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Supporting the HIV, Viral Hepatitis and Sexual Health Workforce

Addressing Systemic Barriers, Stigma and Discrimination Surrounding HIV and Viral Hepatitis: Averting Late Diagnoses and Disease Progression

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Summary

Systemic barriers, and stigma and discrimination impede access to health services for people living with and/or at risk of HIV and viral hepatitis. For those affected, these barriers can contribute to missed and late diagnoses, disease progression, onward transmission, more costly tertiary care and reduced quality of life.

Stigma is multi-dimensional, multi-layered and cumulative. Stigma and discrimination surrounding HIV, hepatitis B (HBV) and hepatitis C (HCV) is inextricably linked to stigma towards groups that are most affected by these conditions. Systemic barriers result from adverse treatment based on individual's sexuality and sexual behaviour; sex, gender identity, gender expression and intersex status; race, ethnicity and cultural and linguistic background; migrant, refugee or visa status; past, present or perceived use of drugs; and engagement in sex work.

An effective response to HIV, HBV and HCV must comprehensively address all forms of stigma and discrimination. Failure to do so perpetuates existing health inequities and barriers to appropriate care, including late diagnoses and other aspects of morbidity and mortality.

Barriers to health care due to stigma and discrimination can exist at a number of levels. This includes laws and guidelines at an institutional or policy level that are discriminatory towards people living with HIV, HBV and/or HCV. Stigmatising attitudes can originate from staff within health services, as well as health consumers such as other clients sharing acute or chronic hospital bedrooms, or in clinics. These attitudes can also be perpetuated within society more broadly, including among people living with HIV and/or viral hepatitis themselves. They may have past experiences of, or are influenced by, stories of discrimination within health services. As such, multiple and varied reforms and initiatives need to take place in order to remove these barriers.

Health care workers require greater training (both pre- and post-vocational) surrounding transmission risk of blood-borne viruses (BBVs), universal standard precautions, diversity training and the effects of stigmatising attitudes and obligations under anti-discrimination legislation.

Data collection processes allowing the affirmation of diverse gender identities and knowledge production to improve health services need to be implemented, as well as extending behavioural surveillance to better inform policy and programs.

Policies and legislation need to be revised to ensure consistent anti-discrimination measures are in place across jurisdictions, and complaints procedures are accessible when discrimination does occur.

Increased resources are required for community education and engagement surrounding HIV and viral hepatitis that is culturally appropriate and acknowledges the effects of multiple layers of stigma.

Key points

Systemic barriers to health care, stigma and discrimination

Stigma and discrimination within the health system have been identified as major barriers to accessing health services, preventive behaviours, HIV test-seeking behaviours, willingness to disclose serological status, care-seeking behaviours, adherence to treatment, the quality of care to PLHIV and/or viral hepatitis, and social support received (Grierson et al. 2011; Land and Linsk 2013; NAPWHA 2017).

Whether stigma and discrimination is real or perceived, it is experienced by those affected as discrimination, and thus affects access to and uptake of health care (NAPWHA 2017).

Stigma and discrimination impacts groups most commonly associated with, and disproportionately affected by HIV and viral hepatitis, including:

- Men who have sex with men (MSM);
- Transgender and gender diverse people;
- Aboriginal and Torres Strait Islander (ATSI) People;
- Migrants and ethnic minority groups;
- People who inject drugs (PWID); and
- Sex workers.

The resultant barriers perpetuate existing health and social inequities, making already vulnerable populations even more vulnerable.

In addition, there exists a tension between efforts to normalise, and thus destigmatise HIV, and maintaining targeted efforts towards those communities most affected by it. With significant advances in both treatment and prevention, HIV in many respects can be treated as a chronic health condition. Yet it is still essential that efforts continue to be targeted towards those groups most affected, without further stigmatising them as ‘vectors’ of HIV or viral hepatitis.

There are several areas where stigma and discrimination can create barriers for people affected by HIV and viral hepatitis:

- Within health services;
- Within policy or legislation;
- Among health consumers and within the broader community; and
- Among people living with HIV, HBV and HCV themselves.

Stigma and discrimination within health services

Stigma and discrimination occur within health services surrounding standard precautions, disclosure, confidentiality, medical forms and data collection.

There is still a lack of trust in universal standard precautions among some health care workers (HCWs). Misconceptions exist regarding potential disease transmission, and fears and stereotypes about population groups most commonly affected by HIV and viral hepatitis (Hassall, Stewart, and Crock 2017).

When HCWs exceed clear policy and guidelines and make decisions about infection control based on their perception of infection risk rather than actual risk inherent in the procedure—such as double-

gloving to examine a patient—this differential and discriminatory treatment can lead clients to avoid such health care services in future.

Several studies have reported the effectiveness of educationally-based interventions in addressing health care workers' fears around HIV and HCV and the effects of stigma (ASHM 2012). Evidence shows that the most effective training programs at reducing stigma and discrimination incorporate the lived experiences and voices of people living with HIV and/or viral hepatitis, and other affected communities (ACON 2017).

Standard medical forms and Client Information Management Systems (CIMS) often exclude people of diverse gender identities and relationship structures (ACON 2017; AFAO 2017). This has the effect of creating a barrier to people in accessing services and failing to capture nuanced data regarding who is most affected by HIV and viral hepatitis.

Maintenance of privacy and confidentiality of people living with HIV, HBV and/or HCV is also critical. There is a need for greater training of HCWs surrounding the discussion and disclosure of a client's serological status or other health issues in front of family and friends, other clients in waiting rooms or hospital ward floors, or to other staff who do not need to know.

Stigma and discrimination within policy and legislation

Barriers exist across the health system that impede the response to HIV, HBV and HCV that can only be addressed through structural change or through legislative or policy interventions (NAPWHA 2017).

Responding to stigma and discrimination within the health system requires the implementation of consistent anti-discrimination laws across all jurisdictions (ACON 2017) and accessibility of complaints mechanisms when discrimination does occur.

Discriminatory laws surrounding sex work remain, despite evidence and recommendations in national HIV and STI strategies supportive of reform (DoH 2014). The presence of these laws reinforces stigma towards sex workers broadly within society and from health care workers.

Stigma and discrimination within the community

Stigmatising attitudes and behaviour experienced within the health system are generally reflective of attitudes within the broader community. This can contribute to fear of testing, engagement with community-based support services and disclosure.

There is a need for ongoing and increased targeted campaigns and community education to normalise and de-stigmatise HIV, hepatitis B and hepatitis C, as well as educate affected communities on prevention, testing, treatment and care.

Stigma and discrimination among health consumers – self-stigma

Internalised stigma is a significant issue for many people living with or at risk of HIV and/or viral hepatitis. It can act in a way that prevents or defers help-seeking and may lead a person to feel that injuries or disease are deserved and therefore unworthy of assistance.

People are not passive receptors of stigma. Initiatives should be expanded that promote strong and positive responses and aim to build resilience and wellbeing among people living with HIV, HBV and HCV.

Defining relevant concepts

Stigma

The concept of stigma is the process of perceiving a characteristic of another as deviant from the social expectations that are held by the majority (ASHM 2012). Stigma is a process that includes a number of interrelated elements, including isolation and labelling, association to negative stereotypes and misconceptions and discrimination based on such labelling (Link and Phelan 2001).

Stigma is multi-dimensional and can include perceived stigma (feeling stigmatised); anticipated stigma (expecting to be stigmatised); internalised stigma (self-stigmatisation); enacted stigma (discrimination); public stigma (being stigmatised by others); compounded stigma (stigma layering); and, structural stigma including resource-based stigma (economic/structural stigma) (Hopwood 2016). These different types of stigma are present throughout the health system, from direct interactions with health care workers, through to policy and legislation.

Discrimination

Discrimination is an enacted form of stigma; the unfavourable treatment of any individual based solely on their membership of a certain group and can result in limiting members of one group from opportunities that are available to others (ASHM 2012). It is the unfair treatment of someone based on a particular characteristic that defines discrimination. Such characteristics may include race, sexual orientation, or particular physical attributes, and lead ultimately to some form of rejection or exclusion (Giddens et al. 2009).

Systemic barriers, stigmatisation and discrimination across the health system

Systematic barriers, and stigma and discrimination impede access to health services for people living with and/or at risk of HIV and viral hepatitis. For those affected, these barriers can contribute to missed and late diagnoses, disease progression, onward transmission, more costly tertiary care and reduced quality of life.

Barriers to health care due to stigma and discrimination can exist at a number of levels. This includes laws and guidelines at an institutional or policy level that are discriminatory towards people living with HIV, HBV and/or HCV. Stigmatising attitudes can originate from staff within health services, as well as health consumers such as other clients sharing acute or chronic hospital bedrooms, or in clinics. These attitudes can also be perpetuated within society more broadly, including among people living with HIV and/or viral hepatitis themselves. They may have past experiences of, or are influenced by, stories of discrimination within health services. As such, multiple and varied reforms and initiatives need to take place in order to remove these barriers.

Barriers at all levels need to be addressed to ensure equity across the health system. A comprehensive response to HIV and viral hepatitis cannot leave any groups or communities behind – particularly those disproportionately affected by, or vulnerable to, HIV and viral hepatitis.

Stigma is multidimensional and multilayered. It not only relates to a person's HIV, HBV or HCV status, but also their assumed membership to one or more other groups which also suffer from stigma and discrimination. The effect is cumulative, creating multiple barriers for a person, all of which need to be addressed for an effective response to these health conditions.

People living with HIV, hepatitis B and hepatitis C

Stigma and discrimination surrounding HIV and viral hepatitis can take many forms and is pervasive within health care settings.

One study that examined the attitudes of nurses towards HIV positive patients found that issues surrounding homophobia, injecting drug use, fears of transmission and knowledge of HIV and AIDS all contributed to stigma and discrimination among nurses (Pickles, King, and Belan 2009). Even though research has shown that the majority of healthcare workers understand how HIV is transmitted, they still revealed fears of the disease and those who were more fearful were more likely to hold stigmatising views, which is particularly evident in non-specialist settings such as GP clinics, as well as rural areas (ASHM 2012; Hassall, Stewart, and Crock 2017; Hepatitis Australia 2017).

These attitudes can result in discriminatory behaviour from health care workers who make decisions about infection control governed by their perception of infection risk rather than the risk inherent in the procedure, ignoring universal standard precautions when treating clients. This may include double gloving or unnecessarily wearing gowns or masks for simple examinations. Other instances include refusal to conduct simple procedures such as giving injections, refusal of treatment altogether, marking client records or biological samples unnecessarily to 'warn' their colleagues of clients' serological status, deliberately scheduling appointments at the end of the day, and forced isolation in hospital wards (ACON 2017).

Clients also report violation of privacy - discussing a client's serological status in front of family or friends, other patients in waiting rooms or on hospital ward floors, or disclosing to colleagues when unnecessary (ACON 2017).

Many people living with HIV or viral hepatitis have reported a sense of shame or self-imposed stigma, and a consequent need for a sense of trust with others, including health care workers (Hepatitis Australia 2017). When HCWs violate that trust with stigmatising and discriminatory behaviour, they create barriers to future help-seeking behaviour as well as deepening internalised stigma that prevents help-seeking and overall wellbeing.

Discriminatory policies and laws also exist, which directly impact upon the lives of people living with HIV and perpetuate stigma at a broader, social level. Laws that criminalise HIV non-disclosure, exposure and transmission put responsibility of HIV prevention solely on people living with HIV. This can deter people from HIV testing, thus exacerbating the issue of late diagnoses, uptake of treatment and onward transmission.

There is inconsistency in legislation across jurisdictions surrounding HIV disclosure (NAPWHA 2017). In 2015, Victoria repealed the country's only HIV-specific law criminalising the intentional transmission of HIV. However, a national framework surrounding HIV disclosure is needed that indicates the requirement for a person living with HIV to take reasonable measures to avoid transmitting to another person is sufficient.

Stigma can also be associated with cultural understandings of disease and disclosure; this is of particular relevance for people living with hepatitis B. Most people living with HBV are often from marginalised and already stigmatised communities, including migrant communities, ATSI people, MSM and PWID (Hepatitis Australia 2017).

Of all new HIV diagnoses in 2016, 32.7% were defined as late, and 19.5% as advanced¹. It is essential to make diagnoses and commence treatment as soon as possible. Early commencement of antiretroviral therapy is not only associated with better individual health outcomes, but effective treatment is an important means of preventing onwards transmission.

There are a number of reasons for late diagnoses of HIV. These include systemic barriers to healthcare; missed opportunities for diagnosis (interactions with HCWs who have not recognised that a health complaint could be related to HIV); and unrecognised exposures to HIV, particularly among heterosexuals and CALD populations.

In 2016, an estimated 7431 (28%) of all people living with HIV did not have suppressed viral load². Of the 7431 people with a detectable HIV viral load, 32% were undiagnosed, 17% were diagnosed but not in care, 30% were in care but not on antiretroviral therapy, and 21% were on antiretroviral therapy but had not achieved a suppressed viral load (see Figure 1). Stigma and discrimination may play a role in people not testing for HIV, in people not being linked to care in a culturally safe environment, for PLHIV choosing not to start ARV therapy, and in the difficulties maintaining adherence to therapy to achieve a consistently undetectable HIV viral load.

¹ Late HIV diagnosis was defined as newly diagnosed HIV with a CD4+ cell count of less than 350 cells/ μ L, and advanced HIV as newly diagnosed infection with a CD4+ cell count of less than 200 cells/ μ L. Newly acquired HIV was not categorised as late or advanced diagnosis, irrespective of CD4+ cell count.

² An suppressed HIV viral load is typically less than 200 HIV-1 RNA copies/mL. The term "suppressed viral load" and the term "undetectable" can be used synonymously. Studies show a person living with HIV on antiretroviral therapy (ART) with a suppressed viral load cannot sexually transmit HIV.

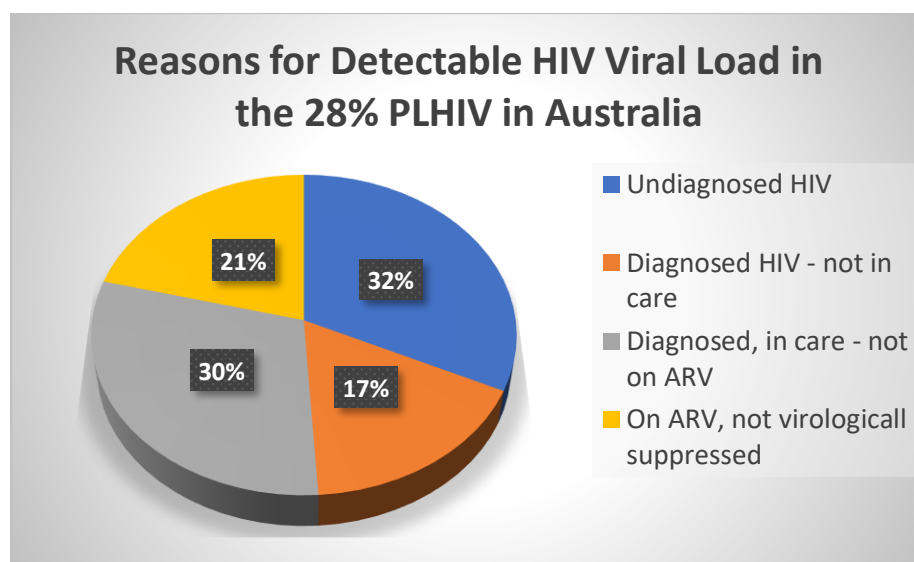


Figure 1. Reasons for detectable HIV viral load in 28% of PLHIV in Australia

Gay, bisexual and other men who have sex with men (MSM)

Gay, bisexual and other men who have sex with men (MSM) are subject to well-documented stigma, in a society where heterosexuality and patriarchal gender identities remain powerful norms. As such, the prevention, care and treatment of HIV, hepatitis B and/or hepatitis C is sought or experienced through a layered experience of stigma and discrimination. This stigma is largely due to prejudice in the dominant cultural imagination of these infections as they intersect with homosexuality.

Heterosexist bias from health care workers, as well as assumptions about HIV risk, can take many forms and have a number of consequences. Health care workers may make assumptions that a client is heterosexual and thus fail to ask appropriate questions. This puts the onus of disclosure of (diverse) sexuality on the client, which may be fraught in many settings. General stigma, misunderstandings or actively discriminatory beliefs about LGBTI practices, sexualities, identities and bodies may result in needlessly intrusive and judgemental questioning from HCWs (ACON 2017). Additionally, opportunities for diagnoses of HIV among heterosexuals may be missed if HCWs do not recognise that health complaints may be related to HIV.

This dichotomy is amazing difficult for HCWs to tread and negotiate – what is thought to be intrusive questions for one patient, is blatant disregard for consideration of sexuality and its health associations, and therefore discrimination, to another. While it is challenging to resolve this issue, greater training for staff on sexual diversity and HIV risk will help mitigate these effects.

In 2016, HIV prevalence among MSM was 7.3%, compared to 0.13% among all people living in Australia. Seventy percent of new HIV diagnoses were among MSM, and another 5% among MSM who inject drugs (Kirby Institute 2017). MSM are also at a higher risk of contracting viral hepatitis than the general population.

However, evidence shows that in a range of settings, universal access to HIV services for MSM together with anti-discrimination efforts can significantly reduce infections both among these men and the wider community (Global Commission on HIV and the Law 2012). Stigma and discrimination

towards MSM need to be addressed as part of a comprehensive response to viral hepatitis, and particularly to HIV.

Transgender and gender diverse people

There has been an historic invisibility of transgender and gender diverse people in HIV and viral hepatitis program and policy development, and challenges these people and communities have faced in accessing health care more broadly (AFAO 2017).

One third of transgender and gender diverse people have reported not consulting a health physician because they were worried that they would not be understood, highlighting a systemic barrier to health care. Lack of training among HCWs in gender diversity can lead to inappropriate and intrusive questions, making clients feel uncomfortable and unwelcome. The problem of accessibility is compounded by additional research that shows transgender and gender diverse people are four times more likely to experience a mental health condition than the general population (AFAO 2017; Smith et al. 2014).

A key concern for transgender communities in accessing health services is recognition (including formal documentation) of their preferred gender (Couch et al. 2007). Standard medical forms as well as Client Informational Management Systems (CIMS) often fail to give options beyond the binary male/female categories, and health care workers are often unaware of the importance of allowing clients to nominate their preferred gender and pronoun.

Medical forms and CIMS need to be updated utilising a broader, more inclusive definition of gender such as that provided by the *Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act 2013*. Here, “gender identity means the gender related identity, appearance or mannerisms or other gender related characteristics of a person (whether by way of medical intervention or not), with or without regard to the person’s designated sex at birth” (AFAO 2017).

This definition was informed through broad consultation and is one that can be accepted as contemporary. It is also person centred, prioritises lived experience and goes beyond binary and strict gender stereotypes to acknowledge gender as dynamic, fluid and ultimately, personal (AFAO 2017).

Lack of routine data collection using (diverse) gender and sexuality indicators creates a number of systemic consequences beyond immediate barriers for the individual. Service improvements are difficult to make when there is a lack of data on needs and patterns of engagement of clients. Population level data collection is also important for policy and planning for areas such as mental health and lifestyle-related illness (ACON 2017).

Moreover, failure to allow transgender and gender diverse people to positively identify their gender undermines knowledge of HIV and viral hepatitis in these communities, creating a notable gap in surveillance (AFAO 2017). Without indicators specific to the needs of transgender and gender diverse people, it is difficult to form a nuanced understanding of diagnoses, late diagnoses and disease progression as distinct from men who have sex with men or heterosexual men and women.

Transgender people face the additional barrier to health care due to its intersection with the legal system. The requirement of court approval to access gender affirming hormones and surgeries can create a diminished sense of bodily autonomy that can lead to frustration with, and mistrust of the wider health system.

Aboriginal and Torres Strait Islander people

Indigenous people often experience health care through a layered experience of systemic racism, cultural inappropriateness of services, and past individual experiences. Indigenous people who face social disadvantage are likely to perceive that discrimination might be experienced in health care services. Mistrust of health services is common and consequent late diagnosis and delayed uptake of treatment occurs regularly in this population group (Negin et al. 2015).

ATSI people are disproportionately affected by viral hepatitis. Indigenous people account for 3% of Australia's population, yet accounted for 11% (24,287) of people living with hepatitis B in Australia (Kirby Institute 2017). An important strategy for the prevention of hepatitis B-related mortality is targeted testing of priority populations, including ATSI people. In addition, while treatment for hepatitis B is not curative, it can prevent morbidity and mortality associated with infection. Given the barriers that stigma create to testing and retention in care, it is necessary that health services are culturally appropriate and free of discrimination in order to address hepatitis B among ATSI people.

While HIV prevalence among ATSI people is the same as the Australian-born non-Indigenous population, the estimated proportion of undiagnosed cases is significantly higher (19.5% and 7%, respectively) (Kirby Institute 2017). This highlights the existence of barriers to testing for the Indigenous community.

Migrants, refugees and CALD populations

Culturally and linguistically diverse (CALD) groups face a number of barriers to accessing health care, often leading to missed and/or late diagnoses of HIV and viral hepatitis, consequent disease progression and other poor health outcomes.

These groups are disproportionately represented in new notifications of HIV, hepatitis B and hepatitis C. From 2012-2016, the proportion of late HIV diagnoses was higher among people born in Central America (45%), sub-Saharan Africa (43%) and Southeast Asia (43%). Of all late HIV diagnoses in 2016 among people born in Southeast Asia and sub-Saharan Africa, almost two-thirds (63%) arrived in Australia less than five years prior to diagnosis, which suggests they probably acquired HIV before they arrived in Australia (Kirby Institute 2017). It is evident that there are significant barriers to testing for HIV among these group once in Australia.

At the end of 2016, there were an estimated 230,034 Australians living with chronic hepatitis B. An estimated 49,696 (22%) were born in Northeast Asia and 39,482 (17%) in Southeast Asia, representing only 4% and 3% of Australia's population, respectively (Kirby Institute 2017). Higher prevalence of hepatitis B in these population groups is reflective of the prevalence rates in their countries of birth, and is largely attributable to the lack of childhood vaccination programs and/or adolescent catch-up vaccination program.

Australia's Second National Hepatitis B Strategy (2014-17) had a target of 80% of all people living with chronic hepatitis B being diagnosed, and 15% of all people living with chronic hepatitis B receiving treatment, acknowledging that treatment is recommended for those with detectable HBV viral loads, abnormal liver function tests or those with advanced liver disease. At the end of 2016, 63% were diagnosed and 7% were receiving treatment. To reach these targets, it is essential that greater efforts are made to target Australians born in the Asia-Pacific region, to improve data collection systems for

greater accuracy in reporting the need for treatment, and removing barriers to testing, care and treatment.

Stigma, discrimination and fear of disclosure surrounding HIV and viral hepatitis often play out differently for members of CALD communities, creating unique barriers to testing and care. Among migrants to Australia, understandings of HIV and viral hepatitis are largely influenced by experiences in their home countries. Research has found the perception of receiving treatment meant being ill and being ill meant death was imminent (NAPWHA 2017). HIV-related stigma, based on risk stereotypes of sexual immorality and fear of contagion and death, creates a major barrier to social support and information. Moreover, fear of gossip and having HIV and/or hepatitis status disclosed within one's community can keep people away from community-based organisations, yet social contact with others from the same ethnic/language community is important for those with a language barrier (Körner, Katsaros, and Luisi 2013). Office location of community-based organisations may also present a barrier – they are often located in the inner city, quite far from many urban growth areas (Körner, Katsaros, and Luisi 2013).

There is a need for greater cultural diversity training for health workers, and more information and resources translated into languages other than English. Moreover, greater work needs to be done with respect to community education, engagement and support, particularly outside of inner-urban areas.

For recently arrived migrants who are ineligible for Medicare, the cost of treatment can be prohibitive, which acts as a disincentive to testing or other help-seeking behaviour. In addition, there is real fear that a positive HIV diagnosis may lead to visa cancellation or refusal of a visa in future.

People who inject drugs

People with past, present or perceived drug use are routinely subjected to stigma and discrimination across society and within the health system. Stigma acts in a way to create pervasive understandings of drug use as somehow separate to what is socially acceptable: as a moral failing, a disease, and irresponsible. Moreover, criminalisation of drugs is often seen as enough justification of discrimination towards users, with no regard for a person's human rights (including the right to health), circumstances, or outcomes of such treatment (AIVL 2017).

People who inject drugs (PWID) may become so accustomed to discrimination that many come to expect such attitudes as the norm, with some not even recognising the lower standard by which they are being treated. For others, awareness that one is being treated unfairly may be accompanied by the feeling that not much can be done about it. Many communities are protected to some extent by anti-discrimination legislation, yet people who use drugs have no such protection under any Australian law (AIVL 2017).

As such, it is often necessary for people who use drugs to prevent the perception that drug use is taking place to avoid discrimination. This is often interpreted, however, as deceptive and malicious behaviour rather than as a form of self-protection (AIVL 2017). It may also create a barrier to receiving appropriate care, if drug use is not known.

While Australia has been successful in managing HIV-related risk among PWID, the same cannot be said for hepatitis C (ASHM 2012; Kirby Institute 2017). Data collected from PWID attending Needle and Syringe Programs showed 51% hepatitis C antibody prevalence in 2016. Rates of receptive syringe sharing have been generally stable over the past 10 years (approximately 1 in 5 people) as reported in the Australian Needle and Syringe Program Survey. However, rates of receptive syringe sharing

have been consistently higher among Aboriginal and Torres Strait Islander people (28% compared to 17% among non-Indigenous respondents) (Kirby Institute 2017).

At a community level, modelling suggests achieving a high coverage of hepatitis C antiviral treatment can reduce the population prevalence of hepatitis C and can therefore, reduce incidence (treatment as prevention). Secondary prevention strategies to reduce the risk of progression to hepatocellular carcinoma include improving access to diagnosis and antiviral treatment (Kirby Institute 2017). To ensure testing, diagnosis and treatment, health care needs to be free from stigma and discrimination towards people who inject drugs.

Sex workers

Sex workers, like people who inject drugs and men who have sex with men, are subject to significant stigma and discrimination due to a dominant cultural imagination associating sex work with immoral, criminal behaviour. Such perceptions are reinforced by discriminatory laws that apply different standards to sex workers than the broader population. The issue is compounded for sex workers experiencing multiple stigmas, such as migrant sex workers and sex workers living with HIV (Scarlet Alliance 2017).

Sex workers in Australia have a consistently lower prevalence of HIV, STIs and viral hepatitis than the general population, yet are still often viewed as vectors of disease and subject to onerous regulation. Sex workers are subject to mandatory testing, which conflicts with best practice recommendations proposed in national STI and HIV strategies (DoH 2014). Mandatory testing is burdensome on the health system and evidence shows that retaining low rates of HIV and STIs among sex workers can be achieved with less frequent and/or voluntary testing (Chow et al. 2014; Jeffreys, Fawkes, and Stardust 2012).

In many jurisdictions, engaging in sex work while living with HIV is prohibited. A lack of understanding and the stigma associated with sex workers living with HIV create barriers for access to services due to fear of discrimination by service providers upon disclosure of HIV status and engagement with the sex industry (Scarlet Alliance 2017; Begum et al. 2013; Jeffreys, Matthews, and Thomas 2010). Instances of disclosure of both HIV status and sex work generally lead to poor treatment and harassment (Matthews 2008). When forced to hide their HIV status or engagement in sex work, barriers are created to accessing appropriate health care, as well as effective peer education and outreach – all protective factors in preventing HIV and STI transmission (Scarlet Alliance 2017).

Outside of the health care system, sex workers are often victimised by police, who may not take complaints and reports of crime seriously. Street-based sex workers also experience police harassment, which is in direct opposition to effective HIV and STI strategies and marginalises sex workers from supportive health organisations and peer education (Scarlet Alliance 2017).

Further resources in languages other than English need to be developed for migrant sex workers surrounding access to health services, community-based support, work rights (including occupational health and safety), and migration pathways.

Cross cutting issues

There are a number of cross-cutting issues surrounding people living with or affected by HIV, hepatitis B and/or hepatitis C.

Workforce training

Improved workforce training on HIV and viral hepatitis, LGBTI and cultural sensitivity, and obligations of health workers under anti-discrimination laws, will improve quality of service provision as well as remove barriers to accessing services.

Implementation of anti-discrimination laws

Lax or non-enforcement of anti-discrimination laws and policies create barriers to consistent and equitable health services for already stigmatised groups (ACON 2017). This is compounded by complaints procedures that can be difficult to identify and vary significantly between settings (such as from a public hospital to a local GP clinic). The need to further disclose one's HIV or hepatitis status may also impact upon a person's decision as to whether or not to report or pursue a formal complaint (Hepatitis Australia 2017).

While legislation or service protocols may change for the better, this does not necessarily affect a change of mindset among the associated workforce. Policy reforms need to be accompanied by workforce training to ensure comprehensive implementation (Hepatitis Australia 2017).

Socio-economic status

People living with HIV who have low socio-economic status have reported feeling uncertain about treatment they will receive from non-HIV specific welfare services. Whether this stigma and discrimination is real or perceived has the same effect – creating a barrier to access services that impact upon the individual's health and wellbeing.

Women living with HIV are more likely to report difficulties in meeting the cost of living, with half of them living beneath the poverty line (NAPWHA 2017).

People living in rural and remote areas

Living in rural areas is associated with late diagnoses of HIV. A lack of culturally appropriate rapid testing centres, specialist services and community-based support services outside of metropolitan areas make access to testing, treatment as support more difficult (ViiV Healthcare 2017).

There are real concerns in rural areas surrounding privacy and unwanted disclosure of serological status at GPs offices or local health services, and from community pharmacies when obtaining medicines (NAPWHA 2017). Similarly, discussions surrounding sexuality and sexual practices, drug use, etc., can be highly fraught when the only health care workers available are known members of the community.

Recommendations to address barriers, stigma and discrimination

Clinical Practice – health workforce training

- There is a demonstrated need for greater education and training (both pre-vocational and post-vocational) for health care workers with respect to:
 - Knowledge surrounding transmission of blood-borne viruses;
 - Reiterating the principles underlying the use of universal standard precautions in clinical practice. This should focus on the underuse, overuse and inconsistent use of standard precautions;
 - Recognising and responding sensitively and without judgement to people of diverse sexualities, genders and bodies;
 - Recognising that all people have a fundamental human right to health and health care, irrespective of vocation or life circumstance (e.g., sex work, drug use);
 - Stigma and discrimination, its impact on clients, and the creation of barriers in accessing health care;
 - Appropriate referral pathways to specialist clinics and community organisations;
 - Legal responsibilities of health professionals under state/territory and federal anti-discrimination laws; and
 - The importance of maintaining client privacy and confidentiality.
- Develop a nationally consistent training package for a variety of audiences, including health workers. Training not only needs to be relevant in terms of content and appropriate in terms of design and delivery. There are a number of existing trainings to draw on such as ACON's Pride Inclusion Programs (ACON 2018).
- Completion of online training modules for continued medical, nursing and other health care workers should be made compulsory, similar to trainings on other topics of clinical practice.
- Training packages should be designed with the input of affected communities, and acknowledge multiple levels of stigma. Evidence shows that the most effective trainings at reducing stigma and discrimination incorporate the lived experiences and voices of people living with HIV and/or viral hepatitis, and other affected communities such as gay and bisexual men, transgender and gender diverse people, people who inject drugs and sex workers (ACON 2018; HepatitisSA 2018).

Clinical Practice – data collection

- Review and amend standard medical forms and Client Information Management Systems (CIMS) to capture diverse baseline gender data sets.
- Offer incentives to non-government managed CIMS to implement the same baseline datasets.
- Implement processes in health care settings that invite people to nominate their preferred gender and preferred pronoun.
- Implement standardised sexual health risk practice assessment that extend behavioural surveillance to elucidate HIV, STI and BBV risk within groups, as well as bridging between groups.

Policy Development

- Implementation of consistent and comprehensive anti-discrimination legislation across all jurisdictions.
- Update laws regarding changing identity documents and accessing gender affirming hormones and surgeries.
- Ensure complaints mechanisms within health services are easily accessible, and acknowledge that many people lodging complaints may already be experiencing stigma associated with their health condition and/or other status.
- Encourage people to file complaints against providers and institutions in cases of stigma and discrimination; provide the necessary support (i.e., informational, practical, psychological and financial) for complaints to be filed and followed through.
- Develop a national framework regarding HIV disclosure, indicating that the requirement for a person living with HIV to take reasonable measures to avoid transmission to another person is sufficient.
- Update laws regarding sex workers living with HIV; laws should be equally applicable to the broader population, that is, that all individuals take reasonable precautions against transmitting HIV.
- Introduce voluntary (HIV and STI) testing of sex workers. Mandatory testing conflicts with best practice recommendations proposed in national HIV and STI strategies and is burdensome on the health system.
- Decriminalise sex work (such as the framework used in New South Wales). This ensures that sex workers benefit from the same occupational health and safety standards as the wider population, and averts the creation of a two-tier system.

Community Education and Engagement

- Expand initiatives that aim to build resilience among people living with HIV, hepatitis B and hepatitis C that include cultivating specific skills for combating stigma and a broader set of life-enhancing skills to improve wellbeing.
- Provide translated health and supportive information for people and communities that do not speak English as a first language.
- Create campaigns that are culturally nuanced and linguistically diverse, targeted toward communities most affected by HIV, hepatitis B and hepatitis C.

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