AIVL
Australian Injecting
& Illicit Drug Users League

MISSING CONNECTIONS

Service user experiences of people living with hepatitis C exiting custodial settings

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July 2019

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ABBREVIATIONS

AIVL	Australian Injecting and Illicit Drugs Users League
BBV	Blood borne virus
DAA	Direct-acting antivirals
HCV	Hepatitis C virus
NSP	Needle and syringe program
OMT	Opioid Maintenance Treatment
PBS	Pharmaceutical Benefits Scheme
PNSP	Prison needle and syringe program
WHO	World Health Organization

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AUSTRALIAN INJECTING & ILLICIT DRUG USERS LEAGUE (AIVL)

AIVL is the Australian national peak organisation representing the state and territory peer-based drug user organisations in relation to issues of national relevance for people with lived experience of drug use.

AIVL's vision is a world where the health and human rights of people who use/have used drugs are equal to the rest of community. This includes a primary focus on reducing the transmission and impact of blood borne viruses (BBVs) such as hepatitis C and HIV – including for those accessing drug treatment services – through the effective implementation of peer education, harm reduction, health promotion and policy and advocacy strategies at the national level.

Member organisations of AIVL are:

Australian Capital Territory (ACT)
Canberra Alliance for Harm Minimisation and Advocacy (CAHMA) and The Connection

New South Wales (NSW)
NSW Users and AIDS Association (NUAA)

Northern Territory (NT)
Northern Territory AIDS and Hepatitis Council (NTAHC)

Queensland (QLD)
QLD Injectors Voice for Advocacy and Action (QuIVAA)
Queensland Injectors Health Network (QuIHN)

South Australia (SA)
Hepatitis SA Clean Needle Program Peer Projects

Tasmania (TAS)
Tasmanian Users Health and Support League (TUHSL)

Victoria (VIC)
Harm Reduction Victoria (HR VIC)

Western Australia (WA)
Peer Based Harm Reduction WA

EXECUTIVE SUMMARY

With the release of the *Fifth National Hepatitis C Strategy* by the Australian Government in December 2018, it's an opportune time to revisit Australia's response to hepatitis C, which disproportionately affects people who/have inject/ed drugs and those in custodial settings.

The goal of eliminating hepatitis C as a public health threat by 2030 edges closer. Whilst progress has been made since the listing of innovative new direct-acting antiviral drugs (DAAs) on the Pharmaceutical Benefits Scheme, Australia cannot afford to rest on its laurels.

Elimination will continue to evade Australia whilst there remain missing connections to evidence-based harm reduction measures, namely prison needle and syringe programs, supported by improvements to the continuity of care for those on DAA treatment, when released back to the community.

Hepatitis C is a serious communicable disease, which if left untreated, can result in chronic liver disease, cirrhosis and/or liver cancer. A holistic approach to identification and treatment needs to be provided to reduce the mortality and morbidity associated with hepatitis C.

Custodial settings, as outlined in the new national strategy, are priority locations where the disease is transmitted. The Australian Injecting and Illicit Drug Users League (AIVL) believes that strengthened efforts need to be made in this area if Australia is to stand any chance of achieving its elimination goal.

Through consultation with its member organisations, AIVL has identified a number of areas, processes and policies which need attention if further progress toward elimination is going to be achieved. A significant gap in processes and procedures at present relates to the focus on continuity of care provided to people exiting custody whilst receiving DAA treatment.

AIVL also believes that the expansion of, and improved resourcing of, peer-based programs could significantly enhance outcomes and ensure continuity of treatment for those who need it.

The Australian Government has provided a robust framework through which elimination could be achieved, however as custodial settings are under the jurisdiction of states and territories commitment and resourcing needs to be provided by them to act in line with the goals and areas of action outlined in the *Fifth National Hepatitis C Strategy*.

A number of best practice actions have been developed to inform systemic changes which would support an improved outcome for people within and exiting custodial settings who are living with hepatitis C and receiving treatment.

Chief Executive Officer
Melanie Walker

INTRODUCTION

People who inject/have injected drugs are overrepresented in custodial settings due to the criminalisation of drug use[1]. Furthermore, people in contact with the criminal justice system are some of the most vulnerable people in society[2]. Injecting drug use is known to be a major contributor to the global burden of blood borne virus infection and transmission[3]. These factors combined, result in incarceration being a risk factor for the transmission of hepatitis C (HCV). As such, people in custodial settings face profound health disparities including a HCV prevalence that is far greater in custodial populations than the general community.

HCV is the most commonly reported blood borne virus in Australia – in 2018 there were 10,913 new notifications[4].

With this is mind it is vital to understand that although places of incarceration act as an incubator for HCV, they also act as an opportune locale to test, treat and thereby reduce the transmission of HCV[5]. As Australia works toward the goal of HCV elimination by 2030, steps must be taken to improve the testing, treatment and care of people both within and exiting custodial settings.

Continuity of care is a critical element of a sustainable custodial health service as outlined by the World Health Organization (WHO)[6]. Comprehensive measures should be taken within all Australian jurisdictions to ensure a consistent approach to both evidence-based harm reduction measures and appropriate supports for detainees upon release which meet the equivalence of care principle.

In 2017, the Australian Injecting and Illicit Drug Users League (AIVL) commissioned a jurisdiction-based needs assessment of people living with hepatitis C as they were discharged from custodial settings, entitled *'A needs analysis for people living with HCV after leaving custodial settings in Australia'*.

The aim was to understand how to improve the completion and success rate of their hepatitis C (HCV) treatment by ensuring a seamless transition to care in the community after release from custody[7]. A desktop review along with surveys and structured interviews were conducted to provide an overview of the policy and procedural processes at the time within each Australian jurisdiction.

It was found that policy responses varied distinctly across jurisdictions. Health services for custodial settings are the responsibility of state and territory governments. In some jurisdictions the local health department provides the health services, while in others it is the justice or corrections department[8].

Whilst the structural policy settings were explored in the aforementioned report and are well documented in a range of broadly available literature, this new report has been informed by the real-life experiences of people who have come in contact with AIVL's member organisations to use their peer-based services.

AIVL held consultations with representatives from its 9 peer-based member organisations in late 2018 and early 2019 to learn more about the real-life experiences of people who use/inject drugs who have exited custody whilst on DAA treatment, and how this experience aligns with existing jurisdictional processes, protocols, policies and procedures.

Feedback received indicates a high degree of inconsistency within and between jurisdictions both in terms of established policies and procedures as well as their implementation – meaning what is written on paper does not always translate to real life practice. Not only were issues of continuity of care identified, but also initial access to treatment itself.

This report will highlight areas which continue to present barriers and challenges to ensuring the equivalence of care whilst incarcerated, along with the continuity of care upon integration back into community. A number of best practice approaches on how improvements can be made to enhance outcomes are provided at the end of the report.

THE GOAL OF HEPATITIS C ELIMINATION

In 2016 the Australian Government made a significant investment to list new direct acting antivirals (DAAs) which have a 98% rate of curing hepatitis C (HCV), onto the national Pharmaceutical Benefits Scheme (PBS). The listing garnered international attention given the commitment it signalled towards achieving the World Health Organization's (WHO) goal of HCV elimination by 2030. Australia is in a position to be a world-leader in the fight against HCV.

Health care in custodial settings is managed differently within each state and territory jurisdiction. However, the Australian Government funded HCV treatment to be accessible without restriction. Thereby costs for DAA treatment are not borne by people who are incarcerated or at a jurisdictional level[9]. Despite this investment, given that implementation of testing, treatment and management of HCV falls outside of the control of the Commonwealth, the goal of elimination in Australia is threatened by a lack of policy and programmatic focus within custodial settings at a jurisdictional level.

Whilst screening and treatment programs do exist within custodial settings across the country, as outlined in AIVL's report *'A needs analysis for people living with HCV after leaving custodial settings in Australia'*, there are notable inconsistencies which undermine the potential success of the Australian Government's efforts[10].

Alignment of policy with implementation is urgently needed if Australia is to optimise its world-leading investment in the goal of eliminating HCV[11]. To achieve targets set by the World Health Organization (WHO) to eliminate HCV by 2030, high-risk populations including those in custodial settings must be prioritised. Modelling has shown that if the incidence of HCV reduces within the prison population, transmission rates within the community will also reduce[12].

With rates of DAA treatment uptake dropping since the drugs' initial listing on the PBS, Australia is at risk of not achieving elimination by 2030 unless there is a concerted and significant effort to target high-risk priority populations. However, placing people on DAA treatment alone is not enough. Appropriate support must be provided to facilitate the best possible outcomes of treatment in conjunction with a range of harm reduction tools to prevent further transmission and/or reinfection.

Prevalence of hepatitis C in custodial settings

Viral hepatitis is a public health issue both worldwide and within Australia. Globally it is among the top 10 causes of death[13]. The major burden of mortality caused by hepatitis C relates to cirrhosis and liver cancer.

There are strong connections between incarceration, injecting drug use and HCV infection[14]. Harm Reduction International has described the prevalence of hepatitis C in Australia's prisons as a 'primary concern'[15]. People entering prison were 4 times as likely to report illicit drug use in the preceding 12 months as people in the general community[16]. Also 18% of prison entrants reported that they had shared injecting equipment in the previous month[17].

The rate of HCV within Australian prisons is estimated to be 31% and 56% among people who inject drugs, thus the condition is becoming normalised[18]. These rates can be attributed to the criminalisation of drug use thus making HCV more prevalent among people in custodial settings. When people who inject drugs are criminalised it should be of no surprise that injecting behaviour continues for many during their imprisonment.

People who inject drugs are a high-risk population for contracting HCV due to the sharing of used injecting equipment. In the developed world including countries such as Australia, most new infections of HCV are associated with injecting drug use[19]. The higher the rates of injecting drug use, the greater risk of exposure to blood borne viruses (BBVs) which is why evidence-based harm reduction measures such as needle and syringe programs (NSP) and pharmacotherapy are vitally important.

However, the provision of pharmacotherapies such as methadone and buprenorphine within Australian prisons without accompanying adequate access to sterile injecting equipment fails to fully address the risks for the ongoing transmission of HCV[20]. And whilst it is known that rates of injecting drug use decrease within custodial settings, given the lack of availability of sterile injecting equipment, rates of sharing increase[21]. The proportion of prison dischargees who reported using a needle that had been used by someone else while in prison was 7.8% in 2018[22].

Most people who are incarcerated will leave custody and re-enter the community. If prisons continue to act as an incubator for communicable diseases and untreated conditions, the release of people will continue to pose a threat and act as a barrier to the achievement of key public health goals. There needs to be political will, effort and resources allocated to ensure that this priority population receives appropriate health care and access to harm reduction measures[23].

Public health and human rights of people incarcerated

"A nation should not be judged by how it treats its highest citizens, but its lowest ones"
– Nelson Mandela

The World Health Organization stipulates that the State has a duty of care to provide safety, basic needs and recognition of human rights, including the right to health care for people who are incarcerated. The right to good health should in no way be diminished by being in detention[24].

International guidelines apply the principle of equivalence to the treatment of people in custodial settings. Equivalence of care is a medical principle, which states that when a person is detained they are entitled to the same standard of medical care afforded to them as would be dispensed to them in the general community in the same country[25].

Australia has committed to the provision of equivalent health care in custodial settings as a result of adopting the United Nations 'Mandela Rules'. Rule 24 states:

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.*

2. *Health care services should be organised in close relationship to the general public health 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.*[26]

Within Australian custodial settings, health care provision is guided by the concept of community equivalence outlined above. This means that in principle, incarcerated people are entitled, without discrimination, to receive the same level of access and quality of health care as the general population, including preventative measures[27 28].

This principle has been adopted by the ACT Labor Party within the *ACT Labor Platform 2018-2019* explicitly stating that prison and custodial arrangements should:

> *'Ensure access to treatment, rehabilitation, aftercare and related support services equal to the standard of service provided to the broader community.'*[29]

The Australian Government's *Fifth National Hepatitis C Strategy 2018-2022* states human rights as one of the guiding principles. Acknowledging that people with HCV have the same rights to comprehensive and appropriate information and health care as other members of the community[30].

A barrier to achieving universal HCV treatment and care within custodial settings relates to the stigma faced by people who inject drugs, people who are/have been incarcerated and people who have been diagnosed with HCV.

Addressing stigma within custodial settings is critical to ensure that equivalence of care is achieved. Power relations are produced within the hierarchies that develop in custodial settings. People in custody in Australia who inject/have injected drugs have

reported that correctional services officers label them as 'junkies'[31]. The effect of stigmatising labels like this, is that issues of trust can influence a person's willingness to engage with testing and treatment, which is further complicated by and connected with the stigma of injecting drug use.

Additionally, the standard of health care that is received by people in custody has important implications for the health of the wider community. Owing to the flux of people between custodial settings and the community, health issues experienced within custody become an issue for the broader community to manage. Therefore, ensuring the equivalence of care during incarceration is not only a matter of international best practice, but a measure that should be taken to achieve positive public health outcomes across the whole of Australian society.

Why custodial settings need to be a priority

The number of people in Australia's prisons rose by 56%, from almost 28,000 in 2008 to about 43,000 in 2018[32]. Custodial settings pose a threat to the health of the people incarcerated within them. Essentially, custodial settings act as incubators for communicable diseases because they are associated with higher rates of transmission than in the community[33].

Due to no prison needle syringe programs operating within Australia's prisons, incarceration itself is an independent risk factor for HCV transmission for people who inject drugs. Due to the criminalisation of drug use, people who use drugs are overrepresented in the prison population. *The Health of Australian Prisoners 2018* report found that 65% of prison entrants reported drug use in the previous 12 months[34].

Moreover, this is a population group which enters into and cycles through the criminal justice system due to a range of factors. Owing to an absence of harm reduction measures there is a greater risk of HCV transmission per injecting incident within custodial settings compared with the community. HCV transmissible risk behaviours and activities are high within the confines of custody.

Aside from the sharing of injecting equipment, other forms of unsafe skin penetration such as tattooing, piercing and sharing razors which are not adequately sterilised enhance the likelihood of HCV transmission[35].

As a result, this population is known to have a greater burden of communicable and noncommunicable diseases than the general population.

Custodial settings need to be a priority focus for public health interventions because inmates are known to have a disproportionate burden of communicable diseases[36]. Imprisonment tends to further entrench the socioeconomic factors that may have initially contributed to incarceration[37]. For example, about 1 in 3 prison entrants have an education attainment level under Year 10[38]. People who are in custodial settings have typically fallen through the gaps of the community-based public health care system.

Custodial settings as an opportunity

Custodial settings are uniquely placed to detect and address public health issues, especially in relation to the screening, treatment, management and prevention of transmission of BBVs. Not only are there positive health outcomes for those incarcerated but the broader community receive benefits owing to an overall improvement in public health outcomes. Health care in custodial settings is essential in forming a public health strategy which will effectively address the global epidemic of HCV[39 40].

First and foremost, custodial settings offer the opportunity to engage with groups of people who are often labelled 'difficult to reach'. As the uptake of DAAs drops in the broader Australian community, and questions are being raised on how to diagnose and treat marginalised people most likely to be affected by HCV. Effectively utilising health care mechanisms within custodial settings provides a means to identify and treat those currently living with HCV.

For some, they may have not received health care for a substantial period prior to entering custody. Therefore, they may have complex physical and psychological needs which are compounded by a poor history of access to and uptake of healthcare services. As such, custody can offer an opportunity to address issues of equity of access through specific and targeted health interventions[41 42].

Custodial settings can provide a buffer to the stressors of community life which can interfere with a person's ability to manage their healthcare. Managed well, HCV treatment can be dispensed effectively in custodial settings with outcomes equal to or

better than community-based treatment[43]. Given the prevalence of HCV within custodial settings which is underpinned by a high percentage of people with a history of injecting drug use, this is a key setting for micro-elimination efforts in relation to HCV[44].

Incarceration ought to provide a window of opportunity to offer evidence-based harm reduction measures in conjunction with available alcohol and drug treatment services to improve the health outcomes of those incarcerated as well as the general public health of the Australian community.

The importance of harm reduction

Within the broader community, harm reduction measures have been in place for decades. Australia has much to be proud of in terms of the range of harm reduction measures available in the community. These measures have proven to be practical, effective, and economically viable in terms of reducing health-related harms caused by injecting drug use[45].

The most significant harm reduction measures are needle and syringe programs (NSPs) and opioid maintenance treatment (OMT) which have been directly correlated with successful intervention in the transmission of HCV and HIV in people who inject drugs[46].

The World Health Organization advocates that to prevent the transmission of communicable diseases among people who inject drugs, availability of sterile injecting equipment and provision of OMT are critical[47]. Furthermore, the Australian Government acknowledges that people in custodial settings are at a heightened risk of HCV transmission which is connected to the limited provision of evidence-based harm reduction programs[48].

Prison Needle and Syringe Programs (PNSP)

Despite strong evidence that needle and syringe programs are effective in reducing the transmission of HCV and other BBVs, Australian custodial settings continue to lack this vital harm reduction measure. The health effectiveness and financial efficiency of NSPs are well established within the community setting[49]. From 2000 to 2009, an investment of $243 million in NSPs resulted in the prevention of an estimated 96,667 new HCV infections and 32,050 new HIV infections in Australia[50].

Participants at AIVL's National Consultation Workshop highlighted the issue of unsafe injecting practices in custodial settings. Although injecting drug use in custodial settings is less frequent than in the community, each act of injecting carries with it a higher risk of BBV transmission due to higher rates of sharing injecting equipment.

In the *Fifth National Hepatitis C Strategy*, the Australian Government calls for 'improved equitable access to successful preventative measures for all priority populations, with a focus on sterile injecting equipment through needle and syringe programs'[51]. People in custody are listed as a priority population. The Strategy goes on to state that the 'absence of this same evidence-based harm reduction service in custodial settings is a policy gap in the hepatitis C prevention effort'[52].

Thus, acknowledgement has been made by the Australian Government – as well as all the state and territory governments - that this is a vital measure, the absence of which is currently impeding Australia's effort to eliminate HCV whilst also failing to uphold the principle of equivalence of care for people incarcerated. However, while states and territories fail to act in line with the agreed National Strategy, progress towards implementing PNSP within any custodial setting in Australia remains hindered.

In some countries, including Canada, Germany, Spain, Switzerland and Iran, PNSP have been functioning for over two decades. Programs have been run in custodial settings of varying sizes and security levels, and sometimes in prisons which have been dramatically over-populated. Research indicates that the presence of PNSP in custodial settings has a positive impact on HCV transmission rates[53 54].

A meta-analysis conducted of PNSP found that there was no record of needles or syringes being used as weapons[55 56]. In fact, there is evidence to suggest that PNSP makes for a safer working environment for correctional services staff as prisoners are less likely to hide needles therefore resulting in less needlestick injuries during cell searches[57].

Concerns have been expressed by correctional services staff regarding the perceived risks associated with needles and syringes being accessible within a custodial setting. The World Health Organization has published evidence of evaluations of existing PNSP which has shown that when implemented and managed well PNSP do not endanger staff and serve to reduce risk behaviours associated with injecting[58].

State and territory governments need to take action in line with existing Strategy and policy frameworks if Australia is going to achieve HCV elimination and uphold its stated principle of providing people who are incarcerated with the same level of health care that is available in the community. Implementing PNSP does not necessitate a trade-off between health and security.

The absence of PNSP in Australia raises questions as to whether the highly stigmatised nature of injecting drug use has contributed to the lack of evidence-based policy action[59]. Policy decisions need to be informed by an evidence-base and not be influenced by moral judgements.

Pharmacotherapy

Pharmacotherapy treatment is another well-established harm reduction measure used within most custodial settings in Australia. Opioid pharmacotherapy drugs – such as methadone and buprenorphine – are designed to reduce cravings for opioids as well as their withdrawal symptoms.

Opioid Maintenance Treatment (OMT) is known to be protective against the transmission of HCV as it reduces the desire to take opioids[60]. Its effectiveness is also strengthened when supplemented by needle and syringe programs[61].

Evidence has shown that the availability of OMT in custodial settings has been associated with reduced rates of injecting drug use, which subsequently reduces the associated risk factors connected with BBV transmission[62].

AIVL's analysis of the availability of OMT in custodial settings highlights the irregularities across jurisdictions[63]. In Queensland OMT has been available only to the incarcerated female population. Whilst in the Northern Territory initiation of OMT is not an option to those newly incarcerated.

This highlights the inconsistency of policies and procedures across jurisdictions in Australia – access to evidence-based harm reduction measures is unacceptably determined by the location in which one is detained.

The World Health Organization states that a failure to implement effective drug treatment can lead to further spread of HCV[64]. Therefore, there must be consistency across all jurisdictions in regard to the availability of OMT within custodial settings.

Direct-Acting Antiviral treatment

The Australian Government's investment in direct-acting antivirals (DAAs) to treat HCV is significant. Furthermore, it is noteworthy as, although custodial settings and their subsequent health provision fall under state and territory jurisdictional power, this life-saving treatment has been made available within all custodial settings across the country thanks to the Commonwealth Government.

HCV treatment such as DAAs should ideally be provided concurrently with harm reduction measures such as PNSP and OMT[65].

The provision of HCV treatment within custody can achieve significant health outcomes. Studies have shown HCV treatment programs in custodial settings to be both feasible and effective[66]. Given the over-representation of the Indigenous population in the custodial system and uptake of DAA treatment being low in community settings, for this priority population that is at high risk, delivery of HCV treatment in custody has particularly strong beneficial outcomes[67].

Yet there are issues surrounding the early release and transfer of detainees during treatment which effects the provision of treatment within custodial settings. In Scotland, a study found that 40% of prisoners were either released or transferred during HCV treatment and outcomes of the affected individuals were poorer than others[68]. Internal transfers resulted in a loss of routine and a breakdown in communication between health care staff.

The Australian prison system sees a high number of prisoners being routinely moved within and between prisons. During the period of 2017-18, prisons in Australia were operating at 116% of design capacity (excluding New South Wales, Victoria and South Australia, which did not provide data)[69]. A strategy employed to manage these situations is moving people between prisons which in turn makes the provision of health care more difficult and inconsistent.

Reinfection

Studies have shown that reinfection does occur after successful HCV treatment[70]. Furthermore, existing policies in Australia have consistently failed to address HCV reinfection[71]. The risk of reinfection among people who inject drugs in custodial settings has been shown to be considerable[72].

If there continues to be an absence of access to sterile injecting equipment in custodial settings and/or suitable access to OMT, reinfection will continue to remain a risk factor for the incarcerated population[73]. This undermines efforts in the broader community to eliminate HCV in Australia. Sustained injecting of drugs is a reality. The significant risk of reinfection within this context needs to be recognised and appropriate policies developed and implemented to address it accordingly.

CONTINUITY OF CARE

Continuity of care is a crucial element of custodial settings health care. Although a person may be released from incarceration, any treatment they commenced whilst in custody should not be jeopardised. The World Health Organization states that to provide the best health outcomes, continuity of care is essential[74].

Correctional staff should be making arrangements to ensure uninterrupted care for prisoners during transfers or upon release. This should be supported and facilitated by management and appropriate policies. The *South Australian Prisoner Blood Borne Virus Prevention Action Plan 2017-2020* explicitly acknowledges the challenge of providing continuity of care upon release[75]. The cost-effectiveness of treatments provided in custody and the broader public health impacts are affected by how well continuity of care is ensured and efforts should be made to strengthen such transitions[76].

Studies in the UK have found that inter-prison transfers and community release both acted as barriers to completing HCV treatment[77 78]. This was due to prisoners being released without notice and pre-planning. For those who were able to complete DAA treatment whilst incarcerated the cure rate was 74% whereas those who were transferred or released during treatment had cure rates of 59% and 45% respectively[79].

In Australia, recent data shows an increasingly high proportion of people in custody on remand whose timing of release is often uncertain. Moreover, it is relatively commonplace for a person on remand to leave prison to attend court, and then be released directly from court to the community[80].

Transitioning back to community is considered a high-risk period and has important health implications for prisoners. The vulnerability of this process is contextualised by a person's increased risk of death following release from custody in the initial weeks from overdose or relapse[81]. This highlights the need for additional support to ensure people make a meaningful transition back into community life.

In relation to HCV treatment, ensuring linkages between care provided in custody and the community is therefore essential. If appropriate hepatology care is organised at the time of release it has been found that a higher proportion of individuals achieve a sustained virologic response to the virus[82].

Correctional services need to work in close collaboration with community-based organisations to ensure that DAA treatment is not interrupted when people enter, leave prison or are transferred within the system. Interventions, such as peer-led programs, which support linkages to care following release are important if the cascade of HCV care is to continue.

Continuity of care is associated with the principal of equivalence of care, ensuring that no one is left in a worse health position owing to their incarceration. Moreover, the significant investment made by in the universal accessibility of DAA treatment by the Australian Government is undermined if this critical link in the chain is allowed to falter.

The real experience

AIVL held consultations with member organisations in late 2018 and early 2019 to learn more about the real-life experiences of people who use/inject drugs who have exited custody whilst on DAA treatment, and how this experience aligns with existing jurisdictional processes, protocols, policies and procedures.

Feedback received indicates a high degree of inconsistency within and between jurisdictions both in terms of established policies and procedures as well as their implementation – meaning what is written on paper does not always translate to real life practice. Not only were issues of continuity of care identified, but also initial access to treatment itself.

There are inconsistencies in regard to who is seen as eligible for DAA treatment. In some jurisdictions remandees are excluded. Unsentenced prisoners represent about one-third of the custodial population on an average day[83]. There are complications owing to time limits and waiting periods. As the full course of DAA treatment typically takes 12 weeks to complete, people in remand pose a challenge for health staff.

Feedback received during AIVL's national workshop consultation included reports that there is difficulty accessing the treatment even when people are tested and eligible. Operational issues were cited as a reason for this barrier to access, stating that 'luck' appeared to play a role in one's likelihood to gain access to treatment. Some reported 'lots of talk' regarding HCV treatment but observed that follow through and the provision of DAAs is often lacking.

Barriers for those who were on treatment included medical history not being passed onto community-based GPs as well as the need for releasees to organise their own medical appointments. Requiring a releasee to organise their own continuity of care is bound with risk.

Discharge planning is a critical process which should ideally support the continuity of health care between custody and the community. A discharge plan provides an individual with a plan for their own continuity of care. Compliance with a treatment plan, including HCV treatment, is reliant upon a person's knowledge of their health conditions, including the medications that they require[84].

The Australian Institute of Health and Welfare recognises that comprehensive and consistent release procedures to ensure continuity of health care are vital for the health of people leaving custody[85].

BARRIERS WHEN RE-ENTERING THE COMMUNITY

Upon exiting custody, it cannot be assumed that a person is re-entering the community with a stable situation. Across jurisdictions people exit custody with a varying range of resources at their disposal, for many this is minimal at best. Furthermore, ties with family and social supports may have been lost during the period of incarceration so there may be no well-established social linkages[86].

Whilst transitioning back to the community, issues of homelessness, unemployment and drug use as well as other competing factors can have an impact on HCV treatment compliance[87]. Incarceration adds a barrier to obtaining employment, especially for those who have spent more than 6 months in custody[88]. Less than one-quarter of prison dischargees had be able to organise paid employment that would begin within 2 weeks of their release from prison[89]. Furthermore, over half of expectant dischargees surveyed anticipated that they would be homeless once released[90].

Transportation to health care facilities upon release can also be problematic. If someone is able to access a health care facility, they may then be faced with the issue of not having Medicare coverage.

The Medicare Benefits Schedule (Medicare) provides residents of Australia with access to no-cost or subsidised health care. Medicare is funded at a national level by the Australian Government. When people are incarcerated, they lose their Medicare and PBS entitlements under Section 19(2) of the *Health Insurance Act 1973*[91]. Health care provided in custodial settings is at the cost of jurisdictional health or correctional services.

Depending on the length of sentence, some people's Medicare access may have expired. Reapplying for a Medicare card upon release is challenging for many ex-prisoners due to a lack of the documentation needed. This often becomes a major barrier to seeking health care services and undermines any connections, transition plans and information exchanges which may have been made by prison and community health services[92]. Recent data shows that 20% of dischargees were unsure if they would have an eligible Medicare card upon release, and 16% believed that they would not have a valid card[93].

Having affordable, bulk-billed, or subsidised health services and medications is necessary for the continuity of care for people leaving prison[94].

Consideration must also be given to the different set of circumstances faced by women upon their release. Women with HCV have specialised needs relating to their reproductive and sexual health and as such tailored, gender-sensitive support should be provided[95].

Furthermore, previously incarcerated women often face the double stigma of being a person who uses drugs and a mother. Their role as a mother or caregiver has a different impact on their perceived role and responsibilities when returning to community life[96]. A women's personal health is more likely to come second to that of her children and the costs associated with attending medical appointments to continue HCV treatment may be a low priority within this context.

As per Maslow's hierarchy of needs theory, if a person exiting custody does not have their basic needs such as shelter and stable source of income covered then the incentive, capacity and likelihood of that person organising and attending medical appointments is highly compromised[97]. HCV treatment is often seen as a relative need and often not the most pressing concern for people upon their return to community life.

Factors likely to contribute to treatment completion include strong post-release support and linkages including; family support, stable housing, employment and established connections to community-based healthcare services[98]. Peer-based assistance navigating social welfare and health care systems is highly beneficial for those who are vulnerable and lacking the knowledge or skill to do so on their own.

The value of peer-based support

Before being released, an individual should be linked with peer-based and community-based services that will ideally help them continue treatment[99]. Custodial settings offer the opportunity to engage high risk populations to improve their health outcomes. Many of the structural barriers that are experienced by this group in the community are removed during their period of incarceration, this should be leveraged as much as possible, to initiate treatment for as many people as possible.

The importance of peer-to-peer education is recognised and well documented. Peer education has been adopted in health promotion owing to its effectiveness over clinically delivered services in terms of messaging and cost benefits[100]. The effectiveness of peers is due to others seeing them as a credible source of information and being seen as trustworthy which other professionally delivered services struggle to achieve due to a lack of rapport. Furthermore, it is known that stigma and distrust typically drives people who use/inject drugs away from accessing essential health care[101]. As such peers can provide moral support and help overcome this barrier.

In terms of HCV treatment in custodial settings, peer-based programs have been shown to be effective in increasing awareness[102]. Participants in a study identified peer educators as potential facilitators to engaging them in HCV screening and treatment. Within custodial settings, the trust of peers, especially those who have already completed HCV treatment is recognised[103].

Peer-led programs are effective within custodial settings. It is therefore reasonable to consider them plausible in the context of enhancing continuity of care. Community and peer-led programs have played a key role in the Australian community-based response of HCV and HIV[104]. These responses have been effective not only due to the rapport and trust between peers and participants, but also the ability of peer-led programs to adapt quickly to the continually changing service delivery, social welfare and primary health care environments.

The *Fifth National Hepatitis C Strategy* acknowledges that case management during the post-release transition period has positive implications for treatment adherence and preventing HCV reinfection[105]. Moreover, it is specified that such work would be enhanced through collaborations with peer-based services and peer-based support models should be developed which allow HCV peers to act as navigators for diagnosis, treatment and care[106].

Whilst the *Fifth National Hepatitis C Strategy* has made peer support explicit as a 'key area for action' to address 'equitable access and coordination' of HCV treatment, this must be translated into the processes, policies, procedures and operations at a jurisdictional level. State and territory governments need to embed connections with such programs in their processes and peer-based organisations need to be adequately resourced to provide the services required.

BEST PRACTICE

1. Focus on peer-based support programs

   People exiting custodial settings would benefit from enhanced access to peer support programs which could help them navigate health care and welfare systems on release. Relationships could be established whilst someone is still incarcerated; relationship and rapport building does not have to wait until someone has been released. Proactive measures could be taken if supported by jurisdictional correctional services policies and processes. Any such programs and supports should also be cognisant of the different needs of women and be adapted accordingly.

2. Implementation of Prison Needle and Syringe Programs

   Custodial settings will continue to act as an incubator for HCV despite universal access to DAAs unless PNSP are introduced. Harm reduction measures available in the community should also be available within the confines of custodial settings. Ensuring equivalence of care is a human rights matter and ought to be a consideration at the forefront of decision making processes which affect the health and wellbeing outcomes of detainees.

3. Workforce development within custodial settings

   Each custodial facility is governed by different policies and procedures, however there ought to be consistency in the knowledge of correctional officers, health care and other relevant staff. Not only does this include an understanding of the risk factors associated with HCV but also understanding adverse effects that stigmatising language have on the health and wellbeing outcomes of detainees. Staff should be encouraged and supported to undergo necessary professional development within this context.

4. Equity of access to services in rural, regional and remote areas

   Regardless of where in Australia someone is incarcerated they ought to have reasonable access to the same health care and harm reduction resources as any other Australian. Disadvantage should not be experienced due to location. This also means that there should be reasonable and fair equity not only within jurisdictions, but across them.

5. Rectify Medicare access barrier

   This reflects a long standing and complex systems issue which creates a financial barrier to ex-detainees making the appropriate and necessary health care connections in the community. This serves to only further penalise people who are trying to re-establish their lives in the community. Achieving better health outcomes for former detainees is in everyone's interest, and at the very least policies and procedures should ensure that all people leaving custodial facilities do so with a valid, current Medicare card.

APPENDIX A: CONSULTATION WORKSHOP OUTLINE

Consultation Workshop 2 – 'Service user experiences for people exiting custodial settings living with HCV'

In early 2018, AIVL released *A needs analysis for people living with HCV after leaving custodial settings in Australia*. The summary media release is provided as an attachment for your information.

This project was commissioned by AIVL to provide a jurisdiction-based needs-assessment report for the Australian Government Department of Health on the needs of People Living with Hepatitis C (PLWHCV) as they are discharged from custody to improve the completion rate and success rate of their hepatitis C (HCV) treatment.

There are three parts to this process:

1. Providing this information ahead of the workshop so that participants can consult with their friends and colleagues beforehand;

2. Going through the consultation questions below in a group at the Annual Meeting to enable identification and discussion of emerging trends and issues; and

3. Follow-up with member organisations post-Annual Meeting.

Questions

Does your organisation deliver any services in custodial settings (prison, remand, police cells etc.)? If so, please describe.

Does your organisation have direct contact with people who have recently left custodial settings?

What are people in/who have recently left custodial settings telling you about their experiences of testing and treatment for hepatitis C in custodial settings?

Are people being lost to hepatitis C treatment on release from custodial settings? If so, what do you think is the most important thing that could be done to improve transitions for people leaving custody in your jurisdiction?

What about hepatitis B and HIV – are service users raising any issues about access to vaccination, testing or treatments in custodial settings?

Are there BBV prevention/harm reduction measures that are available in the broader community that are missing from custodial settings in your jurisdiction (e.g. NSP, bleach, pharmacotherapy treatments etc.)? If so, what are your views on this?

Are there things that are available according to current policies but in reality are not? Does the policy match people's experience?

Would your organisation like to provide additional services designed to support people leaving custodial settings in your jurisdiction? If so, please provide a brief description.

Is your organisation represented on any custodial/justice-related working groups or committees? If so, please name the group or committee and provide a single sentence about its role.

APPENDIX B: AIVL MEDIA RELEASE

Australian Injecting & Illicit Drug Users League

MEDIA RELEASE

18 April 2018

REPORT CALLS FOR NEEDLE & SYRINGE PROGRAMS IN PRISONS TO ADDRESS HEPATITIS C IN AUSTRALIA

The Australian Injecting and Illicit Drug Users League (AIVL) is today releasing a new report, looking at the needs of people living with Hepatitis C after leaving custodial settings in Australia. The report contains a series of recommendations aimed at addressing the spread of blood borne viruses (BBVs) in the Australian community more broadly, including trialling of a Needle and Syringe Program (NSP) in prison and increased focus on transitional arrangements for people returning to the community.

"With the development of new national blood borne virus and sexually transmissible infection strategies currently underway, it is important that people entering and exiting custodial contexts are not forgotten, particularly as they are returning to their families and communities. Ensuring access to the full suite of preventive, harm reduction measures – and ensuring that people are able to continue their engagement with alcohol and other drug and viral hepatitis treatments post-release – are tangible ways that we can protect more Australians from contracting blood borne viruses," said Melanie Walker, Chief Executive Officer (CEO) of AIVL.

"Ensuring that current policies and practices are implemented at the coal face is also a key priority emerging from this research. A typical experience of what occurs in many jurisdictions is the development of a conceptually very good overarching policy, however it does not always follow that good policy becomes good practice. Inconsistent access to bleach, a refusal to implement a regulated NSP, and management refusal to release staff for BBV-related training often occurs.

"In particular, there is a lack of continuity for people transitioning from custody to community. Some jurisdictions have transition guidelines that are embedded in policies but staff knowledge can vary on these policies. As a result, many prisoners frequently slip through the gaps if they are released without notice, an especially common occurrence for those on parole or following court.

"It is also worth noting that people in prison are currently excluded from MBS and PBS subsidies. One consequence of this is that there is no sustainable, scalable mechanism for supporting in-reach by primary care providers, despite strong evidence that early contact with primary care after release from prison is associated with better health outcomes.

"There is clearly a need for a national approach. The current National Hepatitis C Strategy 2014-2017 identifies people in custodial settings as a priority population and the issues and considerations identified at publication in 2014 remain current. In summary, with 250,000 Australians to treat for Hepatitis C and a disproportionate number of people living with Hepatitis C in prison, it is critical that prisons are part of any national strategy for elimination of Hepatitis C. The report found that there is a real need for a national policy to guide prisons in jurisdictions," said Ms Walker.

The full report – "A needs analysis for people living with HCV after leaving custodial settings in Australia" - is available at:
http://www.aivl.org.au/resource/a-needs-analysis-for-people-living-with-hcv-after-leaving-custodial-settings-in-australia/ .
AIVL is the national organisation representing people who use/have used illicit drugs and is the peak body for the state and territory peer-based drug user organisations.

MEDIA CONTACT: Melanie Walker, CEO, AIVL

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