

REVIEW ARTICLE

Optimising community health services in Australia for populations affected by stigmatised infections: What do service users want?

Robyn Horwitz PhD¹ | Loren Brener PhD¹ | Alison D. Marshall PhD^{1,2} |
Theresa Caruana MSW¹ | Christy E. Newman PhD¹

¹Centre for Social Research, University of New South Wales, Sydney, New South Wales, Australia

²The Kirby Institute, University of New South Wales, Sydney, New South Wales, Australia

Correspondence

Robyn Horwitz, Centre for Social Research, University of New South Wales, Sydney, NSW 2052, Australia.
Email: r.horwitz@unsw.edu.au

Funding information

ACT Health Directorate

Abstract

Stigma in health services undermines diagnosis, treatment and successful health outcomes for all communities, but especially for those affected by blood-borne viruses and sexually transmitted infections (STIs). This study sought to examine experiences in accessing and receiving health services, including what characteristics promoted better health, safety and well-being for people with blood-borne viruses or STIs. It conducted 46 in-depth interviews with people who inject drugs, gay men and other men who have sex with men, sex workers, people in custodial settings, culturally and linguistically diverse people, Indigenous Australians and young people in one Australian urban community setting. Findings reveal that stigma persists in the provision of healthcare services, and that previous experiences of discrimination or fear of mistreatment may result in a reluctance to continue to access services. On-going staff training and education are important to ensure healthcare environments are welcoming and inclusive. Specialised services and services that employed peers were seen as favourable. Attending different services for different health needs created particular access challenges and undermined participant ability to engage in more holistic healthcare. The fragmented structure of health services was thus seen as a barrier to accessing health services, and stronger collaboration between health services is recommended.

KEYWORDS

blood-borne viruses, health services, marginalised populations, sexually transmitted infections, stigma

1 | INTRODUCTION

Stigma is a complex construct that involves the social exclusion of people perceived to possess a characteristic that is viewed negatively by a broader social group (Goffman, 1963; Scambler, 2009).

Once stigma is applied or learned, it manifests itself in a range of stigma experiences such as perceived stigma (Zelaya et al., 2012), discrimination (Stangl et al., 2013) and self-stigma (Rao et al., 2012). The stigma becomes discrimination when negative thoughts, beliefs or attitudes translate into the unfavourable treatment of an

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial-NoDerivs](https://creativecommons.org/licenses/by-nc-nd/4.0/) License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2022 The Authors. *Health and Social Care in the Community* published by John Wiley & Sons Ltd.

individual based solely on their membership in a certain group (Giddens et al., 2009). Self-stigma occurs when people internalise the stigmatising attitudes that others hold about them (Gilmore & Somerville, 1994) and come to view themselves with shame and reduced self-worth (Goffman, 1963). Experiencing stigma has been consistently associated with low social support, increased mental health issues, decreased self-esteem, increased rates of depression, non-optimal medication adherence and suboptimal physical health outcomes (Helms et al., 2017; Sweeney & Venable, 2016; Turan et al., 2017).

Individual stigma refers to psychological and behavioural responses to stigma, which may include concealment, negative self-perceptions and compromised mental health (Corrigan et al., 2010, 2013). Interpersonal stigma refers to discrediting and discriminatory acts directed at people that are considered to be of a specific marginalised group that possess or exhibit signifiers or qualities that denote physiological, mental or moral aberrance (Giddens et al., 2009; Hebl & Dovidio, 2005). Structural stigma is formed by socio-political forces within institutions and the community and is enacted through policies and practices that restrict the opportunities, resources and well-being of stigmatised groups (Link & Phelan, 2001). Within healthcare settings, acts and expressions of interpersonal and structural stigma include judgemental comments or interactions, excessive use of infection control practices, extended waiting times, denial of care, inferior care, unjust barriers to service provision and demonstrating a lack of respect (Bos et al., 2013; Cama et al., 2016; Earnshaw & Quinn, 2012).

Whilst people living with sexually transmitted infections (STIs) and blood-borne viruses (BBVs) may all be subject to stigma, each condition has intersecting and distinctive characteristics and challenges. Stigma towards people diagnosed or living with hepatitis C (HCV), HIV, or STIs stems from negative stereotypes about these groups as being immoral, risky and even violent, as well as assumptions that they engage in criminal, devious, or non-normative activities (Emlet et al., 2017). These stereotypes emanate from the preconception that an affected person injects drugs or is sexually promiscuous (Biancarelli et al., 2019). People living with HCV have reported high levels of stigma and discrimination within healthcare settings including the refusal of health services to provide care to people who inject drugs and to treat patients with HCV who are currently injecting drugs (Treloar et al., 2013; Van Boekel et al., 2013). For people living with HIV (PLHIV), experiencing stigma in healthcare settings impacts their engagement with treatment, care and support, at different stages of HIV infection (Chambers et al., 2015; Chan & Tsai, 2016; Ekstrand et al., 2018).

The past decade has witnessed developments in the treatments of STIs and BBVs. Most notable are advances with direct-acting antiviral treatment for HCV and biomedical therapy innovations for HIV, such as treatment-as-prevention (TasP; Falade-Nwulia et al., 2017) and pre-exposure prophylaxis (PrEP; Hamed et al., 2018). Given the preventable and treatable nature of many BBVs and STIs, the promotion of positive health-seeking behaviour and removal of barriers to healthcare services has become a national priority for these

What is known about this topic

- It has been shown that people affected by or at risk of blood borne viruses and sexually transmitted infections need to be effectively engaged with community health-care services.
- Engagement with healthcare has been shown to improve testing and treatment uptake, and health outcomes.
- Stigma is known to be perceived and enacted within social interactions and institutions, including when accessing and receiving health services.

What this paper adds

- This study identified that a holistic and non-judgemental health care approach reduces the expression of stigmatising attitudes and behaviours towards marginalised groups, and increases feelings of safety.
- Some groups (for example sex workers and people living with HIV) were found to be better informed as to the care, testing and treatment they required.
- These groups acted to reduce potential stigma by going to different health services for needs related to blood borne or sexually transmitted infections.

marginalised populations (Australian Government Department of Health, 2018a).

Inadequate or inaccurate knowledge about transmission routes (for instance, that transmission can occur via contact with saliva or skin) and fear of infection in the general population exacerbates stigma towards people living with, or groups associated with, BBVs and STIs (Smith-Palmer et al., 2020). As marginalised communities often avoid situations in which they fear being the target of discriminatory behaviour (Herek, 2002; Pachankis, 2007), the stigma experienced by people affected by BBVs and STIs may result in unequal access to treatment services (Benintendi et al., 2021; Hatzenbuehler, 2016; Paquette et al., 2018; Smith-Palmer et al., 2020; Sweeney & Venable, 2016). Recent improvements and innovative training strategies that prioritise the involvement of marginalised clients, such as providing education in conjunction with social contact, focusing on recovery and hearing testimonies from persons with lived experience, have contributed to a reported reduction in some levels of stigmatising attitudes amongst healthcare workers (Geibel et al., 2017; Gronholm et al., 2017; Knaak & Patten, 2016; Nyblade et al., 2019; Sukhera & Chahine, 2016).

In order to achieve optimum health services for the range of populations most affected by or at risk of stigmatised infections, it is important to better understand what such populations are looking for in a health service to encourage improved access testing, treatment and care. Whilst previous research has shown that stigma is related to reduced engagement with health service provision (Calabrese & Underhill, 2015), there is limited research on how to increase

engagement amongst these particular groups. This study aimed to understand the health service experiences of people affected by STIs or BBVs, including experiences of stigma and discrimination and barriers to treatment and explore what could be done to better engage people living with BBVs and STIs in healthcare services.

2 | METHOD

2.1 | Study setting and population

The study was conducted in the small Australian city. Participants were people who were living with a BBV or STI and were members of one or more priority populations as listed in the Australian national BBV and STI strategies (Australian Government Department of Health, 2018b): Aboriginal and Torres Strait Islander peoples, people who inject drugs, gay men and other men who have sex with men, culturally and linguistically diverse people and refugees, sex workers, people in custodial settings and young people (aged 18–25 years). The study had ethics approval from UNSW HREC HC17751 and ACT Health HREC ETH.11.17.270.

2.2 | Recruitment

Workshops were held with key stakeholders and health services prior to commencing. Healthcare services that cater to the targeted population groups were identified, informed of the research and invited to participate in recruitment for the study. Of the 11 services approached, eight services agreed, spanning a range of health service types including private general practices, public and primary healthcare centres, peer-led community-based organisations, sexual health centres and harm reduction services. Flyers highlighting the study purpose, inclusion criteria and interview dates were displayed in all relevant health services for at least 1 month prior to data collection.

2.3 | Data collection

Participants were recruited using convenience sampling methods. Researchers visited each study site for a period of 2 to 3 days, and potential participants either booked appointments within those dates or contacted the researcher to set up an alternative interview time. Prior to commencing, a detailed information statement was given to each participant and written consent was obtained. For participants unable to attend interviews in-person, interviews were conducted over the telephone, and verbal consent was obtained. Interviews were ~45–60 min long and explored the following areas: experiences of stigma and discrimination when accessing health services, experiences of testing and treatment, experiences in healthcare access and service delivery and strategies to improve service provision and reduce stigma and discrimination (see Table 1). Participants

TABLE 1 Interview schedule: People living with sexually transmitted infections (STIs) and blood-borne viruses (BBVs)

Questions

1. When were you diagnosed with (BBV/STI)?
2. Was your diagnosis in [jurisdiction]?
3. What was your experience of getting diagnosed? Did you feel supported by the clinic or service who told you about your BBV/STI diagnosis?
4. Which services in the [jurisdiction] do you engage with regarding your BBV/STI? Do you connect with any other services or organisations (related to the participant's population group—e.g. drug user organisations)?
5. How did you first hear about or become connected with those services/organisations?
6. How would you describe the service/s? (Prompt for positive and negative descriptors—friendly, engaging, challenging, discriminating)
7. How often do you attend the service or organisation? What prompts you to attend (social connections, health concerns, etc)?
8. How satisfied are you with the service you receive? Can you describe how the staff at the organisation make you feel when you are there? (Prompt for positive and negative responses—e.g. welcomed, appreciated, stigmatised)
9. In the last 12 months, did you ever not go to a health service or an organisation because of how you were treated or may be treated? Can you describe what happened that made you not want to go? What did you do instead (nothing, go to another service)?
10. Have you ever felt discriminated against or stigmatised because of your BBV/STI when accessing services? Have you ever felt discriminated against or stigmatised because of your (population group: sex worker, Aboriginality, drug use, etc) when attending a service?
11. What have you done in situations where you felt you were treated poorly by staff members? (e.g. walked out, made a complaint)
12. What is one thing the service you attend could do better to make clients/patients feel more welcomed?

were reimbursed \$30 for their time. Repeated recruitment attempts were made to garner a wide representation of clients from each priority population group, and data collection ceased when no more potential participants were available. Interviews were recorded and transcribed, and de-identified to protect participant confidentiality.

2.4 | Data analysis

The study team had professional competencies in qualitative research, social science, sociology and psychology. Interview transcripts were read by members of the study team independently, and coding was led by one researcher (using NVivo). The study team met regularly to discuss the codes and identify themes from the data using the processes of reflexive thematic analysis (Braun & Clarke, 2006). The process followed for interrogating the reliability of our different approaches to generating themes from the data involved the production

of tentative codes and themes by the primary author, testing whether similar concepts were generated by other researchers when reading extracts of the same data, and discussions about the reflexive dimensions of the coding process and to ensure the analysis was sufficiently grounded in the data. Deductively defined themes (e.g. experiences of stigma and discrimination in healthcare; personal, interpersonal and structural barriers to healthcare access) along with a number of inductively generated themes from the interview data were generated and agreed upon. The themes presented in this paper each speak to a key aspect of what participants viewed as critical to achieving optimal service provision for people affected by BBVs and STIs.

3 | FINDINGS

Interviews were conducted with 46 participants between July and October 2018. Of these 41 were in-person and five were by phone. As depicted in Table 2, the client sample represents a diverse range of perspectives to capture both breadth and depth experiences of stigma and discrimination within these populations. Participants were sometimes a member of more than one 'priority population', revealing the intersectional impacts and experiences of BBVs and STIs. Themes generated from the participant interviews focused on optimising service provision, noting the importance of high-quality holistic and confidential services that prioritised client safety and comfort, were knowledgeable and competent in meeting the needs of the specific group, and included peers in the provision and development of services. These are described in more detail below.

3.1 | Feeling welcomed

Many participants reported valuing spaces they considered safe and welcoming for the provision of HCV, HIV and other STI-related services. Organisations which openly displayed widely recognised symbols associated with the populations most affected by HCV and HIV seemed to elicit initial trust from clients. This was seen as important because the intentional display of symbols that are 'openly proud' may help to avert feelings of being stigmatised or shame and secrecy amongst client groups.

Most people with HIV know where to go and they know where it's safe ... How do you know that, because they have symbols, like the rainbow flag on the door is a vote of confidence and that instils confidence in the community—Client 17, male living with HIV, 30s

Conversations with participants about their perceptions of services also revealed that 'word-of-mouth' was a key method to gain awareness of services that were non-judgemental and accessible and that service experiences, both positive and negative, would also 'filter back' to the community.

TABLE 2 Demographic characteristics

Total number of participants (n = 46)	Number in each category	Percentage of total sample, %
Gender		
Male	30	65
Female	16	35
Sexuality		
Straight/heterosexual	23	50
Gay/Lesbian	12	26
Bisexual	3	6.5
Unknown or other sexuality	7	15
Priority population		
Diagnosed with hepatitis B	3	6.5
Diagnosed with hepatitis C	27	59
Diagnosed with HIV	15	33
Diagnosed with an sexually transmitted infection	8	17
History of injecting drug use/people who inject drugs (PWID)	26	57
Aboriginal or Torres Strait Islander-identified	6	13
Identified as a non-English migrant or refugee background/culturally and linguistically diverse (CALD)	4	9
Young person (e.g. aged 25 and under)	4	9
History of sex work	3	6.5
History of incarceration	13	28

Reception and front of house staff that were professional were greatly appreciated by participants, emphasising the need for discretion and understanding from the outset. Adverse experiences at the beginning could set a negative tone for the remaining appointment or be a deterrent to treatment.

I think because [front of house staff] seem to swap and change a lot, and they ask questions they don't need to know. You know, like in regards to privacy. "What are you seeing the doctor for?" Now she doesn't need to know that, you know. I'm seeing a doctor because I need to see a doctor. Your job is to take my name and make an appointment and, you know, not say what you need to come in for—Client 37, male living with HCV, 40s

Overall, having a safe space to talk in a non-judgemental environment was seen as very valuable in helping clients, especially when they are feeling unhappy or stressed.

3.2 | Preferring experienced services

Findings revealed that participants felt more comfortable in a service which had more regular contact with people living with BBVs or STIs, and were more likely to be honest in disclosing the issues affecting them where they were confident the service would understand. Participants felt that these services were better trained to work in a non-judgemental and respectful manner. One of the key indicators of service satisfaction reported in the interviews was having access to BBV-focused (or specialised) services. Several participants had a general practitioner (GP), and yet, when it came to discussions involving their HCV, HIV or STI concerns, the majority preferred to access the expertise of experienced services whose staff were better equipped and more sensitive to client needs. For PLHIV, being able to confide in a trusted health professional on sensitive topics (e.g. sexual health risk) was mentioned as a key reason to continue to use the service. Staff were viewed as particularly knowledgeable and well-equipped to respond to both common and perceived uncommon concerns relating to their BBV or STI.

Like my old GP, I probably wouldn't go to him for that, just because I feel like he is not really interested in gay men at all and I don't know, I just feel like coming here, better care ... the screening is better than what you get at the GP clinic... they do throat and rectal swabs everything, like standard of care in general practice wouldn't include that, they tend to just do urine and they don't always do blood-borne virus screening ... I guess the other advantage is you feel comfortable talking about things whereas I don't really want to go to my GP—Client 32, male living with HIV and STI, 20s

In addition to the clinical competence of the organisations, participants stated that they trusted staff at the experienced services more. Open communication between clients and their healthcare practitioners was critical in providing clients with the best opportunity to care for their own well-being. As some participants were uncomfortable openly disclosing their HCV status, the more specialised BBV services played an important role in providing a safe space to discuss their health and other related issues (e.g. housing, pharmacotherapy). Participants also spoke about feeling more satisfied with services that treated their HCV, HIV or STI status as just another everyday occurrence, rather than something new and different.

They have a fairly large gay clientele and they still have several members of staff who are either transgender or gay or for whatever reason more aware of LGBT issues. So, I think as a [clinic], it is more aware

than usual. It's the ordinariness of the patients, there is nothing special about the patient, I mean, whether they are HIV or not, whether they are coming in for hormone treatment or not, that is just the patient and I have never had any treatment other than just the patient—Client 22, male living with HIV, 50s

Negative experiences in general health services were commonly reported by some participants. Health professionals who have less contact with marginalised groups seem more likely, through lack of training and experience, to inadvertently foster an environment that is unwelcoming to clients. A few participants also described feeling some disappointment with the service provided by reception staff in general practices. These incidents were mostly related to client confidentiality.

3.3 | Importance of peers in services

Peer-based services were highly valued by participants. The importance of peers (i.e. people with lived experience of the health condition or of stigma experienced by the population group) in helping to support clients, understanding their experiences and making them feel comfortable in a service was highlighted. Participants commented on feelings of acceptance and validation received from peers that were not found in many other professional relationships. It was further acknowledged that having staff in health services that were peer workers or members of marginalised populations helped to elicit a safe space.

Importantly, many participants spoke about having particular confidence in a service that was peer-based because of their in-depth knowledge, and their understanding of the community. Having peers available in services was something regularly mentioned by clients as significant in ensuring they felt well understood and safe to discuss their health and other concerns.

I have always really been driven by peer-based support staff and education and peer-based training. It's only someone who is in the same shoes as you are that can really understand what you are going through—Client 22, male living with HIV, 50s

Participants were more likely to continue to attend a service if there were peers in the service as they felt this offered them an additional level of understanding and support. Peer workers were seen to be more sensitive to the complexities and challenges faced by clients.

If you need to go to court, I think so they might even accompany you just to you know, peer help, I think and they tell us about these sorts of things as well—Client 28, female living with HCV, 30s

Overall, peer-based services were seen as valuable to clients, making them feel better supported. Peers provided a unique

point of engagement and access for stigmatised clients for whom the health system may sometimes appear judgmental and discriminatory.

3.4 | Confidentiality and discretion

Another issue that was described as particularly important was confidentiality and discretion. Several participants emphasised the importance of having their confidentiality respected, including their HIV, HCV or STI status. Fear of stigma related to a status and/or history of sex work was reported as major barriers to accessing health services.

At the neonatal [clinic], they are really good because I didn't want my status to be on my file, that's public to everybody and they were really good in keeping it discreet...—Client 35, female living with HIV, 30s

Community members also reported concerns about health workers asking them questions about how they may have acquired their HCV or STIs. Whilst clients understood that health workers may need to ask them questions about their health conditions, or may be expressing natural curiosity, they felt that providers should know that seemingly innocent questions could be misconstrued as threatening by those affected.

I guess men have sex with men would be a high risk factor, injecting drug users as well ... so I am not surprised that the doctor might want to know about that, but if you take a step back and you think about it from the patient's point of view, maybe it's not as necessary to know—Client 33, male living with HCV, 20s

Unwarranted or excessive disclosure was also raised by participants, and a way to avoid this was noted to be the use of universal precautions by health workers when drawing blood. Participants commented that some clients are happy to openly discuss their STI or HCV status but others may not be, and clinicians need to be sensitive to these differences amongst clients to prevent them from feeling ashamed. Instances of inappropriate disclosure of STI/HIV/HCV status were still reported amongst clients at some services.

One client raised concerns that health workers defined her health as related to her positive HIV status and every medical issue she had was seen to be a product of her being HIV-positive.

In the hospital proper, I have heard nurses say you know, "go take blood from this person, they are HIV positive by the way", which I can see both sides of it, but in my opinion you should approach every patient as though they are HIV positive ... I get it, you

want to be extra cautious but you should be extra cautious anyway—Client 32, male living with HIV and STI, 20s

There were additional challenges to confidentiality and discretion for community members who were part of more than one minority community. For example, for people identifying as Aboriginal and who were also HIV positive, there is a choice to access a service either through an Aboriginal community-controlled health organisation or a public government health organisation. Some clients have hesitations in using services that target their own population group, such as those specific to indigenous health, due to concerns around confidentiality and the possibility of being identified. Other participants suggested that some Aboriginal clients will choose to specifically use services not connected to their own community, thereby reducing the risk of unwanted disclosure.

I wouldn't go to the that service ... I wouldn't go there because, you know, professional as they are, people tend to talk and then, there are so few [of us] ... it doesn't take much to identify who that particular person would be—Client 36, male living with HIV, 60s

3.5 | Holistic and integrated health services

Participants valued a more comprehensive service that offered holistic care and addressed numerous client concerns, including emotional support. The fragmentation of some health services, which included attending different services for different health complaints was noted as creating particular access challenges and resulted in clients not having important health or welfare concerns attended to.

[Sex] workers will have their sexual health testing done [at one place] and go to their GP for a flu, cold, gastro virus, but the two never meet. Like they never tell their doctor that they are doing sex work or can they have a sexual health testing done. They'd never ask that. They only go for the physical or mental health issues and sexual health testing is completely separate—Client 46, female sex worker, 30s

The care can be a bit fragmented for those people like at [one place] where I have spent a bit of time, a lot of the time, doctors there are very much treating [one condition], but not all the other stuff around it and there are other conditions and like, they are all connected ... I feel like the care could be more holistic—Client 32, male living with HIV and STI, 20s

However, this can be compared with reports from other participants who felt that there were some services which went out of their

way to make their services as accessible as possible and to provide a comprehensive and holistic service which met a range of additional needs for clients. These participants spoke highly of services that went above and beyond in their care of clients.

They run safety and therapy programs, they have family barbeque days and they all are very approachable, so if you have any problems, you can go in and they are free to talk and they have case workers as well which is fantastic. They can help you try and find housing as well and if any problems at all, they are very approachable— Client 28, female living with HCV, 30s

4 | DISCUSSION

This study aimed to show some of the ways in which services could better protect and cater to populations that experience stigma in reference to BBVs and STIs, which includes their presumed association with sexual and drug use behaviours. The findings are relevant to improving service delivery for people living with BBVs or STIs in a variety of international health service contexts, but particularly for those that provide individualised medical and therapeutic care services. Our research shows that previous experiences or fear of mistreatment may result in reluctance amongst marginalised individuals to continue to access services. Findings highlight that negative attitudes and experiences impact people with HCV, HIV and STIs in multiple ways. Any quality components of community healthcare and related innovations should recognise and address this where possible through on-going staff training and by making healthcare environments welcoming and inclusive.

Prior research suggests that stigma is still pervasive in healthcare services and plays a major role in shaping service engagement (Feyissa et al., 2019; Surratt et al., 2021; Treloar et al., 2013). Given reports about the negative attitudes of reception and administrative staff, these findings suggest that the respectful behaviour of reception staff cannot be undervalued. Consistent with prior research that lack of adequate education and addiction-related training amongst staff has been found to be associated with increased levels of stigma (Van Boekel et al., 2013), front of house staff should be trained to respond to clients with consideration of privacy and confidentiality. Using sensitive approaches to managing patient records is important so that private health information is not accessed inappropriately or shared in public settings. Health services catering for people living with BBVs or STIs should emphasise to front of house staff during employee training the importance of maintaining client confidentiality. This might be especially relevant for clients who have already been on the receiving end of many stigmatising experiences by healthcare staff.

This research also highlights the value of peer-based services in providing non-judgemental and supportive environments that help to make people accessing services more comfortable. Existing research suggests that healthcare is more accessible and less

stigmatising when staff have shared many lived experiences with their clients (Muncan et al., 2020) and fosters transparent communication and client participation in healthcare consultations (Morgan et al., 2015). Peer workers bring their own personal knowledge of lived experiences and share vital experiential information that bring credibility, trust and resiliency to marginalised populations (Davidson et al., 2012; Laderman & Mate, 2016). Peer-based programs have been shown to produce better results than non-peer-based programs (Cabassa et al., 2017; Chinman et al., 2014; Davidson et al., 2012). For example, a peer-driven health promotion intervention significantly increased sexual healthcare attendance and STI screening amongst Aboriginal people in Western Sydney (Biggs et al., 2016). The past three decades have witnessed a substantial growth in consumer participation and peer engagement programs, however, their implementation within particular health settings has been limited, especially in high-level involvement activities such as decision making (Hinton, 2010; Rance & Treloar, 2015; Treloar et al., 2011). The findings from this study support current research which suggests that existing consumer participation programs have led to increased consumer satisfaction, better engagement with staff, less negative attitudes amongst staff towards clients, improved service delivery and a disruption in the routine objectification that may characterise treatment (Brenner et al., 2009, 2021; Goodhew et al., 2019; Matthews et al., 2018; Rance & Treloar, 2015). Optimal service provision should therefore include peers with lived experience and investigate the option of greater consumer participation in high-level activities.

A commonly reported barrier to healthcare is the fragmented structure of health services between mental health, alcohol and drug services, specialist and mainstream services and services catering to culturally and linguistic diverse populations (Bäärnhielm et al., 2014; Posselt et al., 2017). Literature highlights the unaddressed need for stronger partnerships and collaboration between services (Isaacs & Firdous, 2018; World Health Organization, 2018). Our findings reinforce this need to design more holistic systems with better linkage to other types of services so that clients have easy access to all necessary tests and treatments. This is further compounded by challenges created by the fact that integration relies on digital health systems. People living with BBVs or STIs are often very reluctant to support the sharing of electronic health records across services because of entrenched fears of breaches of confidentiality. Similarly, a fragmented health structure not only prevents 'continuity of care' for marginalised populations but often places much of the burden on the client to navigate multiple service pathways, sometimes involving settings where prior stigmatising experiences occurred (e.g. hospital-based services; Marshall et al., 2019; Treloar et al., 2013). Permitting clients to access care in settings of their choosing (e.g. HCV care in drug and alcohol settings), whenever possible, and/or the use of peer navigators to assist clients in attending their service appointments, are strategies which will help facilitate improved health outcomes for clients (Grebely et al., 2013).

Whilst attempts were made to recruit and interview an equal representation of priority populations, a limitation of this study is

that we were unable to recruit a sizeable number of people living with hepatitis B (HBV), thus findings related to HBV were not included. As people living with HBV have distinct stigma and transmission routes as compared to people living with HCV, HIV and other STIs, there is a need for further research to be able to compare the health service perceptions and experiences of people and communities most affected by HBV in Australia with those of other BBV.

In addition, refugee and Aboriginal health services declined to participate so we were unable to recruit an adequate sample of culturally and linguistically diverse, migrant and aboriginal participants; findings may have limited applicability for these groups. This suggests that our recruitment strategies were not uniformly successful across all priority populations and that additional community outreach is required to reach those experiencing multiple or intersecting stigmas. Similarly, our recruitment strategy did not include documentation in languages other than English and this undoubtedly hindered our recruitment with some populations. There could have also been selection bias in that those who felt highly stigmatised or not stigmatised at all may have chosen not to participate. Lastly, additional analyses which address the complex intersectionality of the priority populations and their health challenges beyond the single population or health issue would further help to inform clinical/service practice and policy.

Feeling stigmatised by health workers can have far-reaching detrimental effects on people, such as receiving sub-standard treatment and care. An interesting finding from this study is that some marginalised groups (e.g. sex workers and PLHIV) on the whole were better informed about the care, testing and treatment they required and knew how to best navigate the health system to reduce stigma by going to different health services for their different needs. Whilst this increases the burden placed upon individuals in managing their health, it also improves the potential for members of these stigmatised populations to receive the appropriate care. However, not all participants had this knowledge, with some groups being less well informed and less able to arm themselves with the knowledge to offset their disadvantages in order to receive optimum care. On the whole, this study has identified important factors that help clients from these communities feel more comfortable and respected and encouraged to access ongoing care. Identifying ways to further reduce stigma in healthcare is pivotal to improve outcomes for these marginalised and vulnerable groups and to ensure that the burden of disease is reduced.

AUTHOR CONTRIBUTIONS

Robyn Horwitz was primarily responsible for data collection, data analysis and preparing drafts of the full manuscript. Loren Brener developed the design of the study, was involved in data collection and analysis and contributed conceptually to the analysis and write up of the paper. Alison D. Marshall assisted with data collection, analysis of the qualitative data and framing of the manuscript. Theresa Caruana assisted in reconceptualising the paper and adding theoretically literature to it following reviews. Christy E. Newman provided conceptual oversight to the overall qualitative design and analysis of the data as well as contributed to the writing of the manuscript.

ACKNOWLEDGEMENTS

We would like to acknowledge the funding received from ACT Health to conduct this important research. The authors are grateful to the clients and services for their participation in this research and we would particularly like to acknowledge the hard work and input of all the NGOs, stakeholders and staff members of the various services who provided assistance to the research team. Open access publishing facilitated by University of New South Wales, as part of the Wiley - University of New South Wales agreement via the Council of Australian University Librarians.

FUNDING INFORMATION

This study was funded by the ACT Health Directorate.

CONFLICT OF INTEREST

All authors declare they have no conflict of interest.

DATA AVAILABILITY STATEMENT

Due to ethical constraints, anonymised data is available on request from the authors.

REFERENCES

- Australian Government Department of Health. (2018a). *Fifth national aboriginal and torres strait islander blood borne viruses and sexually transmissible infections strategy 2018–2022*. Department of Health.
- Australian Government Department of Health. (2018b). *The national BBV and STI strategies for 2018–2022*. Department of Health.
- Bäärnhjelm, S., Edlund, A. S., Ioannou, M., & Dahlin, M. (2014). Approaching the vulnerability of refugees: Evaluation of cross-cultural psychiatric training of staff in mental health care and refugee reception in Sweden. *BMC Medical Education*, 14(1), 207. <https://doi.org/10.1186/1472-6920-14-207>
- Benintendi, A., Kosakowski, S., Lagisetty, P., Larochelle, M., Bohnert, A. S. B., & Bazzi, A. R. (2021). "I felt like I had a scarlet letter": Recurring experiences of structural stigma surrounding opioid tapers among patients with chronic, non-cancer pain. *Drug and Alcohol Dependence*, 222, 108664. <https://doi.org/10.1016/j.drugalcdep.2021.108664>
- Biancarelli, D. L., Biello, K. B., Childs, E., Drainoni, M., Salhaney, P., Edeza, A., Mimiaga, M. J., Saitz, R., & Bazzi, A. R. (2019). Strategies used by people who inject drugs to avoid stigma in healthcare settings. *Drug and Alcohol Dependence*, 198, 80–86. <https://doi.org/10.1016/j.drugalcdep.2019.01.037>
- Biggs, K., Walsh, J., & Ooi, C. (2016). Deadly liver mob: Opening the door—improving sexual health pathways for aboriginal people in Western Sydney. *Sexual Health*, 13(5), 457–464. <https://doi.org/10.1071/SH15176>
- Bos, A. E., Pryor, J. B., Reeder, G. D., & Stutterheim, S. E. (2013). Stigma: Advances in theory and research. *Basic and Applied Social Psychology*, 35(1), 1–9. <https://doi.org/10.1080/01973533.2012.746147>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Brener, L., Horwitz, R., Rance, J., Gray, R., Poeder, F., & Bryant, J. (2021). Establishing the impact of consumer participation in alcohol and other drug treatment settings in Australia. *Health & Social Care in the Community*, 30, e1183–e1193. [10.1111/hsc.13525](https://doi.org/10.1111/hsc.13525)
- Brener, L., Resnick, I., Ellard, J., Treloar, C., & Bryant, J. (2009). Exploring the role of consumer participation in drug treatment. *Drug and*

- Alcohol Dependence*, 105(1–2), 172–175. <https://doi.org/10.1016/j.drugalcdep.2009.06.016>
- Cabassa, L. J., Camacho, D., Vélez-Grau, C. M., & Stefancic, A. (2017). Peer-based health interventions for people with serious mental illness: A systematic literature review. *Journal of Psychiatric Research*, 84, 80–89. <https://doi.org/10.1016/j.jpsychires.2016.09.021>
- Calabrese, S. K., & Underhill, K. (2015). How stigma surrounding the use of HIV preexposure prophylaxis undermines prevention and pleasure: A call to destigmatize “Truvada whores”. *American Journal of Public Health*, 105(10), 1960–1964. <https://doi.org/10.2105/AJPH.2015.302816>
- Cama, E., Brenner, L., Wilson, H., & von Hippel, C. (2016). Internalized stigma among people who inject drugs. *Substance Use & Misuse*, 51(12), 1664–1668. <https://doi.org/10.1080/10826084.2016.1188951>
- Chambers, L. A., Rueda, S., Baker, D. N., Wilson, M. G., Deutsch, R., Raeifar, E., & Rourke, S. B. (2015). Stigma, HIV and health: A qualitative synthesis. *BMC Public Health*, 15(1), 848. <https://doi.org/10.1186/s12889-015-2197-0>
- Chan, B. T., & Tsai, A. C. (2016). HIV stigma trends in the general population during antiretroviral treatment expansion: Analysis of 31 countries in sub-Saharan Africa, 2003–2013. *Journal of Acquired Immune Deficiency Syndromes*, 72(5), 558–564. <https://doi.org/10.1097/QAI.0000000000001011>
- Chinman, M., George, P., Dougherty, R. H., Daniels, A. S., Ghose, S. S., Swift, A., & Delphin-Rittmon, M. E. (2014). Peer support services for individuals with serious mental illnesses: Assessing the evidence. *Psychiatric Services*, 65(4), 429–441. <https://doi.org/10.1176/appi.ps.201300244>
- Corrigan, P. W., Larson, J. E., & Kuwabara, S. A. (2010). Social psychology of the stigma of mental illness: Public and self-stigma models. In J. E. Maddux & J. P. Tangney (Eds.), *Social psychological foundations of clinical psychology* (pp. 51–68). The Guilford Press.
- Corrigan, P. W., Sokol, K. A., & Rüsich, N. (2013). The impact of self-stigma and mutual help programs on the quality of life of people with serious mental illnesses. *Community Mental Health Journal*, 49(1), 1–6. <https://doi.org/10.1007/s10597-011-9445-2>
- Davidson, L., Bellamy, L., Guy, K., & Miller, R. (2012). Peer support among persons with severe mental illnesses: A review of evidence and experience. *World Psychiatry*, 11(2), 123–128. <https://doi.org/10.1016/j.wpsyc.2012.05.009>
- Earnshaw, V. A., & Quinn, D. M. (2012). The impact of stigma in healthcare on people living with chronic illnesses. *Journal of Health Psychology*, 17(2), 157–168. <https://doi.org/10.1177/1359105311414952>
- Ekstrand, M. L., Bharat, S., & Srinivasan, K. (2018). HIV stigma is a barrier to achieving 90-90-90 in India. *The Lancet HIV*, 5(10), e543–e545. [https://doi.org/10.1016/S2352-3018\(18\)30246-7](https://doi.org/10.1016/S2352-3018(18)30246-7)
- Emlet, C. A., Fredriksen-Goldsen, K. I., Kim, H. J., & Hoy-Ellis, C. (2017). The relationship between sexual minority stigma and sexual health risk behaviors among HIV-positive older gay and bisexual men. *Journal of Applied Gerontology*, 36(8), 931–952. <https://doi.org/10.1177/0733464815591210>
- Falade-Nwulia, O., Suarez-Cuervo, C., Nelson, D. R., Fried, M. W., Segal, J. B., & Sulkowski, M. S. (2017). Oral direct-acting agent therapy for hepatitis C virus infection: A systematic review. *Annals of Internal Medicine*, 166(9), 637–648. <https://doi.org/10.7326/M16-2575>
- Feyissa, G. T., Lockwood, C., Woldie, M., & Munn, Z. (2019). Reducing HIV-related stigma and discrimination in healthcare settings: A systematic review of quantitative evidence. *PLoS One*, 14(1), e0211298. <https://doi.org/10.1371/journal.pone.0211298>
- Geibel, S., Hossain, S. M. I., Pulerwitz, J., Sultana, N., Hossain, T., Roy, S., Burnett-Zieman, B., Stackpool-Moore, L., Friedland, B. A., Yasmin, R., Sadiq, N., & Yam, E. (2017). Stigma reduction training improves healthcare provider attitudes toward, and experiences of, young marginalized people in Bangladesh. *Journal of Adolescent Health*, 60(2), S35–S44. <https://doi.org/10.1016/j.jadohealth.2016.09.026>
- Giddens, A., Duneier, M., Appelbaum, R. P., & Carr, D. (2009). *Introduction to sociology* (7th ed.). W.W. Norton & Company, Inc.
- Gilmore, N., & Somerville, M. A. (1994). Stigmatization, scapegoating and discrimination in sexually transmitted diseases: Overcoming ‘them’ and ‘us’. *Social Science & Medicine*, 39(9), 1339–1358. [https://doi.org/10.1016/0277-9536\(94\)90365-4](https://doi.org/10.1016/0277-9536(94)90365-4)
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Simon & Shuster.
- Goodhew, M., Stein-Parbury, J., & Dawson, A. (2019). Consumer participation in drug treatment: A systematic review. *Drugs and Alcohol Today*, 19(2), 97–112. <https://doi.org/10.1108/DAT-05-2018-0023>
- Grebely, J., Oser, M., Taylor, L. E., & Dore, G. J. (2013). Breaking down the barriers to hepatitis C virus (HCV) treatment among individuals with HCV/HIV coinfection: Action required at the system, provider, and patient levels. *The Journal of Infectious Diseases*, 207(Suppl. 1), S19–S25. <https://doi.org/10.1093/infdis/jis928>
- Gronholm, P. C., Henderson, C., Deb, T., & Thornicroft, G. (2017). Interventions to reduce discrimination and stigma: The state of the art. *Social Psychiatry and Psychiatric Epidemiology*, 52(3), 249–258. <https://doi.org/10.1007/s00127-017-1341-9>
- Hamed, A., Saling, C., Brown, M. S., Szabela, M. E., Jayasingam, R., Siegal, A., & Slim, J. (2018). 1495. Incidence of sexually transmitted infections (STIs) in patients on pre-exposure prophylaxis (PrEP). *Open Forum Infectious Diseases*, 5(Suppl. 1), S462. <https://doi.org/10.1093/ofid/ofy210.1324>
- Hatzenbuehler, M. L. (2016). Structural stigma: Research evidence and implications for psychological science. *American Psychologist*, 71(8), 742–751. <https://doi.org/10.1037/amp0000068>
- Hebl, M. R., & Dovidio, J. F. (2005). Promoting the “social” in the examination of social stigmas. *Personality and Social Psychology Review*, 9(2), 156–182. https://doi.org/10.1207/s15327957pspr0902_4
- Helms, C. B., Turan, J. M., Atkins, G., Kempf, M. C., Clay, O. J., Raper, J. L., Mugavero, J. M., & Turan, B. (2017). Interpersonal mechanisms contributing to the association between HIV-related internalized stigma and medication adherence. *AIDS and Behavior*, 21(1), 238–247. <https://doi.org/10.1007/s10461-016-1320-2>
- Herek, G. (2002). Thinking about AIDS and stigma: A psychologist’s perspective. *Journal of Law, Medicine & Ethics*, 30(4), 594–607. <https://doi.org/10.1111/j.1748-720X.2002.tb00428.x>
- Hinton, T. (2010). *Voices on choices: Working towards consumer-led alcohol and drug treatment*. Social Action and Research Centre, Anglicare Tasmania.
- Isaacs, A. N., & Firdous, F. (2018). A care coordination model can facilitate interagency collaboration when designing recovery-oriented services. *Journal of Psychosocial Nursing and Mental Health Services*, 57(5), 38–43. <https://doi.org/10.3928/02793695-20181128-01>
- Knaak, S., & Patten, S. (2016). A grounded theory model for reducing stigma in health professionals in Canada. *Acta Psychiatrica Scandinavica*, 134, 53–62. <https://doi.org/10.1111/acps.12612>
- Laderman, M., & Mate, K. S. (2016). Behavioral health integration in acute medical settings: An opportunity to improve outcomes and reduce costs. *Joint Commission Journal on Quality and Patient Safety*, 42(7), 331–336. [https://doi.org/10.1016/S1553-7250\(16\)42046-5](https://doi.org/10.1016/S1553-7250(16)42046-5)
- Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, 27(1), 363–385. <https://doi.org/10.1146/annurev.soc.27.1.363>
- Marshall, A. D., Madden, A., & Treloar, C. (2019). Enhancing engagement in hepatitis C care among people who inject drugs. *Addiction*, 114(12), 2104–2106. <https://doi.org/10.1111/add.14698>
- Matthews, H., Pernu, N., & Edgar, A. (2018). Mental health, disability and homelessness and NDIS: NDIS from the inside. *Parity*, 31(8), 64. <https://doi.org/10.3316/informit.000825555551947>
- Morgan, K., Lee, J., & Sebar, B. (2015). Community health workers: A bridge to healthcare for people who inject drugs. *International Journal of Drug Policy*, 26(4), 380–387. <https://doi.org/10.1016/j.drugpo.2014.11.001>

- Muncan, B., Walters, S. M., Ezell, J., & Ompad, D. C. (2020). "They look at us like junkies": Influences of drug use stigma on the healthcare engagement of people who inject drugs in new York City. *Harm Reduction Journal*, 17(1), 1–9. <https://doi.org/10.1186/s12954-020-00399-8>
- Nyblade, L., Stockton, M. A., Giger, K., Bond, V., Ekstrand, M. L., McLean, R., Mitchell, E. M. H., Nelson, L. R. E., Sapag, J. C., Siraprasari, T., Turan, J., & Wouters, E. (2019). Stigma in health facilities: Why it matters and how we can change it. *BMC Medicine*, 17(1), 1–15. <https://doi.org/10.1186/s12916-019-1256-2>
- Pachankis, J. E. (2007). The psychological implications of concealing a stigma: A cognitive-affective-behavioral model. *Psychological Bulletin*, 133(2), 328–345. <https://doi.org/10.1037/0033-2909.133.2.328>
- Paquette, C. E., Syvertsen, J. L., & Pollini, R. A. (2018). Stigma at every turn: Health services experiences among people who inject drugs. *International Journal of Drug Policy*, 57, 104–110. <https://doi.org/10.1016/j.drugpo.2018.04.004>
- Posselt, M., McDonald, K., Procter, N., de Crespigny, C., & Galletly, C. (2017). Improving the provision of services to young people from refugee backgrounds with comorbid mental health and substance use problems: Addressing the barriers. *BMC Public Health*, 17(1), 280. <https://doi.org/10.1186/s12889-017-4186-y>
- Rance, J., & Treloar, C. (2015). "We are people too": Consumer participation and the potential transformation of therapeutic relations within drug treatment. *International Journal of Drug Policy*, 26(1), 30–36. <https://doi.org/10.1016/j.drugpo.2014.05.002>
- Rao, D., Desmond, M., Andrasik, M., Raspberry, T., Lambert, N., Cohn, S. E., & Simoni, J. (2012). Feasibility, acceptability, and preliminary efficacy of the unity workshop: An internalized stigma reduction intervention for African American women living with HIV. *AIDS Patient Care and STDs*, 26(10), 614–620. <https://doi.org/10.1089/apc.2012.0106>
- Scambler, G. (2009). Health-related stigma. *Sociology of Health & Illness*, 31(3), 441–455. <https://doi.org/10.1111/j.1467-9566.2009.01161.x>
- Smith-Palmer, J., Cerri, K., Sbarigia, U., Chan, E. K., Pollock, R. F., Valentine, W. J., & Bonroy, K. (2020). Impact of stigma on people living with chronic hepatitis b. *Patient Related Outcome Measures*, 11, 95–107. <https://doi.org/10.2147/PROM.S226936>
- Stangl, A. L., Lloyd, J. K., Brady, L. M., Holland, C. E., & Baral, S. (2013). A systematic review of interventions to reduce HIV-related stigma and discrimination from 2002 to 2013: How far have we come? *Journal of International AIDS Society*, 16(Suppl. 2), 3. <https://doi.org/10.7448/IAS.16.3.18734>
- Sukhera, J., & Chahine, S. (2016). Reducing mental illness stigma through unconscious bias-informed education. *MedEdPublish*, 5. <https://doi.org/10.15694/mep.2016.000044>
- Surratt, H. L., Otachi, J. K., McLouth, C. J., & Vundi, N. (2021). Healthcare stigma and HIV risk among rural people who inject drugs. *Drug and Alcohol Dependence*, 226, 108878. <https://doi.org/10.1016/j.drugalcdep.2021.108878>
- Sweeney, S. M., & Venable, P. A. (2016). The association of HIV-related stigma to HIV medication adherence: A systematic review and synthesis of the literature. *AIDS and Behavior*, 20(1), 29–50. <https://doi.org/10.1007/s10461-015-1164-1>
- Treloar, C., Rance, J., & Backmund, M. (2013). Understanding barriers to hepatitis C virus care and stigmatization from a social perspective. *Clinical Infectious Diseases*, 57(Suppl. 2), S51–S55. <https://doi.org/10.1093/cid/cit263>
- Treloar, C., Rance, J., Madden, A., & Liebelt, L. (2011). Evaluation of consumer participation demonstration projects in five Australian drug user treatment facilities: The impact of individual versus organizational stability in determining project progress. *Substance Use & Misuse*, 46(8), 969–979. <https://doi.org/10.3109/10826084.2010.540289>
- Turan, B., Rogers, A. J., Rice, W. S., Atkins, G. C., Cohen, M. H., Wilson, T. E., Adimora, A. A., Merenstein, D., Adedimeji, A., Wentz, E. L., Ofotokun, I., Metsch, L., Tien, P. C., Johnson, M. O., Turan, J. M., & Weiser, S. D. (2017). Association between perceived discrimination in healthcare settings and HIV medication adherence: Mediating psychosocial mechanisms. *AIDS and Behavior*, 21(12), 3431–3439. <https://doi.org/10.1007/s10461-017-1957-5>
- Van Boekel, L. C., Brouwers, E. P., Van Weeghel, J., & Garretsen, H. F. (2013). Stigma among health professionals towards patients with substance use disorders and its consequences for healthcare delivery: Systematic review. *Drug and Alcohol Dependence*, 131(1–2), 23–35. <https://doi.org/10.1016/j.drugalcdep.2013.02.018>
- World Health Organization. (2018). *Continuity and coordination of care: A practice brief to support implementation of the WHO framework on integrated people-centred health services*. World Health Organization.
- Zelaya, C. E., Sivaram, S., Johnson, S. C., Srikrishnan, A. K., Suniti, S., & Celentano, D. D. (2012). Measurement of self, experienced, and perceived HIV/AIDS stigma using parallel scales in Chennai, India. *AIDS Care*, 24(7), 846–855. <https://doi.org/10.1080/09540121.2011.647674>

How to cite this article: Horwitz, R., Brener, L., Marshall, A. D., Caruana, T., & Newman, C. E. (2022). Optimising community health services in Australia for populations affected by stigmatised infections: What do service users want? *Health & Social Care in the Community*, 30, e3686–e3695. <https://doi.org/10.1111/hsc.14037>