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SEX WORKERS OUTREACH PROJECT

MY HEALTH RECORD - BRIEFING PAPER

This Paper has been developed to educate PLHIV, sex workers and people who use and inject drugs about the advantages/disadvantages of the electronic medical record system - My Health Record (MHR). The Paper has also been developed to inform government, non-government and the Australian Digital Health Agency about issues of concern for these populations.

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ABOUT

Positive Life NSW - Positive Life is a non-profit community-based organisation that works to promote a positive image of people living with and affected by HIV in NSW. It aims to eliminate prejudice, isolation, stigma and discrimination. Positive Life provides information and referrals and advocates to change systems and practices that discriminate against people living with HIV in NSW and their friends and carers.

SWOP - The Sex Workers Outreach Project (SWOP) is Australia's largest and longest established community-based peer education sex worker organisation focused on HIV, STI and hepatitis C prevention, education and health promotion for sex workers in NSW. SWOP builds strategic, collaborative and multidisciplinary working relationships with sex workers, other key health, government and non-government organisations, and advocates for an equitable and holistic approach to services provided to sex workers.

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BACKGROUND

Introduction - This *My Health Record Briefing Paper* has been developed by Positive Life NSW (Positive Life) and the Sex Workers Outreach Project (SWOP). The paper describes a range of issues raised by consumer groups in relation to MHR. The consumer groups consulted include:

- People living with HIV (PLHIV)
- Sex Workers, and
- People Who Inject Drugs (PWID), People Who Use Drugs (PWUD)

Who this paper is for - The paper has been developed for:

- PLHIV, sex workers and PWID/PWUD
- State and Federal Health Ministers, The Australian Department of Health, NSW Health, and members of the Australian blood borne virus (BBV) sector

How information has been sourced - Information has been incorporated from a range of sources. These sources include:

- My Health Record legislation (*My Health Record Act 2012* (Cth)[1],
- *The Framework to guide the secondary use of My Health Record system data*
- Interviews with CEOs from PLHIV and Sex Worker state and federal agencies. Agencies consulted in the development of the paper include: Positive Life NSW, The National Association of People with HIV Australia (NAPWHA), The HIV/AIDS Legal Centre (HALC), The Sex Workers Outreach Project (SWOP), The Australian Injecting and Illicit Drug User's League (AIVL), Scarlet Alliance (Australian Sex Workers Association)
- Direct consultation with consumer groups, including PLHIV, sex workers and PWID/PWUD, through consumer surveys and community forums/consultations

[1] https://www.myhealthrecord.gov.au/about/legislation-and-governance

ABOUT MY HEALTH RECORD (MHR)

What is MHR?

- MHR is a centralised electronic depository where an individual's health information will be uploaded and stored. The information will be accessible to the individual, their health care providers and other non-clinical individuals involved in the MHR system, including system administrators
- An individual's MHR will include:
  - 1) *information from healthcare professionals* - an overview of an individual's health (Shared Care Summary), reports from blood tests and scans (including HIV and STIs results), prescribed medications (for example, HIV medications and hepatitis C medications, antibiotics for STIs etc.), referral letters to other healthcare professionals, hospital discharge summaries, and
  - 2) *two years of information from Medicare* – including: Medicare and Pharmaceutical Benefits Scheme (PBS) records, Medicare and Repatriation Schedule of Pharmaceutical Benefits (RPBS) records, organ donation decisions, immunisation records
- The MHR has evolved from an earlier version of the proposed electronic health record, called the *Personal Controlled Electronic Health Record (PCEHR)*. The PCEHR was designed to be an 'opt-in' patient controlled electronic medical records system

- **The MHR will become an 'opt-out' system from July 2018. This means a MHR will automatically be generated for every Medicare eligible Australian citizen or permanent resident unless they opt-out in a three month window period which will run from 16 July to 15 October 2018**

- **The default setting for all newly created MHRs will be 'Open'. This means that unless the MHR holder/owner changes the setting and restricts access, all healthcare professionals will have access to that individual's MHR information**

Who can access MHR information?

- 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 unless the medical practice specifically denies these individuals access – which is unlikely
- Non-healthcare professionals will 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

Can you prevent information from being shared?

- If you want to restrict access to certain healthcare professionals, you will have to constantly monitor the information being uploaded to MHR and decide who will have access to what information
- Individuals can choose to withdraw consent (opt-out) to information being used for secondary purpose (for example, passed on to third party agencies or insurance companies), but there are circumstances where privacy controls can be overridden without consent
- It is not possible to opt-out of MHR data being disclosed to or accessible by law enforcement. Despite the systemic privacy provisions within MHR, we believe the *My Health Record Act* can

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

Even if you remove access to information in your MHR, the information is not deleted. It remains available to government and law enforcement agencies for 130 years

MHR and the Law

- MHR is governed by the *My Health Record Act* 2012[2]
- Disclosure of MHR patient information is permitted for a range of non-health related purposes

> **The *My Health Record Act* authorises any participant[3] 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."*** [4],[5]

- Section 70 of the *My Health Record Act* 2012 authorises the System Operator to disclose to law enforcement, information contained in a MHR for the following reasons:
  - *a. The prevention, detection, investigation, prosecution or punishment of criminal offences, breaches of a law imposing penalty or sanction or breaches of a prescribed law*
  - *b. The enforcement of laws relating to the confiscation of the process of crime*
  - *c. The protection of the public revenue*
  - *d. The prevention, detection, investigation or remedying of serious improper conduct or prescribed conduct*
  - *e. The preparation for or conduct of, proceedings before any court or tribunal, or the implementation of the orders of a court or tribunal.*[6]

KEY ISSUES FOR PLHIV, SEX WORKERS AND PWID/PWUD

Your responsibility	• Decide if MHR will advantage or disadvantage you. **If you decide not to have a MHR, opt-out before 15 October 2018.** If you do not opt-out by this date, you will automatically receive a MHR. You will then have to manage any sensitive information that is uploaded to your MHR • If in doubt, opt-out!
Who will benefit from MHR?	• A significant proportion of PLHIV in NSW will benefit from a 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 such as mental health conditions and HIV associated neurocognitive impairment, as well as those who see multiple healthcare providers. 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

[2] https://www.myhealthrecord.gov.au/about/legislation-and-governance
[3] 'Participant' includes any individual authorised to access the MHR. Individuals with access to MHR data include: healthcare professionals and nurses, receptionists and administrative staff, Systems Operators and Registry Operators, service providers contracted by a registered healthcare provider (IT staff etc.).
[4] *My Health Records Act 2012*, s 64(2), available at: https://www.legislation.gov.au/Details/C2017C00313
[5] My Health Record Privacy Policy, *'Who do we disclose information in your My Health Record to, and why?'* available at: https://www.myhealthrecord.gov.au/about/privacy-policy
[6] *My Health Records Act 2012, s 70,* available at: https://www.legislation.gov.au/Details/C2017C00313

- If this describes you and you need further information and support, because you have doubts, reach-out!

Who will not benefit from MHR?

- Other PLHIV will not benefit from MHR, due to risks of disclosure and/or potential criminalisation. Individuals who will be most adversely affected include PLHIV who are sex workers, those who use illicit drugs, those who are involved in the criminal justice system, and those who live in small rural communities, who are Aboriginal or 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
- Possibly PLHIV who are migrants to Australia, culturally and linguistically diverse (CALD) PLHIV and women living with HIV (WLHIV) due to their smaller numbers, who are potentially more identifiable
- The severity of consequences posed by MHR on health, safety and privacy will likely outweigh any potential benefits for many sex workers. The risk of disclosure and criminalisation has far reaching legal, health and social implications for all sex workers, but particularly for those most vulnerable, such as sex workers who are PLHIV, PWID/PWUD, gender and ethnic minorities, or those who belong to other marginalised communities

Intersectionality between PLHIV, sex workers and PWID/PWUD

- Intersectionality between PLHIV, sex work and illicit drug use does occur. The overlap increases and compounds the risk of disclosure, stigma and discrimination and fear of prosecution for illegal activities/behaviours. For example, PLHIV, sex workers and PWID/PWUD face some degree of risk in relation to disclosure and prosecution. However, those most vulnerable to the effects of stigma and discrimination through MHR will be those who are marginalised and those from gender minorities or from migrant, CALD, and Aboriginal and Torres Strait Islander communities

Stigma and discrimination

- Despite effective therapy preventing HIV disease progression and transmission, HIV remains highly stigmatised. This is in part due to stigma associated with homosexuality and anal sex. There are also significant levels of stigma associated with sex work and/or injecting drug use
- To avoid the negative impacts of stigma and discrimination, PLHIV, sex workers and PWID/PWUD are assiduously careful about to who, when and where they disclose their BBV status, sex work status, drug use, sexual identity and risk behaviours. Disclosure is always controlled by the PLHIV, sex worker or PWID/PWUD. MHR has the capacity to enable disclosure to individuals within the MHR system, without their direct authorisation
- Stigma and discrimination is a major barrier to the physical, sexual and mental health of sex workers. Experiencing stigma and discrimination in healthcare settings can deter health service engagement, retention in care and discourage testing and treatment. Sex workers continue to report high levels of stigma and discrimination in healthcare settings, which may be exacerbated by MHR

Privacy, trust, disclosure and healthcare

- PLHIV are reliant on healthcare and lifetime access to combination HIV antiretroviral therapy (cART) to stop HIV disease progression and to prevent HIV transmission. During consultations, private and sensitive information about blood borne virus status (HIV, HCV, and HBV etc.), sexual health (frequency of testing and treatment), and sexual contacts, sexual practices, illicit drug use and sex work are shared with healthcare providers. The relationship between PLHIV, sex worker, PWID/PWUD and their healthcare professionals is built on privacy, trust and honesty and openness
- To safeguard privacy and to limit disclosure, many PLHIV, sex workers and PWUD/PWID 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 currently controlled and limited by the individual PLHIV, sex worker or PWID/PWUD.
- The broad mandate of the *My Health Record Act* weakens the ability of PLHIV, sex workers and PWID/PWUD to manage privacy risks in healthcare settings. The long term legal and social implications associated with MHR will obstruct confidence in, and access to, healthcare and personal safety and foster mistrust and healthcare disengagement

Criminalisation

- Non-consensual disclosure of MHR record information is permitted without judicial review for a broad range of non-health related purposes, including detection and investigation of criminal offences and the preparation of proceeding before any court or tribunal, (see full list p5).
- 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
- Prosecution is possible for BBV/STI transmission, drug use/dealing, for sex work with HIV and a range of other issues

Informed consent?

- The short opt-out period does not reflect a model of informed consent. It is unlikely that most PLHIV, sex workers and PWID/PWUD will be aware of the most problematic aspects of the MHR system and the broad powers afforded under the *My Health Record Act* in relation to the secondary use of MHR data. 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
- 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, sex worker and PWID/PWUD

Not all users will have the capacity/resources to manage privacy settings	• While many PLHIV, sex workers and PWID/PWUD 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 neurocognitive impairment, language barriers and technological limitations will impede an individual's ability to manage their MHR
Negative consequences of MHR	• 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, sex workers and PWID/PWUD and oppose the very reasons for which MHR was developed – to improve individual and public health outcomes • There are concerns that people who have restricted access to specific medical professionals will be coerced into providing access by those medical professionals • Health professionals who have been denied access to an individual's MHR may exert pressure on the individual to provide access on the grounds that they need all information to provide comprehensive healthcare • Centralised data is more vulnerable to data security breaches • Centralised data systems also provide an opportunity for future amendments to legislation that permit increased data linkage between federal and state data sets, and reduced privacy

RECOMMENDATIONS FOR PLHIV, SEX WORKERS, PWID/PWUD

If you have concerns about disclosure or criminalisation, opt-out of MHR until your concerns are allayed. If in doubt, opt out!

Individuals from the following groups are suggested to opt-out of MHR:

- PLHIV who are sex workers
- PLHIV who currently or have previously used illicit drugs
- PLHIV who are sexually active and non-monogamous, polyamorous or single
- PLHIV who are migrants, of a CALD background, Aboriginal and Torres Strait Islander and/or women who are concerned about disclosure
- PLHIV, sex workers, and PWID/PWUD with less than two diagnoses and see only one doctor
- PLHIV, sex workers and PWID/PWUD involved in the criminal justice system
- Sex workers who live or work in states where sex work or aspects of sex work is criminalised
- PLHIV, sex workers, and PWID/PWUD who have concerns about privacy or disclosure

WHAT WOULD MAKE MHR MORE ACCEPTABLE TO PLHIV, SEX WORKERS AND PWID/PWUD

- The opt out period is extended to 12 months to allow individuals to decide whether MHR is of personal benefit to them, or not
- An independent consumer monitoring committee is convened and established to assess and evaluate the implementation of MHR for health consumers
- A default 'closed-record' setting with an immediate prompt to generate a security pin by the MHR owner
- Dynamic consent to the secondary use of MHR data. For example, a process whereby a user could specify the purpose/s for which 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 secondary purpose, patient consent would first need to be received
- Access to MHR data by another party triggers an alert to the MHR owner and is auditable by the MHR owner
- The MHR legislation needs to be repealed and include subpoena and judicial review provisions, which protects the record from being accessed by law enforcement and other agencies for investigative or prosecution
- Ongoing public education campaign about the risks and reality of MHR and how to navigate and manage MHR, in a range of commonly spoken languages

FURTHER INFORMATION

http://www.positivelife.org.au/latest-news/who-is-at-risk-with-a-my-health-record.html

http://www.scarletalliance.org.au/library/MyHealthRecords/

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APPENDICES

LIST OF ACRONYMS

CALD	Culturally and linguistically diverse
cART	Combination antiretroviral therapy
BBV	Blood borne virus
GBM	Gay Bisexual Men
GP	General Practitioner
HAND	HIV Associated Neurocognitive Disorder
HBV	Hepatitis B virus
HCV	Hepatitis C virus
HIV	HIV Human Immunodeficiency virus
IDU	Injecting drug use
LASH	Law and Sex Workers Health Project
LGBTIQ	Lesbian, Gay, Bisexual, Transgender, Intersex, Queer
MBS	Medicare Benefits Schedule
MDMA	Methylenedioxymethamphetamine
MHR	My Health Record
PBS	Pharmaceutical Benefits Scheme
PCEHR	Personally Controlled Electronic Record
PLHIV	People living with HIV
PrEP	Pre-exposure Prophylaxis
PWID	People who inject drugs
PWUD	People who use drugs
STI	Sexually transmitted infection
SWOP	Sex Workers Outreach Project
WLHIV	Women living with HIV

OVERVIEW OF PLHIV, SEX WORKERS, PWID/PWUD IN AUSTRALIA

The following sections detail information based on extensive consultations with PLHIV, sex workers and PWID/PWUD and key stakeholders.

PLHIV in NSW - 2018

- There are an estimated 10,000 PLHIV in NSW (end of 2018). The number of PLHIV in NSW is slowly increasing by approximately 310 per year[7]
- There are an estimated 28,500[8]PLHIV in Australia (end of 2018) and this number is increasing by approximately 1,000 per year
- Populations who are affected by HIV include gay and bisexual men (GBM), heterosexual men and women, trans and gender diverse people, PWID/PWUD, sex workers, people from Aboriginal and Torres Strait Islands backgrounds, people from culturally and linguistically diverse backgrounds (CALD), and people who are incarcerated or have been incarcerated
- HIV primarily affects populations groups who are already marginalised in society
- Overall, the NSW PLHIV population is becoming more diverse. While GBM remain the predominant group of PLHIV (~80%)- both overall and of new infections - the proportion of GBM with HIV is dropping in NSW and there are increasing diagnoses of heterosexual men and women and people from CALD backgrounds
- PLHIV are part of the 35% of Australians living with a chronic health conditions and many live with multiple chronic health conditions (co-morbidities) such as heart disease, diabetes, cancers, respiratory disease, mental illness, osteoporosis, neurological impairments and frailty.[9] These diseases/conditions are associated with ageing, chronic inflammation, and from the use of early crude HIV treatment regimens in the late 1990s with severe and in some cases, irreversible side-effects. Co-morbidities are now the primary cause of illness, disability and death in PLHIV. This is particularly so for PLHIV who were diagnosed in the 1980s and 1990s, before highly effective combination antiretroviral treatment (cART) became available in 1996.
- In an Australian study of HIV positive and HIV negative GBM over the age of 55 years, an increased prevalence of several self-reported comorbidities including thrombosis, diabetes, heart disease, neuropathy and bone disease were reported by HIV positive men compared to HIV negative men. Lifestyle factors such as smoking and use of recreational drugs were more common among HIV positive men. Older HIV positive men experience some non-communicable diseases at higher rates compared to HIV negative GBM of similar age, despite similar rates of smoking and other traditional risk factors[10]
- The NSW PLHIV population is ageing. By 2020, 44.5% of Australian PLHIV will be 55 years or older.[11] This means that a significant proportion of the NSW and Australian PLHIV population now live with co-morbidity, polypharmacy and require regular access to multiple healthcare providers to monitor and treat HIV and other chronic health conditions
- There is currently no cure for HIV infection. PLHIV are reliant on continuous treatment and care for two principal reasons: 1) the use of combination antiretroviral treatment (cART) effectively stops HIV viral replication and HIV disease progression onto AIDS and death, and 2) the

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[7] NSW HIV Strategy 2016-2020, Quarter 4 & Annual 2017 Data Report, NSW Health, http://www.health.nsw.gov.au/endinghiv/Publications/q4-2017-and-annual-hiv-data-report.pdf

[8] 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

[9] https://www.ncbi.nlm.nih.gov/pubmed/28886173

[10] http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0184583

[11] 45% of Australian PLHIV will be 55 years or older by 2020, https://www.acon.org.au/wp-content/uploads/2015/04/Mapping-HIV-outcomes-in-Australia-KIRBY-2010.pdf

suppression of HIV viral replication to a level of >200 copies per ml, (undetectable HIV viral load or UVL) results in PLHIV being unable to transmit the HIV virus to others

- Access to cART is generally through HIV specialist prescribers (s100 prescribers) and cART is dispensed through hospital and community pharmacies. In NSW, the co-payment for cART has been waived for NSW residents. PLHIV with temporary visas status, such as student visas are not eligible for PBS supplied cART, or to the co-payment waiver. They are reliant on compassionate access programs run by some drug companies and personal importation schemes
- PLHIV also rely on access to healthcare to manage co-morbidities (see above) and other sexually transmitted infections such as syphilis, gonorrhoea, hepatitis and non-sexually transmitted infections
- Engagement in the health system is therefore crucial to PLHIV monitoring HIV, accessing cART and preventing disease progression, transmission of HIV, other blood borne viruses and STIs

Sex Workers in NSW – 2018

- Sex work[12] in Australia is governed by a complex matrix of laws which vary from jurisdiction to jurisdiction and are often inconsistent and contradictory. At the federal level, sex workers are not protected by antidiscrimination legislation and there are very few legal avenues available for sex workers to redress discrimination
- In NSW, sex work has been decriminalised since 1993. Decriminalisation strengthens the labour and human rights of sex workers and underpins effective HIV responses and health promotion among sex workers by reducing barriers to health. It is recognised as best practice in HIV prevention, health and human rights by UN agencies and a growing number of international human rights institutions such as the World Health Organisation, UNDP, UNAIDS, the International Labour Organisation, Amnesty International and the Global Alliance Against Trafficking in Women.[13]
- Decriminalisation entitles sex workers to the same rights and protections as workers from other industries – i.e. treating sex work as work – while maintaining existing mechanisms to prosecute criminal activities like violence, trafficking and labour exploitation. Decriminalisation in NSW has improved sex workers' access to justice, and vastly improved the health and safety of sex workers
- Sexual health surveillance data and multiple reports from the Kirby Institute and the Ministry of Health conclude that sex workers in NSW and Australia continue to have some of the lowest HIV and STI prevalence rates in the world.[14,15] In NSW the number of cis-female sex workers living with HIV is negligible or the same as the non-sex working cis-female population. Among cis-male sex workers, the proportion living with HIV is also low[16]

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[12] Sex work is defined as the sale/exchange of consensual adult sexual services. The Lancet medical journal affirms the use of the term 'sex work' as it enables HIV responses among sex workers to be addressed through a labour rights framework in addition to a human rights framework. Please see: https://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(14)61064-3.pdf?code=lancet-site

[13] Murphy, C., 'Sex Workers Rights are Human Rights', [website], https://www.amnesty.org/en/latest/news/2015/08/sex-workers-rights-are-human-rights/

[14] Kirby Institute and the Sex Workers Outreach Project, *Sex Worker Health Surveillance: A Report to the New South Wales Ministry of Health* 2016, Sydney: Kirby Institute, UNSW Sydney; 2016, available at: https://kirby.unsw.edu.au/sites/default/files/kirby/report/Sex%20Worker%20Health%20Surveillance%202016.pdf.

[15] Kirby Institute, *HIV, viral hepatitis and sexually transmissible infections in Australia: annual surveillance report 2017*, Sydney: Kirby Institute, UNSW Sydney; 2017, available at: https://kirby.unsw.edu.au/sites/default/files/kirby/report/SERP_Annual-Surveillance-Report-2017_compressed.pdf

[16] https://sti.bmj.com/content/93/4/299#

- This is due in part to community-based health promotion approaches and the implementation of high industry standards in privacy, consent and participation as recognised in Australia's National HIV, STI and BBV strategies.[17]
- SWOP recently estimated that there are up to 20,000 sex workers in NSW. This figure includes cis-female, trans and gender variant, and cis-male sex workers, and those working on an opportunistic or infrequent basis. This figure considers the diversity of sexual services provided in NSW. The transient nature of sex work undertaken by many sex workers makes establishing specific numbers difficult to establish
- The Law and Sex Worker Health Project (LASH) at the Kirby Institute estimated there are between 5,000 - 8,000 sex workers in NSW in 2012.[18] These numbers however only account for brothel based cis-female sex workers in Sydney's inner city
- At any given time, the sex industry is made up of approximately 80% cis-female sex workers, 10-15% trans and gender variant sex workers, and 10% cis-male sex workers
- SWOP estimates that roughly 60% of the sex industry in NSW is made up of private workers with the remainder working in brothels, agencies and other sexual service premises. The numbers of street-based sex workers is currently negligible. This is due in part to technological advances within the last decade, which has allowed more control over how, when, and where sex workers work. However, it is relevant to note that trans and gender diverse communities and people from Aboriginal and Torres Strait Islander backgrounds, are disproportionately represented within street-based sex work. This is understood as a direct result of existing systemic oppression and illustrates the importance of addressing intersectional issues.

PWID/PWUD in NSW – 2018

- Illicit drug use remains common among gay men and gay PLHIV. The Kirby Institute reported in the FLUX Study[19] that 50.5% of GBM had used an illicit drug in the previous six months. These drugs included crystal methamphetamine and other 'party drugs' such as MDMA and ketamine
- HIV positive men remain more likely to report drug use compared with HIV negative men (78.7% vs. 63.8% in 2016). HIV positive men are disproportionately more likely to report using methamphetamine compared with HIV negative men (30.6% vs 10.4% in 2016) and any injecting drug use (18.5% vs. 2.9%)[20]
- In national research of PLHIV conducted by La Trobe University (HIV Futures 8, 2016), which was not restricted to GBM, 12.74% of respondents indicated IDU in the previous 12 months
- Both HIV and hepatitis C (HCV) can be transmitted by IDU. *The Australian NSP Survey National Data Report* 2012-2016[21] reported in 2016 that HIV antibody prevalence among all respondents was 2.1%. HCV prevalence however, was 57% of all respondents and was consistently higher among respondents who reported imprisonment
- Many PWUD/PWID are living on the margins of society – homeless, living on social welfare, with mental health conditions and other intersectional issues. However, many other PWUD/PWID are

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[17] Australian Government Department of Health, *Seventh National HIV Strategy 2014-2017*, available at: http://www.health.gov.au/internet/main/publishing.nsf/content/8E87E65EEF535B02CA257BF0001A4EB6/$File/HIV-Strategy2014-v3.pdf; Australian Government Department of Health, *Third National Sexually Transmissible Infections Strategy 2014-2017*, available at: http://www.health.gov.au/internet/main/publishing.nsf/Content/8DB875B386DC5672CA257BF0001E377D/$File/STI-Strategy2014-v3.pdf

[18] Donovan, B., et. al., *The Sex Industry in New South Wales: a Report to the NSW Ministry of Health,* 2012, Sydney: Kirby Institute, UNSW Sydney; 2012, available at: https://kirby.unsw.edu.au/sites/default/files/kirby/report/SHP_NSW-Sex-Industry-Report-2012.pdf

[19] https://kirby.unsw.edu.au/project/flux

[20] https://csrh.arts.unsw.edu.au/media/CSRHFile/Sydney_2016_GCPS_report.pdf

[21] https://kirby.unsw.edu.au/report-type/australian-nsp-survey-national-data-report

not on the margins of society. They are mainstream Australians who work, have families, pay tax and contribute to society

Intersectionality of HIV, sex work and drug use

- While there is data on PLHIV, sex workers and PWID/PWUD, we are unaware of reliable data describing the intersectionality of HIV infection, sex work and drug use. However, we are aware that intersectionality does occur. All agencies involved in the development of this paper are aware of PLHIV who do sex work and who also use and inject drugs, and of sex workers who use drugs. For these individuals, the potential for MHR information being used in HIV, hepatitis C or STI transmission cases is a risk. For PLHIV and sex workers who also illicit drugs, the risks of disclosure and of criminalisation for drug use are compounded
- In an effort to highlight some of the key challenges of the MHR system, this paper focuses on three distinct but overlapping communities which all experience high levels of stigmatisation and risk of criminalisation. As communities, PLHIV, sex workers and PWID/PWUD all face some degree of marginalisation, but an intersectional lens shows how and why some community members face more challenges than others. A human rights based approach to evaluating the MHR considers how the most vulnerable members of our communities will be impacted in terms of accessibility to equitable and non-discriminatory health services and the long ranging effects that intersectional stigma and discrimination has on individual and public health outcomes

COMMUNITY CONCERNS – ADDITIONAL INFORMATION

Some PLHIV will benefit from MHR

- MHR will provide potential healthcare benefits for many PLHIV. These PLHIV include those who are ageing and those with comorbidities and who use multiple healthcare providers, those who have had, or are likely to have planned and unplanned hospital admissions, those with memory and comprehension problems due to health conditions such as HAND and mental health conditions, those with complex care needs, and those who are not engaging in illegal or sexual practices that potentially place themselves and others at risk
- For these groups, the sharing of healthcare records between GPs, specialists, allied health professionals, as well as access to MBS and PBS data, will potentially improve the timeliness and quality of healthcare coordination and prevent unnecessary hospital admissions. A MHR may also reduce adverse health events, due to polypharmacy and drug/drug interactions/reactions
- MHR is likely to also fast track hospital admissions, which will become more likely as PLHIV age with co-morbid health conditions
- MHR will potential benefit those working/living in more than one area/jurisdiction

Others will not benefit from a MHR

PLHIV:

- In community consultations with PLHIV, many have expressed concern that the secondary use of MHR data will create risks for them
- PLHIV who have expressed concern include:
  - PLHIV sex workers
  - PLHIV who use illicit drugs and fear investigation and prosecution
  - Women living with HIV and Aboriginal and Torres Strait Islander PLHIV - particularly those living in small rural communities who are fearful of disclosure from non-clinical healthcare service staff and potential discrimination from their own communities
  - PLHIV immigrants and refugees who fear sensitive health information my negatively impact on their visa status or application for permanent residency
  - PLHIV who have a criminal history and are involved with the criminal justice system, and
  - PLHIV who are sexually active, non-monogamous and are either unwilling to use cART, or use cART and are unable to achieve and maintain an undetectable HIV viral load (less than 200 copies per ml) and fear prosecution for HIV transmission (approximately 5% of PLHIV at any one time will struggle to maintain a continuous undetectable HIV viral load)
- While *The Framework to guide the secondary use of My Health Record system data* provides an option for MHR users to withdraw consent by opting-out to the secondary use of their MHR data, we consider many PLHIV, sex workers and PWID/PWUD will either not be aware of the option, or will not exercise the option. There are also questions and concern from community that the *MHR Act* will override withdrawal of consent, for example in legal cases and in criminal investigations
- 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 disengage from healthcare and adherence to cART. Disengagement from healthcare would significantly interfere with prescribing and adherence to cART and would also result in viral rebound, infectiousness, and potential risk of HIV transmission to associates. It would also undermine current public health responses

Sex Workers:

- For many sex workers the potential benefits of MHR do not weigh up against the risk of criminalisation or social stigma following the intentional or inadvertent disclosure of current or

previous sex work. The current criminal framework surrounding sex work in Australia and lack of antidiscrimination and other formal protections will cause many sex workers to decide that it is safer to opt-out of MHR

- Community consultation found that the insecurity felt by sex workers about MHR is due largely to the lack of safeguards in the MHR legislation. Regardless of what the initial intent for the electronic health records system is, the breadth of the MHR legislation allows for the secondary use of health information in ways that makes most sex workers extremely uncomfortable
- Current laws around the transmission of HIV/STIs/BBVs in relation to sex work creates an environment where sex workers with any one of these conditions can potentially find themselves subject to criminal investigation and charges even if they are not putting anyone at risk. For example, a sex worker makes a judgement to work while they have an undetectable HIV viral load, while using other prevention techniques and knows they aren't putting a client at risk. If the cross-referencing of data occurs under MHR provisions and this leads to a criminal charge, the obligations will be on the sex worker to defend this. At best they would be out of a job, and forced to publically disclose their sex work and at worst they would be arrested and prosecuted
- Long term effects of disclosure and/or criminalisation risks may cause sex workers to withhold vital information from healthcare providers or to disengage with health services all together

PWID/PWUD:

- While the use of 'party drugs' such as amphetamines, MDMA, ketamine and cannabis is illegal, rates of illicit drug use are significant, particularly among PLHIV GBM and sex workers. For PWID/PWUD, the risk of criminalisation is very real. Healthcare providers are privy to patient supplied information about drug use. The potential for this information to be accessed and used by law enforcement agencies creates a barrier to MHR participation and healthcare

The impact of stigma and discrimination

For PLHIV:

- Despite the efficacy of cART to control HIV viral replication and HIV disease progression, HIV remains a stigmatised disease. This is essentially due to the routes of HIV transmission and to stigma within sections of Australian society in relation to homosexuality, anal sex and injecting drug use. Furthermore, PLHIV who are heterosexual, Aboriginal and Torres Strait Islander or from CALD backgrounds, report high levels of stigma and discrimination from their communities of origin. This is due in part to cultural difference, lack of awareness around HIV and less tolerant attitudes to homosexuality, bisexuality, anal sex, IDU and the association with HIV infection/transmission
- Despite taking ART and having an undetectable HIV viral load, GBM with HIV report experiencing stigma and discrimination from other GBM and from family and associates. They also report experiencing stigma and discrimination from some healthcare providers and government agency staff
- To limit the negative impacts of HIV associated stigma and discrimination, PLHIV often elect to keep their HIV status private and to be cautious about to whom they choose to disclose their HIV status. The choice to disclose HIV status is seen by PLHIV as a basic right and directly under their personal control. In NSW, disclosure of HIV status without consent, is illegal

For Sex Workers:

- Even in NSW where sex work is decriminalised, sex workers continue to report high levels of stigma and discrimination in mainstream healthcare settings. It is well documented that stigma and discrimination against sex workers in healthcare settings impacts on sex workers' ability to

access health services.[22] Community-based health programs have proven the most successful at bridging this gap

- As previously mentioned stigma and discrimination is intersectional. This means that the effects are compounded for sex workers from populations which face existing marginalisation like migrant, CALD, and Aboriginal and Torres Strait Islander communities, ethnic or gender minorities, and for those who are living with HIV or who use illicit drugs
- In 2018 SWOP conducted a survey of more than 500 sex workers across Australia where 90% of respondents reported experiencing stigma and discrimination in healthcare settings. Reported examples included hospital and emergency visits, whilst receiving mental health services, in social work settings, at sexual and reproductive health check-ups, based on drug use or perceived drug use, perceived inability to effectively follow medical treatment, being over or under treated, being assumed to practice unsafe sex or to be incapable of using contraception and other degrading and disrespectful treatment
- Scarlet Alliance and SWOP are aware of several instances reported by sex workers even when the health service was unrelated to sex work. For example, a respondent from the SWOP community survey explained: *"I could have all my test done at my regular GP, which would save a lot of time and some money. But I prefer to make separate trips to the specialist* [HIV] *services to avoid being given a hard time about* [sex] *work"*
- Stigma and discrimination associated with sex work can have detrimental consequences beyond healthcare settings. Scarlet Alliance and SWOP are aware of multiple instances where disclosure of an individual's sex work status has led to discrimination in housing, custody disputes, immigration and foreign travel, access to banking and lending institutions, when seeking alternative employment, etc. Moreover, due to current legal barriers, those who do experience discrimination on the basis of sex work have few or no avenues to redress discrimination

On PWID/PWUD:

- Stigma and discrimination against PWID/PWUD is endemic across all sections of Australian society. This is an ongoing issue and in part, due to prohibition and criminalisation of commonly used drugs such as cannabis and 'party drugs' including MDMA, ketamine, methamphetamine and opioids. The societal stigma and discrimination that PWID/PWUD experience as they go about their lives, the fear of prosecution for illicit drug use, and the stigma and discrimination associated with having HIV, feed perceptions of marginalisation and worthlessness
- Unwanted disclosure of drug use and/or BBV status exacerbate perceptions of marginalisation and otherness

The relationship between privacy, trust and healthcare

For PLHIV:

- The relationship between PLHIV and their health care provider/s has been, and continues to be, built on privacy, trust and the understanding that PLHIV need to be honest and open with their health care provider/s about any issue that impacts on their healthcare and/or the healthcare of their associates. Issues discussed in a consultation often include highly sensitive information about: BBV status, sexual practice and potential transmission issues, illicit and licit drug use,

[22] Australian Federation of AIDS Organisations and Scarlet Alliance, *Unjust and Counter-Productive: The Failure of Governments to Protect Sex Workers from Discrimination*, 1999, available at: http://www.scarletalliance.org.au/library/unjust-counterproductive ; Renshaw L., et. al., *Migrant Sex Workers in Australia*, Research and Public Policy Series, Australian Institute of Criminology, 2015, available at: http://scarletalliance.org.au/library/Migrantsexworkersreport2015.

relationship matters, financial matters and personal responsibility in relation to the health and welfare of associates

- Over the last 35 years, PLHIV have become accustomed to information shared with health professionals being treated with utmost discretion and confidentiality, and only shared with third parties with their explicit consent and on a case by case basis. The sharing of sensitive personal information - without consent - is considered wholly unacceptable by PLHIV
- For reasons of privacy, many PLHIV consciously choose to segregate different aspects of their healthcare. This is done to corral specific areas of sensitive information, such as HIV status, sexual practice and illicit drug use. For example, a PLHIV may choose to have their HIV care provided by a HIV specialist in private practice or through a public sexual health serviced, their general healthcare provided by a GP, their care for depression/anxiety provided by an allied health care worker in a non-government community service, and to utilise a social worker in a specialist Local Health District service. Each care provider may <u>not</u> be aware of the others involvement in an individual's care. The strategy of healthcare/healthcare information segregation is particularly used by PLHIV who feel stigmatised and discriminated against, and who live in small regional and rural communities where they would be the target and the recipient of HIV-associated discrimination from the general community or family members if their HIV status were to become known. This is particularly so for Aboriginal and Torres Strait Islander and heterosexual PLHIV, but also for some GBM PLHIV and CALD PLHIV who struggle to find acceptance within themselves and/or their community
- PLHIV also fear personal and sensitive health information becoming available to non-clinical healthcare workers (i.e. clinic reception or administrative staff, or sales staff in a community pharmacy for example). While health professionals operate with a clear understanding of their responsibilities in relation to confidentiality, reception and administrative staff often have a less rigorous understanding of their professional obligations and responsibilities. The temptation to disclose sensitive information outside of the clinical environment will have significant and potentially distressing results for heterosexual and Aboriginal and Torres Strait Islander PLHIV within their own communities, but also for GBM. We are aware of heterosexual, Aboriginal and Torres Strait Islander and GBM PLHIV who have had to leave their communities and resettle in another part of the state, or in another state or territory, because they were hounded from their communities by homophobic, trans-phobic, bi-phobic and/or HIV-phobic community members
- Non-healthcare professionals associated with the MHR system will also have access to MHR data. These non-clinicians include the System Operator, registered healthcare provider organisations, the operator of the National Repositories Service, a registered repository operator, a register portal operator, or a registered contract service provider. There are concerns that these individuals may have poor and outdated understanding of HIV, sex work and illicit drug use and believe they are acting in the public interest by disclosing confidential information. Access by these non-clinical individuals increases the likelihood of unnecessary HIV disclosure, loss of home, employment, relationships, increased isolation and social disconnection. It also increases the likelihood of prosecution
- PLHIV currently consider privacy to be sacrosanct in a healthcare context. The realisation that a MHR will either directly or indirectly disclose an individual's HIV status without their consent will be perceived with extreme suspicion and become a barrier to participation in the MHR scheme. Furthermore, the realisation that confidentially can be broken by a new and involuntary healthcare records system – a system which has traditionally strictly maintained their confidentiality - will increase anxiety and undermine the very trust and confidence which has been cultivated over a 30 year period between PLHIV and their healthcare providers

For Sex Workers:

- Trust, privacy and confidentiality in healthcare settings is a priority for sex workers for the same reasons that it is for PLHIV and other stigmatised groups accessing the health system. Often the extent of engagement with a particular health service is often influenced by the degree of trust and privacy
- As a peer-driven community health organisation, SWOP has been integral to building trust between diverse sex worker populations and health and justice services over the last three decades. SWOP maintains the highest level of contact with sex workers compared to any other agency or service provider in NSW reaching more than 500 sexual service premises per year and frequent local and regional outreach activities to the private sector. SWOP provides multilingual and specialised peer-support services to a variety of subpopulations including CALD and migrant communities, Aboriginal and Torres Strait Islander groups and LGBTIQ+ and gender variant communities. In regards to health, the SWOP experience consistently finds that sex workers' engagement with services is contingent on maintaining the highest possible standards of privacy and trust
- Selective disclosure is a strategy used by sex workers in a number of settings to protect against the long-term social and legal consequences of stigma and discrimination associated with sex work and to ensure safety. MHR may add to the vulnerability certain sex workers feel by jeopardizing privacy through intentional or inadvertent disclosure. For sex workers privacy is not just a matter of preference, it is a matter of safety
- There are several cases where an individual's current or previous involvement in sex work has been inadvertently disclosed in healthcare settings. For example, Scarlet Alliance is aware of multiple occasions where people have had their sex worker status and/or drug use disclosed by hospital staff who thought it helpful or their moral duty to disclose the patient's sex work and/or drug use to family members or partners
- Even though the social, legal, and health consequences of non-consensual disclosure can be extreme, the law currently does not protect against the disclosure of someone's involvement in sex work. Unlike HIV status, which is understood as a medical condition, sex work is not a protected status in terms of antidiscrimination and privacy considerations, since it is thought of as an occupation. Such nuances are further complicated under MHR since disclosure can result in criminalisation, discrimination or even a total self-exclusion from health services
- Due to the inconsistency of laws about sex work in Australia and the current lack of antidiscrimination protections, privacy is crucial for sex workers' ability to safely access health services. Sex work or aspects of sex work may be a crime in some jurisdictions, but not others. For example, some sex workers report instances of having registered where sex work is legal, and then face police surveillance and scrutiny because of that record when moving to another jurisdiction. In SWOP's community survey one respondent commented: *'I have sex work charges from working interstate which come up under national police checks so it's a very real concern'*
- Scarlet Alliance expressed concern that even if a sex worker does not disclose their HIV status or sex work, other information contained in the MHR could be used to determine their sex work or HIV status. For example, the frequency of sexual health tests and results, referrals to specialists, notes from consultations with psychologists and prescriptions or records of PEP, PrEP or HIV medication can be used to determine sex work, HIV or drug use status[23]
- Scarlet Alliance highlighted similar concerns about the existing possibility to *re-identify* sex workers personal data. A recent study from Melbourne University demonstrated that it is already possible to identify people from supposedly de-identified health data from the Australian Medicare Benefits Scheme and the Pharmaceutical Benefits Scheme. It is already a

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[23] http://www.scarletalliance.org.au/library/MyHealthRecords/

danger that such information can reveal 'if someone is on HIV medication, has terminated a pregnancy, or is seeing a psychologist'[24]

For PWID and PWUD

- AIVL has raised concerns about the ability of law enforcement and other government services and agencies to identify/locate people who use drugs from a range of MHR indicators, particularly where drug use has not been disclosed
- Targeting PWUD/PWID makes assumptions about health status and health rights. For example, while the goal of eradicating hepatitis C may be a public health priority, it does not justify a potential breach of privacy through an electronic health record. We have concerns that if PWID/PWUD are targeted through MHR, that they will disengage from health care
- Moreover, there is a low level of trust of government by PWID/PWUD, particularly within the context of global political leaning toward authoritarianism and the violation of the human rights of PWID/PWUD (for example, in the Philippines, Russia and the USA). Therefore, trust in the government to maintain the privacy of those who use an electronic health record is low
- There is a risk of unwanted disclosure about hepatitis C and/or drug use to friends and family members who attend the same health care settings. There are also frequent reports of disclosure in hospital settings

The assumption that all individuals will have capacity and resources to control MHR privacy settings

- Control of privacy within MHR, assumes that all users will have the capacity, capability, comprehension and resources to manage privacy settings and control their MHR. However there are subpopulations of PLHIV, sex workers, and PWID/PWUD who may lack the wherewithal to manage MHR settings. For example, those with severe mental health conditions, neurocognitive impairment, an intellectual disability or excessive drug and alcohol use, may struggle to effectively monitor and manage their MHR. Likewise there are a number of practical constraints like language barriers or technological limitations that may obstruct an individual's ability to manage their MHR
- Some PLHIV, sex workers, and PWID/PWUD may not have the ability to understand the content of healthcare documents and to assess if and with whom, particular information needs to be shared, or which information may potentially pose a risk to their safety and welfare
- For example, research has identified a significant proportion of PLHIV have HIV-associated neurocognitive disorder (HAND). Impairment ranges from mild to severe, with sever forms of the condition being categorised as HIV associated dementia. Even in the mild form, PLHIV with HAND find it difficult to organise and satisfactorily complete tasks, become forgetful, agitated, confused and disoriented. It is unlikely therefore that such individuals will manage their privacy settings competently

Informed consent

- The Federal Minister for Health, The Hon Greg Hunt MP, made a notifiable instrument prescribing the MHR *'opt-out'* period begin on 16 July 2018 and end on 15 October 2018
- If individuals do not opt-out during this three month 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. This will include PBS and MBS data, including pathology results and prescribed medications
- The default setting for each new MHR will be initially set to 'Open' (i.e. healthcare data can be shared with all healthcare providers connected with that individual's healthcare). After being

[24] Badge, J. (2018). *'Damaging our trust': Why my health record lets down sexual and gender minorities.* Star Observer

allocated a MHR, healthcare providers will upload health information, unless they have been specifically asked by an individual not to upload a particular document

- 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 and is perceived by many PLHIV, sex workers and PWID to be biased. Furthermore, there appears to be a complete absence of information in other languages for migrant or CALD communities which further undermines a notion of informed consent
- The most pressing problem is that currently, the majority of PLHIV, sex workers and PWID/PWUD do not understand MHR and the breadth of information that will be uploaded and stored about them. Active participation in an opt-out model between 16 July and 15 October, 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'. This is not the case and we believe that those who will be most negatively impacted will be individuals who are unaware and lack the capacity and resources to protect their privacy by controlling their MHR or opting-out
- By the time PLHIV, sex workers and PWID do understand the implications and risks of MHR; they will have likely missed the three month opt-out period and have been routinely assigned a MHR. The MHR and sensitive information will then have to be managed by the PLHIV, sex worker or PWID/PWUD
- Following the automatic creation of a MHR and inadequate information about the risks and uses, it is likely that community members will view this in itself as coercive and immediately lose trust and continue on a trajectory of gradual disengagement
- Concerns have also been raised in relation to the ability of PLHIV, sex workers and PWID who are currently incarcerated to opt-out of MHR during the three month opt-out period
- Although the MHR website includes information on the privacy policy of the 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

Criminalisation

- PLHIV, sex workers and PWID, have all expressed concern about the potential for MHR data to be used for secondary purposes in criminal investigations and legal proceedings
- The *My Health Record Act* allows <u>any participant</u> in the MHR system to disclose information held in a MHR, if they reasonable believe the disclosure will lessen or prevent a serious threat to an individual's life, health, or safety, or to lessen or prevent a serious threat to public health and safety
- The Act defines a *'participant in the MHR system'* as the System Operator, a registered healthcare provider organisation, the operator of the National Repositories Service, a registered repository operator, a registered portal operator or a registered contracted service provider. This means that individuals not trained in healthcare who are more likely to have limited knowledge and experience of HIV, and drug use, such as I.T. specialists and database operators, will be allowed access to information held in the MHR (such as HIV status, illicit drug use etc.), regardless of any privacy settings set by the user. This increases the likelihood of disclosure of sensitive information and possible prosecutions
- While the *Framework to guide the secondary use of My Health Record system data* states *"consumers can choose to have an MHR but elect for their data not to be used for secondary purposes"* by clicking on the *"Withdraw Participation Button"* we consider that many individuals will not have the knowledge or competence to understand and exercise this option. There are also concerns that the MHR Act (s69) *allows "disclosure to courts or tribunals if a court or tribunal other than a coroner orders or directs the System Operator to disclose health*

information included in a healthcare recipient's My Health Record to the court or tribunal." In addition, the MHR Act states in s65*: "Subject to S69, a participant in the My Health Record system is authorised to collect, use and disclose information included in a healthcare recipient's My Health Record if the collection, use and disclosure is required or authorised by Commonwealth, State or Territory law. "*Our understanding is that the provisions within the MHR Act would override consumer control and withdrawal of consent to secondary use of MHR data

- Currently, disclosure of MHR information is permitted for a broad range of non-health related purposes. These purposes include:
  - *The prevention, detection, investigation, prosecution or punishment of criminal offences, breaches of a law imposing penalty or sanction or breaches of a prescribed law*
  - *The enforcement of laws relating to the confiscation of the process of crime*
  - *The protection of the public revenue*
  - *The prevention, detection, investigation or remedying of serious improper conduct or prescribed conduct*
  - *The preparation for or conduct of, proceedings before any court or tribunal, or the implementation of the orders of a court or tribunal.*
- In relation to HIV transmission, the *NSW Public Health Amendment Bill 2017 (the Act)* states *that "A person who knows that he or she has a notifiable disease, or a scheduled medical condition that is sexually transmissible, is required to take reasonable precautions against spreading the disease or condition."* Notifiable diseases under Schedule 2 of the Act include: HIV, Hepatitis A, B, C, D and E, and other STIs. *'Reasonable precautions '*are considered to include: *taking antibiotics for an STI, and in the case of HIV, use of a condom, having an undetected HIV viral load, receiving conformation from a sexual partner they are taking PrEP, and receiving conformation that a sexual partner is immune to hepatitis B.*
- PLHIV who are sexually active and non-monogamous, polyamorous, and not continuously and assiduously practising reasonable precautions such as condom use, PrEP or using cART to achieve and maintain an undetectable HIV viral load, will fear their private and potentially criminal behaviour becomes shared with police, or used to gather evidence in criminal transmission and drug cases. There are also concerns that MHR data will be accessed and used for public health surveillance purposes where aggrieved partners/sex partners have an 'axe to grind'
- PLHIV who receive a sexually transmitted infection diagnosis and are accused of being sexually active, including engaging in sex work, would understandably fear that their health records and sensitive private health information may be provided to and used by authorities to aid an investigation or in criminal matters, by morally crusading citizens who mistakenly believe they are acting the public interest
- In relation to illicit drug use, research in 2016 identified that HIV positive men are disproportionally more likely to use crystal methamphetamine and report injecting drug use. Drug use would likely be discussed with healthcare professionals as a potential risk factor in healthcare
- Information may be passed directly between the MHR System Operator and law enforcement agencies without judicial oversight (warrant or subpoena)
- As a result, a strong likelihood exists that PLHIV, sex workers and PWID will disengage in healthcare when they become aware that their sensitive health information could be divulged to police. In consequence to healthcare disengagement, PLHIV would become non-adherent to cART and experience disease progression and increased infectiousness. It would also stop individuals being frank with health care providers to the detriment of their own health, the healthcare of their associates and public health in general

Issues for Sex Workers

- MHR poses risks for sex workers to be criminalised both based on health status and the contradictory jurisdictional laws around sex work. The threat of criminalisation through MHR surveillance may be enough to deter some sex workers from disclosing vital health information or from engaging in health services all together
- Because sex workers' health is still greatly affected by legislative barriers, SWOP and Scarlet Alliance are deeply concerned about MHR health data being used for law enforcement purposes without judicial oversight. SWOP's community survey found 100% of respondents expressed concern about *section 70 of the My Health Records Act*, which allows access and disclosure of personal information for law enforcement purposes
- The risk of criminalisation of sex workers via MHR will discourage engagement with health services and alienate those most marginalised. Potential criminalisation through MHR surveillance undermines patient confidentiality, informed consent and the trust between sex workers and health care providers, all of which have previously enabled effective public health outcomes among sex workers despite existing legislative barriers
- SWOP and Scarlet Alliance are concerned that persons untrained in health will have access to sensitive MHR data. In terms of criminalisation, it is a concern that individuals who lack a contemporary understanding of health promotion and sexual health and transmission or who may operate from a punitive framework in regards to sex work will be mandated to decide whether or not a person is a 'threat to public health'

Issues for PWID/PWUD

- For PWID/PWUD, criminalisation is an important consideration. The procurement and consumption of illicit drugs is a criminalised behaviour and a common activity amongst PLHIV and sex workers. PWID/PWUD have concerns that information about drug use will be passed to police in criminal investigations and to crack-down on illicit drug use. There are also considerations that drug use will be used in custody cases and result in the removal of children
- Many PWID/PWUD are living on the margins of society – homeless, living on social welfare, with mental health conditions and other intersectional issues. We are concerned that these individuals will be further marginalised by MHR.

Healthcare and coercion

- There is an assumption that healthcare professionals will be better able to provide quality healthcare if they have immediate access to <u>all</u> relevant healthcare information. This however, is not always the case. Positive Life is aware of numerous cases of health professionals either not reading health records or choosing to ignore the information within the individual's health record, or after the information has been directly by the individual. Such cases often involve the administration of drug/s which the patient knows they are allergic. For example, we have been told of cases where health care workers have been directly told by the PLHIV they are allergic to a particular drug, and it has still been administered with unfortunate consequences. Cases involve the administration of morphine, antibiotics and other narcotic analgesics, but also drugs where there is a clear contraindication. This appears to happen particularly in a hospital setting. The value of comprehensive health records/information is wholly dependent upon the willingness of the health professional reading the notes and acting appropriately. Access to more information doesn't always result in better health outcomes
- Concern also exists amongst PLHIV, sex workers and PWID/PWUD and the organisations that represent them, that when healthcare providers see healthcare information has been uploaded to the MHR and that they are not authorised to view the information, they will pressure individuals for access on the grounds that they are unable to provide comprehensive healthcare without being in full possession of all pertinent information. While we consider the majority of healthcare professionals to be ethical and would not withhold care, or leverage the power

imbalance between health professional and patient, reports of coercion happen from time to time and are extremely problematic for vulnerable PLHIV, sex workers and PWID/PWUD and for retention in care
- Some PWID living with hepatitis C have made a conscious decision to not take hepatitis C treatment. There have been concerns raised that the MHR will be used to target people living with hepatitis C and pressure them to start treatment

Metadata

- Currently, there is a lack of available information about how MHR data is stored and secured
- In reality, MHR will become a registry of PLHIV, sex workers, PWID/PWUD and other marginalised and stigmatised Australian population groups.
- Centralising data makes data accessibility more vulnerable to future law changes or data security breaches. For example, if sex work and/or HIV status is ever uploaded onto MHR it can never be completely deleted
- Accessibility to law enforcement and the ability for healthcare participants to disclose information to law enforcement surveillance may change over time. There have been cases where there has been incremental creep in data linkage policy and Australian citizens are justly wary of centralised data, data security breaches and changes in legislation to allow data linkage. Positive Life and SWOP are aware of data breaches in both the UK and Singapore's health systems
- Breaches in data security are appearing to becoming more frequent. News reports of failures in data security systems and attacks from foreign countries infiltrating Australian government data systems have become common. There are concerns that the MHR data security will be breached and that information will be used for marketing, research and other currently unknown purposes
- Unanswered questions remain about how further data linkage mechanisms may re-identify people or be used to criminalise or aid a criminal investigation. SWOP's community survey of sex workers found that 95% of respondents had concerns about data remaining in the registry for 30-130 years and the inability to completely delete information from the MHR system
- Most PWUD/PWID do not understand the issue of metadata and data-re-identification. A well-founded distrust of government and health services is fuelling a general distrust in the way MHR data is collected and used
- While the government advises that participants can change their MHR settings to receive a notification when anyone accesses their record, the MHR access-logging system does not track the identity of the individual who accessed the record, only the name of the institution
- While there have been few data breaches of the health system during the last five years, a centralised electronic health records system, that includes a majority of Australian citizens poses a significantly greater incentive for potential breaches by criminal elements