7 May 2021

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To the Audit Office of New South Wales,

Submission into the Access to health services in custody: Audit

Thank you for the opportunity to provide feedback on the Access to health services in custody: Audit. We are:

Positive Life NSW (Positive Life) is the lead peer-based agency in NSW representing people living with and affected by HIV in NSW. We provide leadership and advocacy in advancing the human rights and quality of life of all people living with HIV (PLHIV), and to change systems and practices that discriminate against PLHIV, our friends, family, and carers in NSW.

The HIV/AIDS Legal Centre (HALC) is the only not-for-profit, specialist community legal centre of its kind in Australia. HALC provides free and comprehensive legal assistance to people in NSW with HIV or Hepatitis-related legal matters and undertake Community Legal Education and Law Reform activity in areas relating to HIV and Hepatitis.

Hepatitis NSW provides information, support, referral and advocacy for people affected by viral hepatitis in NSW. We provide workforce development and education services both to prevent the transmission of viral hepatitis and to improve services for those affected by it. We advocate for improvements in quality of life, information, support and treatment, and to prevent hepatitis B and C transmission.

The NSW Users and AIDS Association (NUAA) is a peer-based drug user organisation. NUAA strives to improve our advocacy for, and services supporting, the diversity of people impacted by stigma and discrimination caused by the criminalisation of drug use across NSW through working with a broad range of stakeholders and partners to support system change.

Background

The Justice Health and Forensic Mental Health Network (JHFMHN) is responsible for providing health care to adults in custodial environments. In order to facilitate access to healthcare, JHFMHN works with Corrective Services NSW to manage patient access to care in custodial environments along with access to healthcare in non-custodial environments such as hospitals or specialist community health services. Healthcare is also provided by private health providers in three private prisons in NSW and patients are moved across the public and private prison environments.

The Audit Office of New South Wales is conducting an audit to assess whether adults in custody have effective access to healthcare in a complex service environment. The aim of the audit is to assess factors such as:

- the timeliness of access to care,
- the continuity of healthcare as patients are moved across the system, and
- the reporting of health outcomes to system managers.

We commend The Audit Office of New South Wales for engaging and consulting with the community and other stakeholders to review the access to healthcare for incarcerated persons and

ensure health equity and access outcomes are in the best interests of all current, prior, and future incarcerated persons in NSW.

Prison Population Demographics

People in prison (hereafter referred to as 'incarcerated persons') are a particularly vulnerable population. Incarcerated persons are generally more disadvantaged and have higher health care needs than the general Australian population. Incarcerated persons experience higher rates of mental health conditions, chronic physical disease, communicable disease, tobacco smoking, high-risk alcohol consumption, illicit use of drugs, and injecting drug use than the general population.[1]

The most recent data from the Australian Bureau of Statistics (ABS) states that as at 30 June 2020 there were 41,060 incarcerated persons in Australia, and 12,730 in NSW.[2] These are point in time statistics, and do not include total numbers of incarcerated persons moving through the justice system in a given year.

The NSW prison population is primarily male (93.4%), although statistics do not capture gender demographics beyond the binary. As such, there is no thorough and accurate data recording trans and gender diverse (TGD) incarcerated persons. Aboriginal and Torres Strait Islander people are significantly overrepresented in Australian and NSW prisons, comprising just 2.8% of the general population but making up 26.2% of the NSW prison population.[3]

People living with HIV (PLHIV)

HIV is a blood-borne virus (BBV) that can be treated and controlled by highly effective combined anti-retroviral treatments (cART) also known as anti-retroviral therapy (ART). HIV is a chronic manageable health condition, akin to diabetes or heart disease. If HIV is not treated by ART, over a number of years it will compromise the immune system to the point where acquired immunodeficiency syndrome (AIDS) develops. ART slows the progression of the HIV virus as well as preventing secondary infections and complications, which means people diagnosed with HIV have a life expectancy similar to that of someone without HIV. Sustained treatment on ART suppresses the level of HIV virus in the bloodstream to a level that is undetectable on a viral load test, which means HIV cannot be passed on during sex.[4]

<u>Available Data</u>

Data on the number of PLHIV in incarceration settings in NSW, and Australia-wide, is lacking. The NSW Inmate Census 2019 does not record demographics beyond the gender binary, age, Aboriginal and Torres Strait Islander identity, country of birth, English speaking status of country of birth, prior adult imprisonment, maximum period of imprisonment, and inmate security classification.[5] The ABS similarly does not capture BBV or STI status of incarcerated persons.

Although all incarcerated persons are offered a BBV and sexually transmitted infection (STI) test upon entry into an incarceration setting, this policy is voluntary, and due to widespread stigma and discrimination of BBVs and STIs, including HIV, anecdotal reports indicate that testing is not

[1] Australian Institute of Health and Welfare. (2020). Health of prisoners. Retrieved from https://www.aihw.gov.au/reports/australias-health/health-of-prisoners
[2] Australian Bureau of Statistics. (2020). Prisoners in Australia. Retrieved from https://www.abs.gov.au/statistics/people/crime-and-justice/prisoners-australia/latest-release
[3] Australian Bureau of Statistics. (2020). Prisoners in Australia. Retrieved from https://www.abs.gov.au/statistics/people/crime-and-justice/prisoners-australia/latest-release
[4] Positive Life NSW. (2021). Human Immunodeficiency Virus (HIV). Retrieved from https://www.positivelife.org.au/wp-content/uploads/2021/03/plnsw-fs-hiv101.pdf
[5] Tang, H. and Corben, S. (2020). NSW Inmate Census 2019: Summary of Characteristics. Corrective Services NSW. Retrieved from https://www.correctiveservices.dcj.nsw.gov.au/documents/research-and-statistics/sp48-nsw-inmate-census-2019.pdf

frequently accepted.[6] We continue to strongly support the principles of voluntary testing, informed consent and confidentiality of all people in incarceration and encourage improved education programs to encourage testing for BBVs. Fear and experiences of stigma and discrimination of BBVs, as well as stigma, discrimination, and power imbalances inherent in incarceration settings, discourages people living with BBVs from disclosing their status upon entry into incarceration settings. In intermittent surveys undertaken such as the National Prisoner Health Data Collection (NPHDC) collected by the Australian Institute of Health and Welfare (AIHW), NSW is the only state or territory to not participate in that data collection.[7] The AIHW Report on the Health of Australia's Prisoners 2018 uses additional data sources, including the National Prison Entrants' Blood-borne Virus Survey (NPEBBVS), of which NSW and WA did not participate in data collection.[8]

Australia-wide (with the exception of NSW) data from the most recent NPHDC survey which tested 803 people as they entered 62 prisons over a two week period in 2018 showed that zero participants tested positive for HIV.[9] Data from the NPEBBVS (with the exception of NSW and WA) was conducted over two weeks in 2016 which surveyed 431 of the 862 consecutive prison entrants in the participating jurisdictions, which found zero participants tested positive for HIV.[10] However, this is clearly not an accurate reflection of PLHIV in incarceration settings Australia-wide and in NSW as data from Adahps indicates.

Adahps (formally the AIDS Dementia and HIV Psychiatry Service) provides a range of services to assist people living with HIV related cognitive impairment and complex health needs in NSW. Adahps coordinates the NSW Persons in Custody HIV Community Referral Project (PICS), which is a joint initiative between Adahps and JHFMHN. The project connects incarcerated PLHIV to an appropriate service in the area where they will be living post-release/discharge. PICS is a state-wide project and has been in operation since 2011. Referrals for incarcerated persons are coordinated by JHFMHN, and by Adahps in the community.

Data collected over the ten-year period between 2011 to 2021, reported by the current Adahps program coordinator via interview on 22 April 2021[11], shows that 307 referrals have been made through the program, consisting of 167 unique individuals living with HIV. These include 147 men, 13 women, 6 transgender people, and 1 person whose gender was unknown. 34 of the 167 PLHIV were Aboriginal and/or Torres Strait Islander. These 167 PLHIV over the 10-year period do not include PLHIV who may have refused a referral to PICS, or those incarcerated in a private prison, nor those who may be currently incarcerated but have not progressed through incarceration to release yet.

Access to healthcare in incarceration settings and transitioning to post-incarceration

The United Nations (UN) Standard Minimum Rules for the Treatment of Prisoners states that: "1. The provision of health care for prisoners is a State responsibility. Prisoners should enjoy the same standards of health care that are available in the community, and should have access to necessary health-care services free of charge without discrimination on the grounds of their legal status, and 2. Health-care services should be organized in close relationship to the general public health

[6] Frommer, M. and Maynard, T. (2016). Equity inside and out? HIV, treatment access and prisoners. HIV Australia, 14(1). Retrieved from https://www.afao.org.au/article/equity-inside-hiv-treatment-access-prisoners/
[7] Ibid.
[8] Australian Institute of Health and Welfare. (2018). The health of Australia's prisoners. Cat. no. PHE 246. Canberra: AIHW. Retrieved from https://www.aihw.gov.au/getmedia/2e92f007-453d-48a1-9c6b-4c9531cf0371/aihw-phe-246.pdf.aspx?inline=true
[9] Ibid.
[10] Butler, T. and Simpson, M. (2017). National Prison Entrants' Blood-borne Virus Survey Report 2004, 2007, 2010, 2013, and 2016. Kirby Institute (UNSW Sydney). ISBN-13: 978-0-7334-3772-4. Retrieved from https://kirby.unsw.edu.au/sites/default/files/kirby/report/JHP_National-Prison-Entrants-Report-2004-2007-2010-2013-2016.pdf
[11] Hampton, G (Senior Social Worker -ADHAPS). Interview. Conducted by Rhys Evans (HALC), 22 April 2021.

administration and in a way that ensures continuity of treatment and care, including for HIV, tuberculosis and other infectious diseases, as well as for drug dependence."[12] The World Health Organisation (WHO) Health in prisons: A WHO guide to the essentials in prison health also asserts these principles that incarcerated persons have the same right to health care as everyone else.[13] Furthermore, the Australian Medical Association (AMA) in its Position Statement on Medical Ethics in Custodial Settings states that "prisoners and detainees have the same right of access, equity, and quality of health care as the general population."[14]

The Medicare Benefits Scheme (Medicare) provides most Australians with access to no-cost or subsidised health care, and the Pharmaceutical Benefits Scheme (PBS) provides access to medicines at a lower cost for Australian residents. Both schemes are funded by the Australian Government, however health services delivered to people in incarceration settings are the sole responsibility of state and territory governments.[15] The way in which these health services are delivered varies by jurisdiction, with the NSW system being the responsibility of JHFMHN. While international human rights laws state that all incarcerated persons have the right to health care equivalent to that provided to the general community, the Australian Federation of AIDS Organisations (AFAO), the National Association of People with HIV (NAPWHA), and academics in the field note that "concerns have been expressed by some researchers about the adequacy of medical services and care available within correctional facilities, compared with services available under Medicare."[16,17]

Due to the limitations in data availability as outlined above, it is not possible to accurately determine the number of PLHIV in NSW incarceration settings, nor the number of PLHIV who may have difficulties accessing healthcare and medications. Anecdotal reports gathered by AFAO and NAPWHA indicate that due to the stigma and discrimination associated with HIV, some incarcerated people forego accessing healthcare and medications to protect themselves from being identified as HIV-positive and thus being subjected to discrimination. Indeed, NAPWHA is aware of one case in NSW where an incarcerated PLHIV had to be moved to another incarceration setting after he was physically assaulted when his HIV status was exposed and that his daily visits to the clinic were to collect his HIV medications.[18]

Evidence gathered by Adahps indicates that BBV screening and information provision to incarcerated persons is variable, dependent on the location within the jurisdiction the incarceration setting is, although BBV testing is considered for most incarcerated persons upon entry.[19] There is one staff member at JHFMHN who is responsible for tracking the treatment and progress of all

[12] United Nations Office on Drugs and Crime. The United Nations Standard Minimum Rules for the Treatment of Prisoners. Retrieved from https://www.unodc.org/documents/justice-and-prison-reform/GA-RESOLUTION/E_ebook.pdf
[13] World Health Organisation. (2007). Health in prisons: A WHO guide to the essentials in prison health. Retrieved from https://www.euro.who.int/__data/assets/pdf_file/0009/99018/E90174.pdf
[14] Australian Medical Association. (2013). AMA Position Statement: Medical Ethics in Custodial Settings. Retrieved from https://ama.com.au/sites/default/files/documents/position_statmenet_on_medical_ethics_in_custodial_settings_2013.pdf
[15] Australian Institute of Health and Welfare. (2018). The health of Australia's prisoners. Cat. no. PHE 246. Canberra: AIHW. Retrieved from https://www.aihw.gov.au/getmedia/2e92f007-453d-48a1-9c6b-4c9531cf0371/aihw-phe-246.pdf.aspx?inline=true
[16] Frommer, M. and Maynard, T. (2016). Equity inside and out? HIV, treatment access and prisoners. HIV Australia, 14(1). Retrieved from https://www.afao.org.au/article/equity-inside-hiv-treatment-access-prisoners/
[17] Plueckhahn, T. M., Kinner, S. A., Sutherland, G., and Butler, T. G. (2015). Are some more equal than others? Challenging the basis for prisoners' exclusion from Medicare. The Medical journal of Australia, 203(9), 359–361. https://doi.org/10.5694/mja15.00588
[18] Frommer, M. and Maynard, T. (2016). Equity inside and out? HIV, treatment access and prisoners. HIV Australia, 14(1). Retrieved from https://www.afao.org.au/article/equity-inside-hiv-treatment-access-prisoners/
[19] Hampton, G (Senior Social Worker -ADHAPS). Interview. Conducted by Rhys Evans (HALC), 22 April 2021.

PLHIV in public NSW incarceration settings, of which there are typically 50 to 60 individuals. It is through this staff member that all public referrals to PICS are made through informed client consent.

Some issues that have been noted in the operation of the PICS program include the following.[20] Firstly, that the referral pathways between Adahps and private incarceration settings are not formalised and are difficult to establish and maintain. A NSW-wide standard of care and referral pathways should be established, regardless of whether the incarceration setting is public or private. Additionally, where there is a deficit in healthcare access within the private or public system, the alternate system should step in to provide resources to support the incarcerated persons adequately, ensuring their safety, dignity, and quality of life at all times regardless of which facility they are located in. PLHIV in custody have a right to equitable healthcare and the current system is somewhat fragmented.

Secondly, trans and gender diverse incarcerated persons being referred into the program report that their pronouns are often not respected within custodial settings, and they are frequently misgendered. Recognising and adhering to a person's gender identity is vital in fostering humanising and respectful relations in any situation, and in particular in healthcare settings and situations where there is a power differential, including incarceration settings. A NSW-wide standard of care, focused on dignity and respect of gender diversity should be implemented, frequent training provided to staff, and monitoring and reporting processes implemented to ensure these standards are complied with.

JHFMHN are currently partnering with ACON to provide education to their staff around gender, and review their policy and service model for trans and gender diverse people. There is organisational support for rolling out a training program for gender affirming health care in partnership with ACON.

Medication is often provided in incarceration settings on a monthly basis, which can be an issue when an incarcerated person is being discharged/released. For example, this may not be an issue if the person in custody is discharged one week after receiving their script. However, if they are discharged one week or a few days prior to receiving new medication this can be an issue. Many patients are released unexpectedly from court so they do not return to their centres to pick up their medication.

Usually people leaving custody need to re-establish their life, and solve problems such as housing, food, and relationship management. These issues tend to be primary considerations for people leaving custody. Health care demands, meeting medical and pharmaceutical timelines are often not prioritised due to the competing demands listed above. Difficulties can extend beyond medication supply availability post-incarceration, especially when taking into consideration delays in availability of healthcare appointments, blood tests, medication dispensing, etc. This is also relevant to those incarcerated persons released and then deported to another country. This has implications for adherence, potential transmission of HIV, and future health impacts.

Support for PLHIV in the community post-release also needs to be enhanced. Community health care workers need education, support, and training in working with previously incarcerated persons. There are a number of complexities with clients presenting with multiple co-morbidities. Information is often lost during client movement across health care systems both in custody and across NSW Health Local Health Districts. A system-wide approach is required to address potentially inconsistent rollout.

Access to healthcare and medications for PLHIV in incarceration settings is restricted by privacy and confidentiality issues, and compounded by stigma and discrimination. Anecdotal evidence

[20] Ibid.

suggests that privacy and confidentiality of incarcerated PLHIV seeking health care and medication is not a commonly reported issue, however both HALC and Positive Life work with clients post-incarceration who have reported their hesitancy to deal with documents and other processes that refer to HIV when not ensured of their privacy being maintained. The Royal Australian College of General Practitioners (RACGP) notes that incarcerated persons (custodial patients) have very little ability to exert free choice, have little or no privacy, and have little economic means and are reliant on the prison authorities to provide basic needs.[21]

Tobacco smoking remains very high among incarcerated persons, with the Kirby Institute reporting that almost 90% of survey respondents reporting they currently smoke.[22] There is also no apparent downward trend in the numbers who report they are current smokers. PLHIV have even higher rates of smoking than the general population, with significant associated adverse physical effects. The Australian Research Centre in Sex, Health and Society, La Trobe University HIV Futures 9 study found that in 2019, the rate of tobacco smoking among PLHIV participants was considerably higher than that of the Australian population, with 28.1% reporting they were smokers and 18.4% reporting they were daily smokers (compared to 14.5% of Australians overall).[23] Effective smoking cessation programs in incarceration settings that sustain cessation whilst in incarceration and in the community post-incarceration should be offered for this population.[24]

Due to the small numbers of PLHIV in incarceration settings in NSW, and the approximate and incomplete nature of the data relating to this population, it has been anecdotally reported that HIV may not be a priority issue within JHFMHN, in lieu of responding to other health issues. This appears to be consistent with the lack of information available on the Corrections NSW and JHFMHN websites on HIV and the services available to incarcerated and post-incarceration PLHIV. Though the population of incarcerated PLHIV may be relatively low proportionally (although exact numbers are unavailable), the nature of the complexity of living with HIV and the associated co- and multi-morbidities associated with living with HIV, as well as persistent stigma and discrimination, means that health access and equity for PLHIV is of paramount importance in securing positive health outcomes. Indeed, people who are in or have recently been in custodial settings are named as a priority population in the NSW HIV Strategy 2021-2025, as well as those populations who are overrepresented in incarceration settings, including Aboriginal and Torres Strait Islander people, people who inject drugs, and men (men who have sex with men named in the Strategy).[25]

AFAO and NAPWHA note that health education programs are the most widely used strategy for reducing the onward transmission of BBVs in incarceration settings. However, while incarcerated

[21] The Royal Australian College of General Practitioners. (2019). Custodial health in Australia: Tips for providing healthcare to people in prison. Retrieved from https://www.racgp.org.au/FSDEDEV/media/documents/Faculties/SI/Custodial-health-in-Australia.pdf

[22] Butler, T. and Simpson, M. (2017). National Prison Entrants' Blood-borne Virus Survey Report 2004, 2007, 2010, 2013, and 2016. Kirby Institute (UNSW Sydney). ISBN-13: 978-0-7334-3772-4. Retrieved from https://kirby.unsw.edu.au/sites/default/files/kirby/report/JHP_National-Prison-Entrants-Report-2004-2007-2010-2013-2016.pdf

[23] Power, J., Amir, S., Brown, G., Rule, J., Johnson, J., Lyons, A., Bourne, A. and Carman, M. (2019) HIV Futures 9: Quality of Life Among People Living with HIV in Australia, monograph series number 116, The Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Australia. Retrieved from https://www.latrobe.edu.au/__data/assets/pdf_file/0007/1058614/HIV-Futures-9.pdf

[24] Butler, T. and Simpson, M. (2017). National Prison Entrants' Blood-borne Virus Survey Report 2004, 2007, 2010, 2013, and 2016. Kirby Institute (UNSW Sydney). ISBN-13: 978-0-7334-3772-4. Retrieved from https://kirby.unsw.edu.au/sites/default/files/kirby/report/JHP_National-Prison-Entrants-Report-2004-2007-2010-2013-2016.pdf

[25] NSW Ministry of Health. (2020). NSW HIV Strategy 2021-2025. Retrieved from https://www.health.nsw.gov.au/endinghiv/Publications/nsw-hiv-strategy-2021-2025.pdf

persons are informed about the risks of infection and transmission, they are not consistently provided with the means to reduce their risk of acquiring BBVs.[26]

A NSW-wide standard of healthcare access, quality, and safety should be developed by JHFMHN in consultation with key related stakeholders which outlines how it intends to address and implement the NSW HIV Strategy 2021-2025 prevention, testing, treatment, and stigma objectives, as well as quality of life objectives. This standard should be developed with guidance from the RACGP Report: Custodial health in Australia: Tips for providing healthcare to people in prison.[27]

People living with hepatitis

Hepatitis B and hepatitis C are BBV's that manifest as liver infections. It is estimated that in NSW 80,363 people were living with hepatitis B as of 2018[28] and an estimated 48,381 people were living with hepatitis C.[29]

Effective treatment is available to people living with hepatitis B who are diagnosed, however not everyone needs to take medication to manage the condition. The management of Hepatitis B involves regular blood tests and ultrasounds of the liver. Hepatitis B can be transmitted through blood-to-blood contact and unprotected sex but cannot be transmitted through saliva, skin-to-skin contact or through airborne transmission. The vast majority of adults can spontaneously clear the virus and a vaccination against hepatitis B is available. If left untreated or unmanaged, hepatitis B can lead to liver cancer, cirrhosis, or liver failure. Most people living with hepatitis B will not show any initial symptoms.

Hepatitis C is a curable virus that is transmitted through blood-to-blood contact. Since 2016, new interferon-free direct acting oral antivirals (DAA) became available to all Australians. Prior to the introduction of DAA, uptake of treatment for hepatitis C was low in both community and incarceration settings due to the considerable side-effects of the treatment regimens. The DAA treatment regime has a high cure rate (approximately 95-98%) following a course of treatment of either 8 or 12-weeks.[30] If left untreated, hepatitis C can develop into chronic hepatitis C and cause long-term health problems, particularly for the liver. Most people living with hepatitis C will not show any initial symptoms and it is estimated 28 per cent of adults living with hepatitis C will spontaneously clear the virus.

Available data

Similar limitations in data availability for incarcerated PLHIV also exist for people living with viral hepatitis due to limited uptake of testing. The NPEBBVS 2016 survey notes that previous research has found that hepatitis C is between thirty to forty times higher among people who are incarcerated nationwide in comparison to the general community.

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[26] Frommer, M. and Maynard, T. (2016). Equity inside and out? HIV, treatment access and prisoners. HIV Australia, 14(1). Retrieved from https://www.afao.org.au/article/equity-inside-hiv-treatment-access-prisoners/

[27] The Royal Australian College of General Practitioners. (2019). Custodial health in Australia: Tips for providing healthcare to people in prison. Retrieved from https://www.racgp.org.au/FSDEDEV/media/documents/Faculties/SI/Custodial-health-in-Australia.pdf

[28] Romero N, McCulloch K, Allard N, MacLachlan JH, Cowie BC. (2019). National Surveillance for Hepatitis B Indications: Measuring the progress towards the targets of the National Hepatitis B Strategy – Annual report 2018. Melbourne: WHO Collaborating Centre for Viral Hepatitis, The Doherty Institute, p19. Retrieved from https://www.doherty.edu.au/uploads/content_doc/National_Surveillance_for_Hepatitis_B_Indicators_2018.pdf

[29] Kirby Institute. (2019). Hepatitis C elimination in NSW: monitoring and evaluation report. p5 Retrieved from https://kirby.unsw.edu.au/sites/default/files/kirby/report/Hepatitis_C_Elimination_in_NSW-Monitoring_Evaluation_Report_2019.pdf

[30] Hepatitis Australia. (2020). Curing hepatitis C. Retrieved from https://www.hepatitisaustralia.com/Handlers/Download.ashx?IDMF=7140e8e2-e5a5-44a2-b2f6-cfa2542baf37

In the general community, people living with hepatitis C make up less than 1% of the population. As NSW did not participate in the 2016 NPEBBVS, the most up to date data for the state is from the 2013 survey where 69 participants were from NSW among the 793 nationwide.[31] The results indicated that approximately 26% of NSW participants tested positive for hepatitis C while entering custody, under the national average of approximately 31% in 2013. However, nationally this number dropped to 22% in 2016, but as previously noted no comparable data is available for NSW within the 2016 NPEBBVS. The SToP-C study conducted in four incarceration settings in NSW between 2014 and 2019 found 19% of its 3,691 participants tested positive for hepatitis C on initial screening.[32]

Custodial settings offer a unique opportunity to treat people with undiagnosed hepatitis C. In 2018, 59% of people discharged from a custodial setting nationally reported having been tested for hepatitis C while incarcerated. In 2018, 25% of people who started treatment in NSW did so while incarcerated.[33] NSW has also reported virtual elimination of hepatitis C from 12 prisons.

In the general population of NSW, it is believed that people living with hepatitis B make up approximately 1% of the population. In the 2013 NPEBBVS, 17% of participants entering incarceration from NSW were living with hepatitis B. Nationally in 2016 about 1 in 6 entrants into incarceration tested positive for hepatitis B. In 2016, 46% participants screened as part of the NPEBBVS showed no evidence of immunity through vaccination of post-exposure.

Access to healthcare in incarceration settings and transitioning to post-incarceration

Knowledge of, and access to healthcare for viral hepatitis in incarceration settings relies heavily on education programs and information services. The Hepatitis Infoline (Infoline) run by Hepatitis NSW provides confidential and free information on viral hepatitis to people who live in NSW, including people in custodial settings. The Infoline can be accessed for free on prison phone systems. Each year, the Infoline receives approximately 1500 to 1600 calls from incarcerated persons where they requested information on viral hepatitis, including information on testing and treatment in custody.[34] Between approximately 10-15% of callers request Hepatitis NSW to advocate to JHFMHN on their behalf. Whilst Hepatitis NSW does advocate for incarcerated people in accessing testing and treatment, the COVID-19 pandemic has dramatically reduced these services as public health nurses within JHFMHN have been required to prioritise COVID-19 related issues. Hepatitis NSW continues to advocate for people in custody in urgent matters.

Hepatitis NSW also issues information packages for people in custody through their Infoline. The package includes:

- information on hepatitis C transmission testing and treatment;
- information for Aboriginal people and hepatitis C in NSW;
- information on hepatitis B testing;
- a guide on how to use the Offender Telephone System (OTS); and
- multiple copies of 'patient's self referral' forms.

[31] Butler, T, Callander, D, & Simpson, M. National Prison Entrants' Bloodborne Virus Survey Report 2004, 2007, 2010 and 2013. (2015). Kirby Institute (UNSW Australia). ISBN: 978-0-7334-3532-4. Retrieved from: https://kirby.unsw.edu.au/sites/default/files/kirby/report/JHP_National-Prison-Entrants-Report-2004-2007-2010-2013.pdf

[32] Lafferty, L, Rance J, Grebely J, Dore, G, Lloyd, A, Treloar, C, SToP-C Study Group (2020). Perceptions and concerns of hepatitis C reinfection following prison-wide treatment scale-up: Counter public health amid hepatitis C treatment as prevention efforts in the prison setting

[33] Justice Health and Forensic Mental Health Network. (2019). Breaking free from Hepatitis C. Retrieved from: https://www.justicehealth.nsw.gov.au/patient-support/breaking-free-from-hepatitis-c.pdf

[34] S, Davidson (Hepatitis NSW – Programs Manager). Interview. Conducted by Rhys Evans (HALC – Projects, Policy and Law Reform Solicitor), 21 April 2021.

The inclusion of the self-referral forms through the information package ensures requests can be made without approaching correctional service officers directly to obtain a form. Fear of stigma and discrimination if a person's BBV status is disclosed continues to act as a barrier for access to testing and treatment of viral hepatitis. Additionally, re-infection of hepatitis C can lead to internalised stigma as people in custodial settings can feel shame about accessing testing and treatment on multiple occasions. Education through the information pack and the Infoline are important services to help tackle stigma. Anecdotal evidence from Hepatitis NSW and HALC indicate that a considerable concern for people in custodial settings living with a BBV is accidental disclosure to correctional service officers. People in custodial settings should continue to be informed to speak directly to their health clinic nurse about testing and treatment and that all information disclosed remains confidential.

Peer education must continue to be central to addressing BBVs in correctional centres. NUAA has worked closely with JHFMHN on several harm reduction projects that have successfully changed attitudes and behaviour of people in custodial settings to hepatitis C prevention, testing and treatment. These include:

- Peer education as part of the Hepatitis in Prisons Elimination (HIPE) program
- *Insider's News*, a harm reduction magazine distributed through NSW correctional centres. The resource has won a national hepatitis C harm reduction resource award.
- Peer education programs ("Peer Harm Reduction in the Yard")
- Working with Jailbreak, a Community Restorative Centre radio program to produce hepatitis C and HIV messaging

Overall, anecdotal evidence provided by Hepatitis NSW and NUAA indicates that access to testing and treatment for viral hepatitis in custody is managed well by JHFMHN. This has been greatly assisted by the introduction of DAA and Dried Blood Spot (DBS) testing in custodial settings and effective education and information services from organisations such as Hepatitis NSW and NUAA outlined above. However, some reports of issues faced by incarcerated people in accessing healthcare while in custody include the following: [35]

- The closure of prisons and transfer of patients in incarceration can cause serious delays for testing and treatment. Additional issues can arise when transition is from public to private facilities, and vice versa, where handover of medical records face delays.
- Structural issues of the custody setting. For example, a person in custody may be called to see the nurse while they are working. They may be unaware that they have been called up or may not want to attend as they wish to prioritise work over healthcare. Similarly, security protocols and lock ins may cause delays in people's ability to see the nurse.
- Delays in access to testing and treatment. All four organisations contributing to this submission have anecdotally been informed that requests for testing, results, and treatment can be met with significant delays. This is despite people in custody submitting multiple patient referral forms.

Issues faced by people living with viral hepatitis when transitioning back into the community after incarceration are similar to those faced by PLHIV. These include:[36]

- Continuity of treatment after release. Health care demands are not often prioritised as issues such as housing, employment and relationships management take priority over treatment.

[35] R, Bearpark (Hepatitis NSW – Health Promotion Coordinator). Interview. Conducted by Rhys Evans (HALC – Projects, Policy and Law Reform Solicitor), 26 April 2021. S, Wilkinson (Hepatitis NSW – Project Officer Health Promotion & Community Support). Interview. Conducted by Rhys Evans (HALC – Projects, Policy and Law Reform Solicitor), 21 April 2021.
[36] Ibid.

- Lack of referral pathways to community healthcare services. This can cause issues where patients may be required to undertake follow up blood checks after completing treatment.

The scale-up of hepatitis C treatment-as-prevention in incarceration settings is an essential next step in transmission prevention and potential elimination. The SToP-C study identified a range of factors to be addressed for successful scale-up including adequate funding and resourcing, correctional staff and governance support and addressing re-infection risks.[37] It should be noted that any scale-up should be in conjunction with other harm reduction practices.

Previous programs introduced in custodial settings include the Hepatitis in Prisons Elimination (HIPE) program. HIPE met early success with the aim of eliminating hepatitis C from 12 custodial settings. The program gave incarcerated people a safe place to learn about and discuss hepatitis C with opportunities to be tested and treated where appropriate. It was through the HIPE program that NSW became the first jurisdiction to have achieved virtual elimination of hepatitis C in a custodial setting. A phase 2 scale-up of the program was planned, however has not proceeded. Further, it is our understanding the HIPE program is no longer running.

While education programs are the most widely used strategy and have met considerable success, hepatitis C poses a significant threat as once cured, re-infection can still occur. As both hepatitis B and hepatitis C can be transmitted through blood-to-blood contact, engagement in injecting drug use (IDU) without proper precautions is of serious concern. The NPEBBVS between 2004 and 2016 found that prison entrants with a recent history of IDU were "13-67 times as likely as prison entrants without a recent history of IDU to test positive for hepatitis C antibodies."[38] We note again the small sample size of the NPEBBVS and that these results should be scrutinised accordingly. However, IDU with unsterile injecting equipment accounts for a majority of new hepatitis C infections in Australia.[39] Although the proportion of respondents to the *Australian Needle Syringe Program National Survey* (ANSPS) who reported injection in custodial settings has declined over a 25-year period, the number remains considerably high between 29% and 36% over the past decade.[40]

People in custodial settings are characterised by engagement in at risk behaviours, including IDU and are at an increased risk of exposure to BBV's and reinfection of hepatitis C as demonstrated by the above data. Both the national and state hepatitis B and hepatitis C strategies recognise custodial settings as priority settings.[41] Despite this, only the current national Hepatitis C strategy recognises that current approaches to hepatitis C in custodial settings are primarily limited to treatment and should engage in evidence-based harm reduction programs. While treatment for re-infection is available within the NSW prison system, many people in custodial settings are reluctant to take it up without being supported to practice appropriate harm reduction techniques.[42]

[37] Lafferty, L, Rance J, Grebely J, Dore, G, Lloyd, A, Treloar, C, SToP-C Study Group (2020). Perceptions and concerns of hepatitis C reinfection following prison-wide treatment scale-up: Counterpublic health amid hepatitis C treatment as prevention efforts in the prison setting

[38] Australian Institute of Health and Welfare. (2019). The health of Australia's prisoners 2018. Retrieved from: https://www.aihw.gov.au/getmedia/2e92f007-453d-48a1-9c6b-4c9531cf0371/aihw-phe-246.pdf.aspx?inline=true

[39] NSW Ministry of Health. (2014). NSW Hepatitis C Strategy 2014-2020. Retrieved from: https://www.health.nsw.gov.au/hepatitis/Publications/hepatitiscstrategy.pdf

[40] Heard, S; Iversen J; Geddes L & Maher, L. (2020). Australian NSP survey: Prevalence of HIV, HCV and injecting and sexual behaviour among SNP attendees, 25-year National Data Report 1995-2019. Sydney: The Kirby Institute, UNSW Sydney. Retrieved from: https://kirby.unsw.edu.au/sites/default/files/kirby/report/ANSPS_25-Year-National-Data-Report-1995-2019.pdf

[41] Australian Government Department of Health. (2018). Third National Hepatitis B Strategy 2018-2022.
Australian Government Department of Health (2018). Fifth National Hepatitis C Strategy 2018-2022.
NSW Ministry of Health (2014). NSW Hepatitis B Strategy 2014-2020.
NSW Ministry of Health (2014). NSW Hepatitis C Strategy 2014-2020.

[42] Lafferty, L, Rance J, Grebely J, Dore, G, Lloyd, A, Treloar, C, SToP-C Study Group (2020). Perceptions and concerns of hepatitis C reinfection following prison-wide treatment scale-up: Counterpublic health amid hepatitis C treatment as prevention efforts in the prison setting

Current strategies in NSW primarily focus on treatment and education, with only Opioid Treatment Programs (OTP) and the disinfectant Fincol introduced as harm reduction techniques. Strict instructions must be followed to ensure the efficacy of Fincol. Key stakeholders herein and JHFMHN acknowledge that Fincol is an important harm reduction measure. However, feedback from incarcerated persons indicate that the instructions are difficult to follow for IDU in custody. Fincol is also not readily available in all areas in NSW prisons. Given Fincol does not have a strong evidence base, it would be useful to adopt an alternative that is effective and easy to use.

The Second Australian Viral Hepatitis Elimination Conference's Key Finding Reports notes that one of the three big barriers to hepatitis C elimination is the lack of controlled sterile needle programs in any Australian prisons.[43] Effective evidence-based harm reduction programs such as the provision of sterile needles and syringes should be recognised as a key action in both the national and NSW hepatitis C strategies to effectively minimise risk of transmission and re-infection in custodial settings. The introduction of Needle and Syringe Programs (NSPs) in the broader community has been highly effective in preventing the transmission of BBVs and health and community care should be accessible to all, irrespective of incarceration status, in line with national strategies. In combination with education programs, harm reduction programs would ensure Australia is on-track to achieve the World Health Organisation elimination targets by 2030.

We note that delays in access to testing and treatment are not unique to hepatitis and HIV treatment but also to most health care in custodial settings. NUAA has received reports from people in incarceration of delays in access to treatment for diabetes, mental health treatment, blood and urine tests and drug and alcohol treatment.

Opioid Treatment Program

OTP delivers pharmacotherapy and associated services to opioid dependent people. It has been found to be effective in retaining opioid dependent people in treatment and reducing drug injecting and syringe sharing among IDU. The program also reduces the risk of drug related death following release from custody. OTP is also an effective harm minimisation technique that reduces the transmission of BBVs through IDU. Recently there has been a scale up of the availability of OTP through the introduction of Long-Acting Injectable buprenorphine treatment.

Patients who are on an OTP prior to entering custody can continue treatment unless this is clinically contraindicated, and opioid dependent people already in custody may begin treatment if assessed to be appropriate.[44] While the NSW Clinical Guidelines indicate OTP is available to people in custody not already on the program, anecdotal evidence from Hepatitis NSW suggest that this is not as prominent for a range of reasons.

Traditional OTP is resource intensive and OTP places have been limited due to resource and financial restraints faced by JHFMHN. The introduction of longer acting depot buprenorphine has changed the landscape, however there is a substantial waiting list due to high demand from people who have been seeking to initiate OTP for some time.

The nature of longer acting buprenorphine means that it is unsafe to begin people in custody who may be on remand or serving short sentences of only two to three months. It is reported that up to

[43] ASHM. (2019). Key Findings Report - 2nd Australasian Viral Hepatitis Elimination Conference. Retrieved from: https://ashm.org.au/Conferences/conferences-we-organise/australasian-viral-hepatitis-elimination-conference/
[44] NSW Ministry of Health. (2018). NSW Clinical Guidelines: Treatment of Opioid Dependence – 2018. Retrieved from: https://www1.health.nsw.gov.au/pds/ActivePDSDocuments/GL2018_019.pdf

25% of people in custody on an OTP will be released into the community unexpectedly.[45] Close adherence to OTP is an essential component to its success and disruption in treatment can compromise the health of the patient. Removal of daily dosing of buprenorphine in favour of longer acting depot buprenorphine limits the opportunities for these people to receive OTP. Arranging placements for opioid dependent people after release is also often challenging for JHFMHN with limited placements available externally. In particular, if depot buprenorphine is not available where a patient will be living post-release, they are not initiated onto the program. It is essential that JHFMHN and the NSW Ministry of Health expand OTP both in custody and the wider community and establish clear referral pathways to ensure continuity of treatment upon release.

Finally, while OTP is effective for prevention of hepatitis C in people who use opioids, there is no equivalent treatment available for people who use methamphetamine, a considerable proportion of the population of people who inject drugs.[46]

Monitoring and reporting of health access outcomes

Although there is a lack of comprehensive and accurate data on the number of incarcerated persons living with HIV, BBVs, and STIs in NSW, and their access to healthcare whilst in and transitioning out of incarceration settings, we believe this to be in the best interests of privacy and confidentiality of this population. Disclosure of an individual's BBV and STI status should always be optional, provided with fully informed and freely given consent, and protected by the strictest privacy and confidentiality provisions.

We note the limitations of monitoring and reporting of health access outcomes given these restrictions on data, and recommend as an alternative to identified demographic-related monitoring and reporting mechanisms, that JHFMHN develops and maintains quality controlled standards and processes for ensuring incarcerated persons receive adequate healthcare, irrespective of BBV status but taking into consideration the added complexities of living with a BBV in an incarceration setting. These standards can and should be developed in consultation with key related stakeholders, such as Positive Life NSW, HALC, Hepatitis NSW, NUAA, Adahps, ACON, AFAO, NAPWHA, and RACGP.

Conclusion

Healthcare for incarcerated persons, including those living with BBVs, should be provided in line with international standards from the UN and WHO, whereby all incarcerated persons have the right to access an equivalent standard of healthcare as available in the wider community. Incarceration settings provide a unique public health opportunity to provide comprehensive and equitable BBV healthcare access to vulnerable and high-risk populations, including prevention, testing, treatment, and quality of life initiatives. Prevention initiatives need to target incarceration setting entrants, particularly those with a history of injecting drugs and those who are in an incarceration setting for the first time, to initiate prevention strategies including education, hepatitis B vaccination, hepatitis C treatment, and HPV vaccination and testing.[47] Incarceration settings have

[45] NSW Ministry of Health. (2019). Clinical guidelines for use of depot buprenorphine (Buvidal and Sublocade) in the treatment of opioid dependence. Retrieved from: https://www.health.nsw.gov.au/aod/Publications/full-depot-bupe-interim-gl.pdf

[46] Geddes, L., Iversen, J and Maher, L. New South Wales Needle and Syringe Program Enhanced Data Collection Report 2020, The Kirby Institute, UNSW Sydney, 2020.

[47] Butler, T. and Simpson, M. (2017). National Prison Entrants' Blood-borne Virus Survey Report 2004, 2007, 2010, 2013, and 2016. Kirby Institute (UNSW Sydney). ISBN-13: 978-0-7334-3772-4. Retrieved from https://kirby.unsw.edu.au/sites/default/files/kirby/report/JHP_National-Prison-Entrants-Report-2004-2007-2010-2013-2016.pdf

the opportunity to be transformational centres for rehabilitation and support, rather than vessels for punishment.[48]

If additional information or citations in relation to this submission are required, please feel free to contact Alexandra on alexs@halc.org.au, Jane on janec@positivelife.org.au, Steven on sdrew@hep.org.au, or Mary on maryh@nuaa.org.au.

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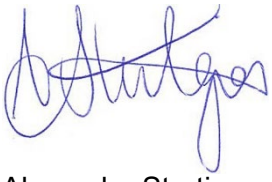

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[48] The Royal Australian College of General Practitioners. (2019). Custodial health in Australia: Tips for providing healthcare to people in prison. Retrieved from https://www.racgp.org.au/FSDEDEV/media/documents/Faculties/SI/Custodial-health-in-Australia.pdf