



Submission to:

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

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Submitted by: Hepatitis Australia Inc.

Hepatitis Australia, incorporated in 1997, is the peak community organisation to progress national action on issues of importance to people affected by hepatitis B and hepatitis C. Our mission is to provide leadership and advocacy on viral hepatitis and support partnerships for action to ensure the needs of Australians affected by, or at risk of viral hepatitis, are met. Our members consist of the eight state and territory hepatitis organisations.

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Introduction

Hepatitis Australia welcomes the opportunity to lodge this submission with the Senate Community Affairs Reference Committee addressing the *My Health Records Amendment (Strengthening Privacy) Bill 2018*, in response to the Inquiry's terms of reference:

- a. the expected benefits of the My Health Record system;
- b. the decision to shift from opt-in to opt-out;
- c. privacy and security, including concerns regarding:
 - i. the vulnerability of the system to unauthorised access,
 - ii. the arrangements for third party access by law enforcement, government agencies, researchers and commercial interests, and
 - iii. arrangements to exclude third party access arrangements to include any other party, including health or life insurers;
- d. the Government's administration of the My Health Record system roll-out, including:
 - i. the public information campaign, and
 - ii. the prevalence of 'informed consent' amongst users;
- e. measures that are necessary to address community privacy concerns in the My Health Record system;
- f. how My Health Record compares to alternative systems of digitising health records internationally; and
- g. any other matters.

Our communities of interest include families and individuals living with hepatitis B and hepatitis C in Australia (totaling over 400,000 people) and many more at risk or otherwise affected. Hepatitis B and hepatitis C -affected populations are heterogeneous and, whilst containing many highly vulnerable people, are often perceived as only affecting those most marginalised and disadvantaged. These highly stigmatised conditions are often assumed to associate from injecting drug use, poor hygiene, homelessness, and/or imprisonment. Health care settings are the most commonly reported context for hepatitis C discrimination¹. Accordingly, privacy and confidentiality are crucial considerations for the wellbeing of people affected by hepatitis B and hepatitis C.

In their everyday engagement with communities of interest, the state and territory member organisations of Hepatitis Australia exchange information with people about a range of relevant matters including My Health Record. People are generally reporting low levels of knowledge and awareness of My Health Record (including in relation to 'opt-out' processes and deadlines), and have expressed concerns about the potential for privacy breaches or third party use of personal health information; difficulty managing or deleting their own health record (for reasons including system complexity, computer literacy, or simply not having access to a computer, a smart phone or the Internet); and disapproval about the lack of informed consent inherent in an 'opt-out' system.

Summary of key points and recommendations

The implementation of My Health Record on an 'opt-out' basis is not supported by Hepatitis Australia and its members based on the current information available to us and the needs of our communities of interest. An 'opt-in' system would be supported and in this submission, in consultation with its members, Hepatitis Australia has identified a number of other ways to

¹ http://www.antidiscrimination.justice.nsw.gov.au/Documents/hepc_report.pdf

enhance the system and improve its suitability for our communities of interest. These include ensuring access to information on the benefits and risks, securing formalised informed consent prior to creation of an individual health record, strengthening legal provisions preventing release of information without consent or judicial review, and creating each health record with security and privacy settings defaulting to the most protective options.

Expected benefits of the My Health Record system

Hepatitis Australia recognises that the My Health Record system has great potential to improve access to and the quality of health care across a range of primary, secondary and tertiary health care settings. With access to appropriate information and support, My Health Record could help improve the health of and consumer experience for people affected by hepatitis B and hepatitis C. However, whilst concerns endure about informed consent and privacy, people affected by highly stigmatised chronic conditions may paradoxically have both the most to gain and the most to lose.

The decision to shift from opt-in to opt-out

Hepatitis Australia asserts in the strongest terms that the My Health Record system should be implemented on an 'opt-in' basis.

'Informed consent' is a core principle in the provision of health care in Australia and underpins the Australian Charter of Healthcare Rights. Informed consent incorporates ethical considerations (e.g. the right to personal autonomy and free agency), legal considerations (including a protected right to consent to or refuse health care) and practical considerations (such as the processes through which health care providers inform consumers about options, risks and benefits, and through which consumers are subsequently supported to make the best possible decisions). Viewed through a lens of informed consent, the My Health Record system implemented on an 'opt-out' basis raises ethical and practical concerns in particular for vulnerable and marginalised populations.

An 'opt-out' system assumes a level of access, engagement and understanding that may not be present or possible in vulnerable and marginalised populations. 'Opt-out' assumes competency, choice, and consent where any or all of those things may be absent. For example, some 14% of Australian homes lack Internet access (23% in remote areas)². In addition, only 41% of Australians aged 15–74 possess "health literacy above the minimum level regarded as necessary for understanding and using information relating to health issues"³. In custodial settings (where hepatitis C prevalence is estimated to be 22% across Australian prisons⁴) prisoners have little or no capacity to opt-out or to control their health record.

Implementing the My Health Record system on an 'opt-in' basis would help ensure people are making an informed choice about joining the system, and at a time when they feel comfortable to do so (e.g. satisfied that concerns about privacy have been resolved).

² <http://www.abs.gov.au/ausstats/abs@.nsf/mf/8146.0>

³ <https://www.aihw.gov.au/reports/australias-health/australias-health-2018/contents/indicators-of-australias-health/health-literacy>

⁴ https://kirby.unsw.edu.au/sites/default/files/kirby/report/JHP_National-Prison-Entrants-Report-2004-2007-2010-2013.pdf

Privacy and security

Hepatitis Australia supports changes in the Bill 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 System for a person if they have cancelled their registration with the My Health Record system – that is, they have cancelled their My Health Record.

Hepatitis Australia is aware of concerns circulating about the 'break glass provisions' (Subdivision B – Collection, use and disclosure other than in accordance with access controls), specifically:

- Disclosure of personal records under section 64 (2) of the *My Health Records Act 2012* on the grounds that disclosure "is necessary to lessen or prevent a serious threat to an individual's life, health or safety ... [or] public health or public safety".
- Disclosure of personal records under section 70 for law enforcement purposes.

Hepatitis Australia notes that the *My Health Records Amendment (Strengthening Privacy) Bill 2018 Explanatory Memorandum* states "on 31 July 2018 the Minister for Health announced his intention to strengthen the MHR Act to make clear that information will not be released without a court order". As the *My Health Records Amendment (Strengthening Privacy) Bill 2018* does not appear to (a) address concerns about disclosure under section 64 (2) or section 70, or (b) capture the full extent of the Health Minister's 31 July 2018 stated commitment, Hepatitis Australia recommends sections 64 (s) and 70 be amended to prohibit the 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.

Currently, as a record is created, the default privacy settings are 'open'. People who perceive a need for more protective settings, assuming they have the necessary computer skills and access to do so, are then able to adjust relevant settings to restrict access. These arrangements risk unintentional or unwanted disclosure of potentially highly sensitive health information. A NSW Anti-Discrimination Board enquiry⁵ found that health care settings were the most commonly reported context for hepatitis C discrimination and called for greater protection of individuals' hepatitis C status within the health system, recommending limiting the sharing of hepatitis C status amongst health professionals. For people living with hepatitis B or hepatitis C, unnecessary and unintentional disclosure has the potential to impact on the quality of health care they receive and the associated stigma can negatively impact efforts to increase treatment uptake⁶. For these reasons the Guiding Principles Underpinning Australia's Response to Blood Borne Viruses and Sexually Transmissible Infections states that "People with BBV and STI have ... the right to the confidential and sensitive handling of personal and medical information"⁷

As such, there does not need to be a data breach for unintentional or unwanted disclosure to occur and to result in harmful consequences for people affected by highly stigmatised conditions. Instead of the current default settings, as each health record is created all security and privacy settings should be activated with defaults to the most protective options. This should include a default to 'do not participate' for sharing data for research and other secondary purposes.

⁵ http://www.antidiscrimination.justice.nsw.gov.au/Documents/hepc_report.pdf

⁶ <https://csr.h.arts.unsw.edu.au/research/publications/reports-trends-in-behavior/>

⁷ <http://www.health.gov.au/internet/main/publishing.nsf/content/ohp-bbvs-hepb>

The Government's administration of the My Health Record system roll-out

There has been an insufficient level of communication to the general public about the system, its benefits and risks, and deadlines for opting out. This may result in large numbers of people having a My Health Record created for them without their consent. This is a particular risk for the most vulnerable communities (including people who are homeless, have mental health conditions, have low English literacy, poor health literacy) and others who may require more intense support to make appropriate decisions relevant to personal circumstances.

Hepatitis Australia recommends that national communication activities be expanded and better targeted to support the broadest possible awareness and understanding of My Health Record, including the benefits and risks and use of privacy settings, and that all deadlines related to the My Health Record are put on hold until such time that all current concerns have been satisfactorily addressed.