

PositiveLifeNSW
the voice of people with HIV since 1988

napwha national association of
people with HIV australia

**Submission to the Senate Standing Community
Affairs Reference Committee on *My Health Record***

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Contact

Craig Cooper
Chief Executive Officer
Suite 5.2, Level 5
414 Elizabeth Street
Sydney NSW 2000

W: positivelife.org.au

Positive Life NSW - (Positive Life) is the state-wide peer based non-profit organisation that speaks for and on behalf of people living with and affected by HIV (PLHIV) in NSW. We provide leadership and advocacy in advancing the human rights and quality of life of all PLHIV, and to change systems and practices that discriminate against PLHIV, our friends, family and carers in NSW.

Aaron Cogle
Executive Director
Suite G5/1 Erskineville Road
Newtown, NSW, 2042

W: napwha.org.au

National Association for People with HIV Australia - (NAPWHA) is Australia's peak non-government organisation representing community-based groups of PLHIV. We provide advocacy, policy, health promotion, effective representation, and outreach on a national level, and work includes a range of health and education initiatives that promote the highest quality standard of care for HIV-positive people.

Introduction

Positive Life NSW (Positive Life) and NAWPHA welcomes the opportunity to provide feedback on the My Health Record (MHR) System during referral of the matter to the Senate Standing Committee on Community Affairs. This submission is in two parts:

- **Part 1** addresses questions posed by the Senate Community Affairs Reference Committee in relation to the My Health Record system
- **Part 2** addresses the My Health Records Amendment (Strengthening Privacy) Bill 2018

Context of PLHIV – 2018

People living with HIV (PLHIV) are wholly reliant on lifetime access to health care. This is so HIV infection can be monitored and treated with combination antiretroviral therapy. Despite the efficacy of combination antiretroviral therapy to control HIV disease progression and limit HIV sexual transmission, HIV remains a highly stigmatised health condition which predominantly affects populations already marginalised in society - Gay and Bisexual men, Trans and gender diverse populations, Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse backgrounds and people who inject drugs (PWID)/people who use drugs (PWUD). There are an estimated 28,500¹ PLHIV in Australia (by end of 2018) and approximately 10,000 live in NSW.

Intersectionality between PLHIV and drug use is common. Gay PLHIV are more likely to report drug use than the heterosexual population. The Kirby Institute reported that 50.5% of Gay, Bisexual men had used an illicit drug in the previous six months,² and 78.7% of men living with HIV reported illicit drug use at some time in the Sydney Gay Community Periodic Survey (2016).

Part 1

The following subsections (A-G) respond to questions posed by the Senate Community Affairs Reference Committee in relation to My Health Record.

A. The expected benefits of the MHR system: A proportion of PLHIV in NSW will benefit from the ‘primary use’ of the MHR and the sharing of health information. These PLHIV include: those who are ageing, those with comorbidities, those who are likely to have hospital admissions, those with complex care needs (mental health conditions, HIV associated neurocognitive impairment, drug and alcohol abuse) as well as those who see multiple healthcare providers for the clinical management of HIV and other chronic health conditions. PLHIV who are not engaging in illicit drug use or sexual practices that place others at risk will also potentially benefit from the convenience of a MHR.

For these individuals, the MHR system will improve the coordination and accessibility of timely patient healthcare and health outcomes and reduce waiting times for test results and inefficiencies (pathology, polypharmacy etc.). MHR is also likely to reduce the incidence of adverse medical events and ensure medical practitioners have the information they need to treat patients in a responsive and timely way.

Information contained in a MHR is summary information lacking in specific detail. Further, there are limits to health professionals’ ability to assess large amounts of historic data contained in a MHR within limited

¹ Australian Annual Surveillance Report of HIV, viral hepatitis, STIs 2016, https://kirby.unsw.edu.au/sites/default/files/kirby/report/SERP_Annual-Surveillance-Report-2016_UPD170627.pdf

² <https://www.flux.org.au/publications>

consultation times. These factors will mean that the potential benefits of MHR will not be truly unlocked until intelligent data-search technology is at a sufficient level of development in the future.

Other PLHIV will not benefit from MHR due to risks of disclosure and the potential for criminalisation. Individuals who will be most adversely affected include PLHIV who are sex workers, PLHIV who use illicit drugs, PLHIV who are involved in the criminal justice system, PLHIV who live in small rural communities, (such as heterosexual and Aboriginal PLHIV), and those who are sexually active, non-monogamous and unable to maintain an HIV undetectable viral load or receive frequent STI diagnoses. For these individuals, the risk of disclosure, discrimination and being investigated or prosecuted for illegal behaviour (HIV transmission, STI transmission, illicit drug use/drug dealing) is of significant concern. The severity of consequences posed by the My Health Record on health, safety, liberty and privacy will likely outweigh any potential benefits for these PLHIV.

B. The decision to shift from opt-in to opt-out: The MHR system has evolved from an earlier version of the electronic health record, the *Personal Controlled Electronic Health Record (PCEHR)*. The PCEHR was designed to be an 'opt-in' patient controlled electronic medical records system but became an 'opt-out' system from July 2018, whereby a MHR will automatically be generated for every Medicare eligible Australian citizen or permanent resident unless they opt-out in a five-month window period from 16 July to 15 November 2018. The default setting for all newly created MHRs will be 'Open' - unless the MHR owner changes the setting and restricts access. All healthcare professionals and system users will have automatic access to that individual's MHR information in the 'Open' setting.

Positive Life thinks the principle of 'patient data sovereignty' is paramount. We consider that the ownership and confidentiality of an individual's personal electronic health data must remain under the control of that PLHIV, especially given that a breach of confidentiality can impact so disproportionately on some PLHIV. For example, if there is only one woman living with HIV in a certain postcode, accessing confidential data could unintentionally disclose her HIV status.

If individuals do not opt-out during this prescribed period, it is assumed that consent to register has been given and a MHR for that individual will automatically be generated. The individual's MHR will be populated with healthcare data from the previous two years, including PBS and MBS data, pathology results and prescribed medications. After being allocated a MHR, healthcare providers will automatically upload health information, unless they have been specifically asked by an individual not to do so.

PLHIV who miss the opt-out period and subsequently decide they do not want a MHR because of the risk of disclosure or criminalisation may episodically, intermittently, or permanently choose to disengage from healthcare and adherence to combined antiretroviral treatment (cART). Disengagement from healthcare would significantly interfere with the prescribing and adherence to cART and would result in viral rebound, infectiousness, and a potential risk of HIV transmission to associates. Concerns have also been raised in relation to PLHIV who are cognitively or intellectually impaired, who live without access to the internet, or who are currently incarcerated. For PLHIV within these groups, it is likely they may miss the opt-out period or not even be aware there is an opt-out period. Positive Life and NAPWHA therefore supports the option proposed in the *My Health Records Amendment (Strengthening Privacy) Bill 2018* that permits an owner of a MHR to cancel the record at any time and have all information permanently deleted by the System Operator.

C. Privacy and security, including concerns regarding:
i. the vulnerability of the system to unauthorised access:

Unnecessary or unwanted disclosures of information on a MHR can have extremely detrimental effects on people's lives. For example, disclosure of HIV status can put HIV-positive people and patients in situations where they may face stigma, discrimination or violence.

Centralised data is more attractive and therefore potentially more vulnerable to data security breaches. Breaches in data security appear to be becoming more frequent. News reports of failures in data security systems and attacks from foreign countries infiltrating Australian government and private data systems have become common. Positive Life and NAPWHA have concerns that MHR data security systems will be breached, and that information will be shared for research and other purposes. Centralised data systems also provide an opportunity for future legislative amendments that permit increased data linkage between federal and state-based data sets.

In addition to 'unauthorised access', Positive Life and NAPWHA has significant concerns about the wide range of authorised users who will have access to the system's data. The range of healthcare providers who will have access to an individual's MHR in the 'Open' setting is broad and includes all healthcare providers associated with an individual's healthcare, including allied health professionals, physiotherapists, counsellors, dentists and pharmacists – unless they are specifically excluded by the MHR holder. Clinic reception, administration staff and contractors to a medical practice will also have access to the system unless the medical practice specifically denies these individuals access, which is unlikely.

Non-healthcare professionals will also have access to MHR data. These non-healthcare professionals include the MHR System Operator, a registered healthcare provider organisation, the operator of the National Repositories Service, a registered repository operator, a register portal operator, or a registered contract service provider.

There are legitimate community concerns that the MHR will put PLHIV, sex workers and PWID/PWUD at greater risk of criminal prosecution due to the wide range of individuals and bodies who are not healthcare professionals who will have access to MHR data. Such individuals may have limited, outdated and stigmatising understandings of HIV, sex work and drug use, yet believe they are acting in the public interest by disclosing sensitive health information.

The unauthorised access of information contained in a MHR is a crime under the MHR Act. However, there is no mechanism for people whose privacy has been breached to get compensation for negative consequences that flow from such a breach, or to hold the person responsible to account for, say, disclosure of an HIV status.

In reality *most* people will be unable to benefit from the limited MHR privacy settings. In order to restrict the access settings, people will need to understand the content of each document (which is often complex scientific and medical information), then make an assessment of how sensitive the information is and then decide who it needs to be shared with. People will need the technical ability to operate the system to appropriately restrict access. In most cases, and particularly in the case of people with a chronic condition such as HIV, My Health Record can quickly be expected to become a repository for a vast number of documents for each patient. Those patients without sufficient time to learn the system, and log on and assess large numbers of health documents, will be unable to effectively avail themselves of MHR's privacy features. This is likely to include anybody with limited time (such as anybody in full-time employment or with children etc.), anyone with restrictions on their ability to access the internet (such as those in rural areas or without the economic means to do so), anyone without the necessary information technology skills and anyone without the capacity to make their own decisions.

ii. the arrangements for third party access by law enforcement, government agencies, researchers and commercial interests: The current arrangements for third party access by law enforcement, government agencies, researchers and to commercial interests are of significant concern to Positive Life and NAPWHA. These

arrangements pose a risk to PLHIV who are sex workers, who use drugs (licit and illicit), and who are immigrants and refugees living with HIV. The information contained within an individual's MHR will be accessible to any of these agencies without an individual's explicit consent. The option to opt-out of the secondary use of MHR data is inadequate and insufficient. Most MHR users will not be aware of the secondary use of their data and the opt-out requirement, or the potential risk to themselves. This poses a considerable risk to PLHIV and will undermine the primary purpose of MHR and trust in the health system.

The MHR Act currently authorises any participant in the MHR system to disclose information held in a MHR without consent "if they reasonably believe the disclosure will lessen or prevent a serious threat to an individual's life, health, or safety, or lessen or prevent a serious threat to public health and safety". This is an overly broad and subjective test that authorises the sharing of highly confidential information on the basis of outdated and stigmatising, but nevertheless 'reasonable' beliefs. Positive Life and NAPWHA believe that this test should be narrowed so that disclosure of information on a MHR is only permitted in cases where there is an imminent threat to the life of an identified individual.

Some examples of 'secondary use' of MHR with or without individual's explicit consent include linking health data across systems and passing information to law enforcement even when there is no evidence of a crime; in the preparation of legal proceedings before any court or tribunal; benign or active surveillance of individuals or populations; and marketing for clinical trials and research. It is not currently possible to opt-out of MHR data being disclosed to or accessible by law enforcement agencies. Despite the systemic privacy provisions within MHR, we believe the MHR Act will override other privacy provisions outlined in *The Framework to guide the secondary use of My Health Record system data*. The law always trumps policy and guidelines. Positive Life and NAPWHA therefore supports removing the ability of the MHR System Operator to disclose health information to law enforcement agencies and government agencies without an order by a judicial officer or the healthcare recipient's consent.

The ability for patients to be able to speak openly and honestly with their doctor about subjects which are stigmatised or illegal such as homosexual sex, sex work or drug use is vital to securing optimal health outcomes for the individual. The long established principle of patient/doctor confidentiality underscores this point. Currently the MHR Act allows sharing of information to agencies outside of the health sector such as ASIC, the ATO, the immigration department, ASIO and the Police. Any sharing of health information for non-health related purposes undermines the ability of patients to trust their health professionals and speak openly and honestly. Positive Life and NAPWHA believe that the MHR Act should be changed to reflect the principle that health information should only ever be used for purposes relating to improving health.

iii. arrangements to exclude third party access arrangements to include any other party, including health or life insurers: Currently, individuals can choose to withdraw consent (opt-out) to information being used for secondary purposes (for example, passed on to third party agencies), but there are circumstances where privacy controls can be overridden without consent, as outlined above. Positive Life and NAPWHA believes this is insufficient, and the Act should be amended to exclude any secondary use of individual MHR data and third-party access arrangements. Anything less than to do so, will undermine the purpose of the MHR system and individual's trust and engagement in the health system more generally.

The purpose and effect of section 68 of the Act is not clear but it suggests that the providers of indemnity insurance may be able to access information from the MHR system. There is a history of PLHIV in Australia being denied insurance, such as travel insurance, on the basis of HIV status. Positive Life and NAPWHA are concerned that section 68 could lead to healthcare providers being unable to

access affordable indemnity cover in relation to their HIV-positive patients. This may result in PLHIV being unable to access the care they need.

D. The Government's administration of the My Health Record system roll-out, including:

i. the public information campaign: There have been no educational campaigns informing citizens about whether a MHR would benefit or disadvantage them. Any information which has been published by the government provides a positive perspective on MHR and is perceived by many PLHIV to be biased. The most pressing problem is that currently, the majority of PLHIV do not understand MHR and the breadth of information that will be uploaded to the system and then potentially shared. Active participation in an opt-out model wrongly assumes a level of knowledge, health literacy, general literacy, and technological proficiency, as well as the time and capacity to manage MHR privacy controls by all individuals'. We believe this is not so. PLHIV who will be most negatively impacted will be individuals who are unaware and lack capacity and resources to protect their privacy by either controlling their MHR or opting-out.

Although the MHR website includes information on the privacy policy of MHR, the information is detailed, complex and not easily understood. While the policy articulates privacy protection for individuals, it does not adequately or clearly explain the situations in which privacy provisions can be overridden and information passed to other agencies, such as law enforcement. Nor does it adequately describe that even if an individual removes access to information in their MHR, the information is not deleted. It remains available to government and law enforcement agencies for 130 years.

There are important differences between the much stricter privacy protections that apply to patient information held in a doctor's records and the weaker protections that apply to that same information once it has been transferred to a MHR. These complexities were evidenced by the recent media surrounding MHR in which high level government representatives and health professionals were unable to agree on the likely consequences of the MHR Act on patient privacy. An extensive public education campaign is required to explain the intricacies of the new system.

It is likely that many PLHIV, sex workers and PWID/PWUD who miss the opt-out period will intermittently disengage from healthcare or restrict information they would normally provide to healthcare workers, especially after they become aware that their personal information can be passed to law enforcement agencies. This consequence will surely undermine the health outcomes of PLHIV and oppose the very reasons MHR was developed – to improve individual and public health outcomes. Positive Life and NAPWHA therefore supports the proposed amendments that allows for the cancellation of an individual's MHR and the permanent deletion of information from the system.

ii. the prevalence of 'informed consent' amongst users: The duration of the opt-out period does not reflect a model of informed consent. It is unlikely that most PLHIV will be aware of the most problematic aspects of the MHR system and the broad powers afforded under the MHR Act before the opt-out period ends. The fact that MHR data can be passed to third parties such as law enforcement agencies without their knowledge or consent, or without judicial review, will gradually become understood by PLHIV, sex workers and PWID/PWUD and have ongoing and negative consequences for health and safety.

Positive Life and NAPWHA note that the opt-out process to date has been fraught with complications. People are required to provide two kinds of personal identification to opt-out online. For many people online opt-out has been unavailable and they have had to endure long waits on the phone in order to opt-out. The complexity of the process is likely to dissuade many people from opting out, suggesting that the idea of truly informed consent to be opted-in is illusory in many cases.

While many PLHIV will have the capacity and resources to manage MHR privacy settings and to decide which healthcare documents should be uploaded and shared, others will not. Constraints such as the impacts from alcohol and illicit drug abuse, neurocognitive impairment, language barriers and technological limitations will all impede an individual's ability to manage their MHR. Assumed consent is not informed consent, and uninformed consent is not consent. The MHR therefore fails to achieve a process of informed consent for PLHIV.

E. Measures that are necessary to address community privacy concerns in the My Health Record system:

Positive Life and NAPWHA recommends the following measures to address community concerns regarding privacy and the MHR system:

- MHR holders can cancel their MHR and all data for that individual will be permanently deleted from the system;
- A default 'closed-record with highest security setting' on generation of a MHR with immediate prompt to review privacy settings by the MHR owner;
- Dynamic consent to the secondary use of MHR data. For example, a process whereby a user would specify the purpose/s their data could be used. When data was used for that purpose, the user would be notified. If data were to be used for a new purpose, patient consent would first need to be received;
- Access to MHR data triggers an alert to the MHR owner and is easily auditable by the MHR owner;
- Disclosure of MHR information for law enforcement and other government agencies is only available for purposes related to improving health, under judicial oversight and with a court order;
- Ongoing public education resources and campaigns are provided about the risks and benefits of MHR and how to navigate and manage MHR security settings;
- Ongoing public education campaigns are implemented in a range of commonly spoken languages.
- That section 68 be removed so that health information from the MHR system cannot be made available to insurers.
- That Data from the MHR system is not made available for a profit.
- That section 64 be amended to state that HIV status is not a reasonable grounds for a disclosure and that disclosures of information from a MHR are permitted only where there is an imminent threat to the life of an identified individual. Such disclosures should be governed by an independent oversight body with appropriate specialist knowledge (which must include the *lived experience*) of the relevant situation or condition.
- That the list of government bodies able to apply to access MHR data be restricted to criminal law enforcement bodies and the courts only.
- The creation of a scheme that allows people whose MHR has been accessed without authorisation to obtain compensation for adverse consequences associated with that breach from the person/agency responsible.

F. How My Health Record compares to alternative systems of digitising health records internationally: No comment.

G. Any other matters: Trust in the health system is critical for PLHIV remaining engaged in healthcare, and therefore for us to be able to work with government and the health system, ensuring HIV transmission targets are achieved under the national HIV Strategy. The contract we have with our doctors is rooted in confidentiality and non-judgemental healthcare. MHR places this relationship at risk. PLHIV are reliant on lifetime access to healthcare, cART to prevent HIV disease progression and transmission. During consultations, private and sensitive information about blood borne virus status (HIV, HCV, and HBV etc.), sexual health (frequency of testing and treatment), sexual contacts, sexual practices, illicit drug use, and sex work are shared with healthcare providers.

To safeguard privacy and to limit the risk of disclosure, many PLHIV elect to separate different parts of their healthcare. For example, HIV may be monitored and treated by a HIV specialist, general health by a GP, sexual

health by a public sexual health service and mental health by an allied healthcare provider in a non-government setting. Communication and disclosure of sensitive information by and between healthcare providers is controlled and strictly limited by the PLHIV. There are concerns that health professionals who have been denied access to an individual's MHR may exert pressure on the individual to provide access on the grounds they need all information to provide comprehensive healthcare.

Stigma and discrimination remains a major barrier to the physical, sexual and mental health of PLHIV. Experiencing stigma and discrimination in healthcare settings deters health service engagement, retention in care and discourages testing and treatment. PLHIV who are sex workers and who use or inject drugs continue to report high levels of stigma and discrimination in healthcare settings, which may be exacerbated by MHR and the potential sharing of sensitive information. To avoid the negative impacts of stigma and discrimination, PLHIV, particularly those who are sex workers and/or PWID/PWUD, assiduously control to who, when and where they disclose their BBV status, sex work status, drug use, sexual identity and risk behaviours. Disclosure is and always should be controlled by the PLHIV, sex worker or PWID/PWUD. MHR has the capacity to enable disclosure to individuals within the MHR system, and outside the clinical environment without direct authorisation. This will result in unintended privacy exposure and disengagement from healthcare.

The current system of uncentralised, incomplete and dispersed health records currently has a protective effect for communities that experience higher levels of surveillance, policing and criminalisation than the general community. By centralising health data and making it available to government agencies we increase the risk that marginalised communities will be unjustly targeted by enforcement agencies in future.

Healthcare is currently provided very well in the Australian system despite incomplete information. For example, patients may forget to report symptoms that they consider irrelevant or that have resolved, over-the-counter medications are often forgotten and patients with chronic conditions (especially stigmatised ones) routinely confine discussions about their chronic condition to their treating specialist while seeking care for everyday maladies from a G.P. This situation currently does not prevent the provision of effective care. Positive Life and NAPWHA are concerned that if healthcare providers can see, on the MHR system, that information is present but not available to them they will seek access to that information from the patient on the basis that they must have complete information before they can offer treatment. This kind of coercion, the withholding of care by people in respected and trusted positions of influence, may lead many patients to 'volunteer' access to documents unnecessarily. This would be impossible to monitor and may lead to increased numbers of unnecessary disclosures.

Part 2

My Health Records Amendment (Strengthening Privacy) Bill 2018: Positive Life and NAPWHA supports proposed amendments to the *My Health Record Act (2012)* to strengthen privacy.

Specifically, we support:

- Removing the ability of the MHR System Operator to disclose health information to law enforcement agencies and government agencies without an order by a judicial officer or the healthcare recipient's consent; and
- Requiring the System Operator to permanently delete health information stored in the National Repositories Service if an individual decides to cancel their MHR.

Issues not addressed by the proposed My Health Records Amendment (Strengthening Privacy) Bill 2018

A. Disclosure by My Health Record information by participants on the grounds to lessen or prevent a serious threat to public health and safety: Under Section 64(2) of the Act, a MHR participant is authorised to collect use and disclose information if they reasonably believe the disclosure will lessen or prevent a serious threat to public health and safety. The definition of MHR ‘participant’ is broad and includes non-clinical MHR participants, for example, clinic reception or administrative staff or sales staff in a community pharmacy. These individuals are more likely to hold outdated and stigmatising beliefs about PLHIV, HIV and lifestyle choices. While health professionals operate with a clear understanding of the responsibilities in relation to confidentiality, reception and administrative staff often have less rigorous understanding of their obligations and responsibilities. The temptation to disclose sensitive information outside the clinical environment will have significant and potentially devastating results for some PLHIV. We have been told of PLHIV who have had to move to another part of the state or interstate because they were hounded from their communities by people who held homophobic, trans-phobic, HIV phobic and drug-phobic views. We recommend further amendment to prohibit disclosure of MHR information by any participants in the MHR system without judicial review and a court order from a magistrate or judge. The broad and subjective test of ‘reasonable belief’ should be dispensed with. Further, disclosures of information on a MHR should only be permitted in relation to an actual, serious and imminent threat of harm to identified individuals.

It is now well established that properly treated, HIV poses no threat to public health, public safety, or an individual’s life, health or safety. Therefore, HIV status alone and HIV status in the presence of effective treatment and an undetectable viral load should be specifically identified, whether in legislation or regulations, as insufficient grounds to warrant such a disclosure.

B. My Health Record privacy settings for newly created My Health Records: The initial default ‘open’ setting creates vulnerability for consumers who are unaware of the broad scope and authorised access to information in the system when these settings are in operation. A default ‘open’ setting exposes MHR participants, particularly PLHIV, PLHIV who are sex workers and PWID/PWUD to the sharing of sensitive information between all members of that individual’s healthcare team. This will expose PLHIV who do not have the capacity to adjust privacy setting to unnecessary risk of disclosure. We recommend that all new MHR be initially generated with the highest privacy setting. Individuals should be notified immediately to review their MHR and adjust settings according to individual needs. This process also needs to apply to data sharing for secondary purposes. Permission to share data for secondary purposes needs to be initially set to ‘do not share’. Individuals can subsequently change the setting according to their preferences.

C. Notification when a My Health Record is accessed: While some individual will have the ability and interest to control privacy settings, others will not. When a MHR is accessed by a My Health Record participant (clinician or non-clinician), the owner of the MHR should be notified of the access by SMS or email. This would prompt individuals to monitor information access and regularly review privacy settings.

D. Independent consumer monitoring committee: The Australian health system has increasingly moved toward a consumer centred healthcare model and Positive Life and NAPWHA applauds this move. With any new system as complex as MHR, it is likely there will be issues that need to be rectified during implementation. Positive Life and NAPWHA recommends that an independent consumer monitoring committee is convened and established to monitor, assess and evaluate the MHR system and provide input from a consumer perspective.