of Usability. *Perspectives in Health Information Management*. 2017;14(Fall):1f.

