

Lived experiences of stigma and discrimination among people accessing South Western Sydney Local Health District Drug Health Services

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Health
South Western Sydney
Local Health District



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All interviews were conducted by Annie Madden, AO.

Executive summary

This report presents findings and recommendations from a qualitative research project on experiences of stigma in healthcare settings for people accessing inpatient withdrawal management ('detox') services in South Western Sydney Local Health District (SWSLHD). Using an in-depth qualitative interview method, the project collected and analysed the accounts of people who had recently used inpatient withdrawal management services. The analysis explores the experiences of participants in attempting to access healthcare services, their plans and expectations for healthcare, the role of stigma in healthcare access, and how stigma may shape their engagement with different forms of healthcare. In doing so, the project aims to better understand healthcare access, usage and benefits for people completing inpatient withdrawal management services, as well as impediments to accessing healthcare, in order to improve access, participation and health outcomes. While stigma is known to be a widespread issue for people who consume alcohol or other drugs, less is known about how it shapes engagement with healthcare in Australia. As explained below, the 20 interviews conducted for this project were distributed across people with diverse backgrounds, experiences and circumstances. Interview questions addressed experiences of alcohol and other drug use, engagement with healthcare services, concerns about services, and experiences of and strategies to negotiate stigma. This report details the project's primary findings on these issues and offers recommendations for improving policy and service provision.

The first findings section, entitled 'Positive experiences of healthcare and health professionals', indicates that participants did have positive and professional healthcare experiences. This section has a particular focus on non-judgmental care experiences. However, it also shows that **participants did not have sufficiently consistent experiences of quality care for these to become routine.**

The next section, 'Experiences of stigma in healthcare: Hospitals', explores participants' accounts of negotiating distrustful and discourteous encounters in hospitals. **This section indicates that hospitals**

are not always welcoming environments for people accessing SWSLHD Drug Health Services. Instead, they are sites in which forms of implicit and explicit discrimination are experienced. This dynamic impeded participant access to hospital-based healthcare.

The third section, 'Experiences of stigma in healthcare: General practice', presents participant's experiences of stigma in general practice settings. Participants often felt 'judged' in these settings and felt they were positioned as untrustworthy. **Like hospitals, general practices were not necessarily considered welcoming environments, making them less accessible to clients of SWSLHD Drug Health Services.**

The next two sections shift focus from healthcare settings to interpersonal relationships and encounters. 'Judgment and stigma among consumers' explores participant views about drug use, and other drug users, that can be characterised as judgmental and stigmatising. This section highlights that drug consumption experience does not determine views about other people who consume drugs. **This emphasises the need to recognise differences in the experiences and views among healthcare consumers, and to acknowledge that participants planning to access further alcohol and other drug treatment negotiate a complex context in which views about drug consumption vary in important ways.**

Section five, 'Stigma with families', indicates that **SWSLHD Drug Health Services users often encounter discrimination within the family.** Importantly for this project, these experiences impede their capacity to communicate about alcohol and other drug-related health problems and healthcare needs.

The penultimate section, 'Primed for stigma: Encounters in healthcare' emphasises the complexity of healthcare stigma for SWSLHD Drug Health Services staff and services users. This section indicates that the **participants' extensive experiences of stigma created particular expectations, and suggest healthcare workers need to use targeted strategies to gain the trust of consumers, and more broadly be sensitive to their comportment and ways of engaging.**

This complex dynamic emphasises that the broader contexts of healthcare encounters, including discriminatory encounters, can inform the meaning of professional practices, regardless of intent.

The final findings section, 'Discharge plans', focuses on a key aspect of healthcare access and continuity for those leaving inpatient withdrawal management: healthcare discharge plans. While service users exiting inpatient withdrawal management should leave with

a detailed discharge plan, we found many could describe these plans only vaguely, and many plans faced obstacles from the outset. This suggests that, **given the stigma and discrimination recounted throughout this report, people accessing SWSLHD Drug Health Services may need more robust strategies to support healthcare access following inpatient withdrawal management.**

Recommendations

Recommendations to tackle stigma within SWSLHD health services

1. Conduct analysis of staff attitudes to alcohol and other drug-related health issues in SWSLHD health services
2. Conduct anti-stigma training across SWSLHD health services
3. Audit complaints processes across SWSLHD health services

Recommendations to improve healthcare experiences

4. Work with peer representative organisations to train and employ peer workers in healthcare settings accessed by people who consume alcohol and other drugs in SWSLHD
5. Work with peer representative organisations to develop and conduct consumer rights training in SWSLHD Drug Health Services
6. Support families of those accessing SWSLHD inpatient withdrawal management services to negotiate with other health services, and to understand alcohol and other drug issues

Recommendations to improve healthcare access following inpatient withdrawal management

7. Develop greater coordination between SWSLHD inpatient withdrawal management services and other health services
8. Establish greater continuity of care for clients accessing SWSLHD inpatient withdrawal management services
9. Increase follow-up of service users after exiting SWSLHD Drug Health Services facilities such as inpatient withdrawal management
10. Ensure discharge plans are robust and service users are confident about how to implement them

Background, aims and method

Research on healthcare access and uptake among people who consume alcohol and other drugs and who have undertaken treatment in Australia is limited. Qualitative studies exploring experiences of life after accessing alcohol and other drug treatment services are few, and knowledge of experiences of transitioning from inpatient treatment to community-based healthcare is equally limited. It is known that Australia currently has significant unmet demand for alcohol and other drug treatment (Ritter, Chalmers & Gomez, 2019). Further, Australian research suggests that while follow-up care is a fundamental component of effective alcohol and other drug treatment, many struggle to establish a continuity of care after completing a period of treatment (Lubman et al., 2014). Upon leaving treatment a number of challenges emerge that impede access to follow-up healthcare, including geographical location, long waiting lists, lack of availability of services, and negative staff attitudes (Lubman et al., 2014). It is in this general Australian context that SWSLHD Drug Health Services operates and services users attempt to access healthcare.

Access to healthcare has also been linked to the dynamics of stigmatisation around particular health conditions. The stigmatisation of alcohol and other drug consumption, 'addiction', and related treatment practices is well known. Indeed, 'addiction' and 'alcoholism' are listed as two 'discredited attributes' in Erving Goffman's classic work on stigma (Goffman, 1963). Different forms of drug consumption attract different kinds of stigma, with these differences depending on social context. The extent and variety of stigma associated with alcohol and other drug consumption mean that some form of stigma is almost universal for those diagnosed with addiction or accessing treatment for related issues (Room, 2005). Research shows that heroin and alcohol addiction are stigmatised differently (Meurk et al, 2014). Similarly, the stigma faced by heroin consumers is often more acute than that faced by cannabis consumers (Brown, 2015). Drug consumption stigma is also shaped by gender, ethnicity, social class and other dimensions of social stratification (for example, Sorsdahl, Stein & Myers, 2012). While there is no intrinsic reason for the stigmatisation of alcohol and other drug

consumption, loss of control over consumption levels, and over everyday life and life choices more generally, have been central to understandings of addiction since the notion was originally developed (Room, 2005). As Fraser et al. (2017) argued in a recent article on alcohol and other drug-related stigma in the context of addiction or dependence, narrow definitions of addiction and what it means to consume drugs regularly at high levels shape clinical and public responses. Stigma is understood in this work as colouring the substance of everyday life, rather than as isolated moments of discomfort or unequal treatment. In this respect stigma works to reinforce social marginalisation and inequality (Room, 2005). More specifically, it has been shown to negatively affect access to both generalist health services and specialist alcohol and other drug services, to reduce help-seeking and to negatively affect health and wellbeing. The material and social implications of alcohol and other drug stigma for people accessing healthcare in South Western Sydney are the primary concerns of this research.

Stigma and healthcare access

The literature on stigma in relation to alcohol and other drug services shows the ways it can impede access to healthcare services (Lloyd, 2013). As explored in Lloyd's (2013) review of research on stigmatising attitudes towards people who consume drugs, public hospitals are cited as particularly important sites of stigma. Lancaster, Seear and Ritter's (2018) recent research in Queensland emphasises the contemporary relevance of this issue for Australian hospitals. While they explore a wide range of experiences of stigma, hospitals and emergency departments were identified as particularly relevant contexts for the people who consume alcohol and other drugs. Another recent study, this time conducted by Paquette, Syvertsen & Pollini (2018), found that people who consume drugs face near constant stigma when accessing healthcare. In their study, the discrimination that stems from this stigma ranged from subtle interpersonal interactions to explicit forms of substandard care. In this sense, stigma can take different forms and is not always recognisable as explicit discrimination. It is not simply about interpersonal interactions but can

inhere within institutional processes and structures. Paterson et al. (2013) argue, for example, that hospital communications processes and other department and institutional structures contribute to the stigma faced by people who consume drugs. This stigma is especially concerning because it can position those who consume drugs as a lower priority for healthcare (Olsen et al., 2003) in public healthcare settings at least partly shaped by strained resources (Ritter, Calmers & Gomez, 2018). Additionally, it can impede access to necessary therapies such as adequate pain management (for example, Earnshaw, Smith & Copenhaver, 2013). Moreover, experiences of stigma and related discrimination can discourage people who consume drugs from attending healthcare services such that when they do come into contact with health services they present with more advanced health problems (for example, Weiss et al., 2004).

Research also suggests that stigma impedes access to specialist alcohol and other drug services (Lloyd, 2013). For example, Semple, Grant and Patterson (2005) argue that stigma can act as a barrier to treatment for methamphetamine dependence. Similarly, Keyes et al. (2010) argue perceptions of alcohol-related stigma limit access to alcohol consumption treatment. Stigma works against important harm reduction initiatives too. For example, research suggests stigma can limit engagement with needle and syringe programs (Simmonds & Cooper, 2009). Likewise, stigma shapes experiences of specialist treatments. For example, some service users feel engagement with drug treatment services singles them out and labels them publicly as drug users or 'addicts' (Radcliffe & Stevens, 2008). In addition, particular aspects of treatment regimens such as the supervision of methadone consumption or the collection of urine samples, are experienced as stigmatising and have been found to hinder access to key aspects of mainstream life such as employment (Fraser, 2006; Radcliffe & Stevens, 2008). Furthermore, completing treatment does not necessarily lead to reduced experiences of stigma and discrimination. Some research suggests that engagement in drug treatment can lead to increased stigma from friends, family and employers, and that this can continue even after successfully completing

treatment (Earnshaw, Smith & Copenhaver, 2013). Finally, alcohol and other drug consumption stigma can have a negative impact on the attainment of health goals such as ceasing drug consumption itself (Lloyd, 2013; Luoma et al., 2007).

Taken together, the body of research on stigma in the context of alcohol and other drug use and treatment suggests that stigma is an almost ubiquitous experience for people who try and access healthcare for drug consumption issues, and consistently works to impede access to healthcare services. In this respect, the stigmatisation of people who are thought to consume alcohol and other drugs excessively is a well-known issue in Australia and elsewhere. This project seeks to explore the potential relevance of stigma for people receiving alcohol and other drug-related care, specifically those who have recently exited the inpatient withdrawal management ('detox') service in SWSLHD, and who are in need of further healthcare, the purpose being to develop deeper understandings of ways to address it and improve the provision of healthcare to this group.

Project aims

This project was designed to support SWSLHD Drug Health Services to deliver high quality healthcare services and enhance outcomes for individuals with experience of alcohol and other drug-related problems.

Based on in-depth qualitative interviews, the project's aims were to:

- 1 Identify and document** experiences of stigma and discrimination among individuals accessing healthcare services after exiting the SWSLHD inpatient withdrawal management service;
- 2 Explore and analyse** how service users understand and frame these experiences, and how, if at all, they affect their ability and willingness to access services;
- 3 Identify systemic issues** in relevant settings that contribute to stigma and discrimination.

Project approach

The concept of stigma has been used by researchers in many different ways (for a discussion see Tyler & Slater, 2018). In this project, we approached the stigma experienced by participants by drawing on Fraser et al.'s (2017) concept of addiction stigma. This approach sees stigma as a 'process of social production' (p.195), and stresses that it should not be understood as solely composed of individual attitudes or beliefs but as a force of social organisation that helps shape important public institutions such as healthcare services. This approach focusses on what stigma achieves and how it works to shape the conditions in which we live. When stigma is understood in this way as a socially productive force, we can map how it positions some as productive and worthy individuals and others as illegitimate and unworthy. This allows us to open out the focus of our investigations from individual conduct (for example, that of those who find themselves stigmatised, or those working within historically marginalising institutional settings) to trace stigma as an overarching dynamic. In this way, we can think through the structural conditions feeding stigma, and consider broader responses as well as individual and local ones.

Method

The report is based on data generated from 20 qualitative, semi-structured in-depth interviews conducted with alcohol and other drug consumers who had accessed the inpatient withdrawal management service in SWSLHD within the last 12 months. Recruitment was managed with the help of staff in the relevant service. Potential participants were informed of the project, and those interested in finding out more telephoned the research team. Additional information about the project was given and eligibility was confirmed. Participants were also screened to ensure variation in gender, age and drug types.

The service is the only inpatient withdrawal management unit in South Western Sydney Local Health District, and as such, it is the only publicly funded service in the health district. Clients are referred via several mechanisms:

- ▶ Self-referral by telephoning the DHS intake line;

- ▶ Referral by other local health professionals either through the intake line or, more commonly, by direct communication between SWSLHD staff (especially other DHS staff at other sites) and the senior staff specialist and/or the Nursing Unit Manager; and
- ▶ Other referral pathways such as treatment mandated by the Court.

Prior to admission, unless a direct referral is made by another DHS staff member, clients are booked in for an assessment by a DHS clinician (non-medical, unless requested). If accepted, urgent cases are prioritised.

Admissions mostly only occur during a four-hour period on Monday to Friday, with clients experiencing more serious problems admitted earlier in the week. This is because there is no access to on-site medical cover after hours, and so it is necessary to minimise chances that clients will become seriously ill when there is no doctor available.

The service prioritises people with alcohol and other drug consumption-related issues that require medical/nursing observation and intervention, for example, alcohol dependence or benzodiazepine dependence. Other clients may be admitted for a variety of complicating social and psychological issues as well, or to interrupt a period of harmful consumption of alcohol and other drugs. Clients are also accepted for issues with substances such as methamphetamines and other amphetamine-type stimulants, and cannabis. The unit also accepts people with opioid dependence, for which the main effective intervention is usually substitution with methadone or Suboxone®, and referral to an outpatient program.

The service only accepts people aged between 18 and 70, and does not admit women who are pregnant (they would often require obstetric supervision and/or may be at risk of premature labour or even miscarriage). Finally, the unit does not accept seriously ill people (medically or psychiatrically), due to a lack of medical cover after hours.

Patient admissions and discharges January 2018 to June 2019

2018	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
Admissions	33	49	63	51	42	58	49	54	52	49	48	42
Discharges	36	45	67	55	62	56	49	57	52	45	51	48

2019	Jan	Feb	Mar	Apr	May	Jun
Admissions	41	45	42	49	57	44
Discharges	46	43	49	48	56	46

The 20 eligible participants comprised 10 men and 10 women, aged between 25 and 60. All described recent regular consumption of a range of licit and illicit drugs including alcohol, cannabis, methamphetamine and heroin. Eighteen were unemployed and listed various government welfare schemes as their primary income, and two others were employed full-time. Fourteen had not completed secondary school, four had attained a tertiary certificate and two had completed secondary school without any other qualifications. More information on the participants is presented in Appendix 1.

All participants provided informed written consent at the outset of their interview. Interviews explored experiences with alcohol and other drug consumption, perspectives on different healthcare services, positive and negative experiences with healthcare, experiences of and strategies to negotiate stigma, health issues and healthcare, and broader plans for the immediate future.

The interviews were digitally recorded and transcribed, and all participants were assigned pseudonyms to protect their identities. Other identifying details were also removed from the transcripts. The de-identified transcripts were entered in NVivo12 qualitative data management software.

Analysis proceeded using an iterative inductive approach in which a list of codes was developed based on themes emerging from the data, current research and the aims of the project (see Appendix 4). Once the code list was reviewed by the research team and finalised, the data were coded. The coded data were then analysed to produce the report sections presented below (quotations included in the analysis

are accompanied by the gender, age and the primary drug consumed by the participant, for example, 'Angela (F, age 60, alcohol)'.

The study was approved by SWSLHD Research and Ethics Office (Local Project Number: HE18/205).

Key findings

The following sections discuss the study's key findings and recommendations. They are organised under the following headings, which reflect the focus of the interviews on experiences of stigma and healthcare access for our participants:

- 1** Positive experiences of healthcare and health professionals
- 2** Experiences of stigma in healthcare: Hospitals
- 3** Experiences of stigma in healthcare: General practice
- 4** Stigma and other people who consume drugs
- 5** Stigma within families
- 6** Primed for stigma: Encounters in healthcare
- 7** Inpatient withdrawal management discharge plans

1. Positive experiences with healthcare and health professionals

While experiences of stigma were very common for almost all of the participants in this research, many also offered positive experiences, and described with appreciation non-stigmatising healthcare practices and interactions. Importantly, however, many of the descriptions of positive experiences seemed to reflect but not exceed expected community standards on basic levels of professional practice. In this sense, while many participants have particularly acute and complex health issues, many did not articulate particularly complex or high expectations of healthcare services. Instead, they expected, and appreciated, forms of treatment that would be considered typical, or indeed the minimum, for many members of the community.

Non-judgmental care

Perhaps unsurprisingly, many participants explained that they simply desired non-judgmental care from health professionals. They also expressed gratitude when they received it. For example, Amelia (F, age 34, heroin) described her therapist as ‘excellent’ because he ‘doesn’t judge’:

The therapist. Mate, he’s going to be an excellent, excellent, therapist [...] Just the way he interacts. Just the way he talks to people. He doesn’t judge. In this industry, I don’t think there’s any time for judgment.

Pippa (F, age 36, heroin) was pleased with her general practitioner (GP) for similar reasons:

[My new GP] listen[s] to me. He doesn’t judge me. He said, ‘I’ve seen it all before,’ you know. He’s not in a position to judge because everyone has problems.

In this way, while Pippa and Amelia argue against judgmental healthcare practices they cannot take them for granted. Indeed, they are grateful when they do not encounter this form of stigma.

Other participants such as Angela (F, age 60, alcohol) and Peter (M, age 49, methamphetamine) offered very similar descriptions when asked about preferable service:

[A good service would] just let me be me, because I’m a bit [of an] out there kind of lady [...] Yeah, and not be judgmental, you know, not be judgmental. (Angela)

I don’t know what it was for, to tell you the truth, the first time I went there, but I found [the GP] friendly and open and not judge ... didn’t judge me, you know. (Peter)

Angela’s and Peter’s accounts demonstrate this dynamic, and suggest that encountering non-judgmental healthcare professionals is considered worthy of mention rather than simply being experienced as the norm. A similar dynamic emerges in Claire (F, age 25, methamphetamine) and Tracey’s (F, age 48, methamphetamine) reflections:

[Health services should] stop treating [people] like they are addicts, stop [...] looking down on them [...] treat them normally. (Claire)

[Health professionals should] actually listen to the person and check out their problem instead of just looking at them and thinking the worst. (Tracey)

The participants in this research were critical of the stigma they encountered in healthcare. Yet, stigmatising encounters such as those documented in the other sections of this report seemed to shape their expectations of healthcare so they positioned non-judgmental encounters as positive examples of good care rather than bare minimum practices that could be taken for granted.

Basic care as exceptional care

Many participants described as exceptional professional practices that are often taken for granted by other members of the community. For example, Georgie (F, age 50, alcohol) explained that she had been ‘lucky’ because the health professionals she interacted with did not ‘look down’ on her when she had a blood test.

When I go for a blood test, I say, ‘Look, I’m an ex-IV drug user [so] forget that arm’. I said, ‘if

you can't get there, there's a good vein in my right foot but I've banged my veins out with methadone'. I'm honest [...] Most of them [say] 'thanks for being honest' and they don't look down [on me]. I've never had someone take blood off me that has looked down on me, and they've never said to me, 'Oh you are hep C positive' [in a negative way], nothing like that. So I've been quite lucky.

Similarly, Pippa (F, age 36, heroin) described the way the pharmacist that dispenses her opioid pharmacotherapy treatment respects her privacy:

[My pharmacist] doesn't advertise [that I am being dosed with methadone], like, you know, he does it discreetly. He doesn't make you stay there and wait until your dose is finished [...] He [is] understanding.

This dynamic does not suggest that participants never expressed grievances about the care they received. Indeed, Samantha (F, age 37, heroin) argued that health services could be improved if they acknowledged the differing life experiences of each service user and avoided assumptions about commonality:

[Health services could be improved by] realising and remembering that none of us are the same. We're all different. We all come from different walks of life. We all have different drug use, even though sometimes it can be the same drug or we might use it the same way, but our lives are always different, we're mapped out differently.

Yet, Samantha's argument that services could be improved by treating patients as individuals suggests that she does not encounter this very basic requirement as regularly as she should. Other participants such as Peter (M, age 49, methamphetamine) and Leo (M, age 43, alcohol) positioned receiving referrals as particularly helpful rather than an ordinary aspect of healthcare.

I find mostly the public sector, like, the hospitals

and things that are publicly run, I find them very helpful, very non-judgmental [...] Like, if you need phone numbers or referrals or, you know, like, information on different places, they're more than willing to help you. (Peter)

[Health services have] been very helpful. They've always written down numbers and either made phone calls and made appointments for me, and everything like that. You know, I couldn't be any more thankful. (Leo)

This research indicates that consumers of healthcare services in South Western Sydney who have a history of alcohol and other drug issues do encounter positive, professional care experiences.

However, their accounts also suggest that many who experienced standard care considered it to be exceptional. This is not to suggest that participants were unaware of how drug consumption stigma shaped their healthcare experiences or that they did not desire better care. Rather, their accounts suggest that within a context of significant disadvantage and consistent and explicit stigma, when healthcare consumers encounter standard and even basic professional care practices, they may describe their experiences in ways that obscure the deficiencies of their care.

It is possible to infer from this response to standard care that participants had not had sufficiently consistent experience of it to take it for granted. This is particularly concerning in that many people who consume drugs, and are marginalised in ways similar to almost all of the participants, have complex healthcare needs (Prior et al., 2016; Searby, Maude & McGrath, 2016) and, indeed, may require excellent healthcare rather than basic care that they accept as good enough. These accounts also suggest that people who consume drugs may benefit from advocacy initiatives focused on providing additional information on the right to high-quality healthcare and the responsibility of healthcare professionals to deliver it (see Recommendation 5) (AIVL, 2008).

2. Experiences of stigma in healthcare: Hospitals

Reflecting Australian (Lancaster, Seear & Ritter, 2017) and international research (Lloyd, 2013), the participants in our study identified public hospitals as key sites of stigma. Participants routinely reported stigmatising and discriminatory encounters in hospitals that were often distressing. This stigma took shape in different ways. For example, one participant described experiences of stigma related to excessive wait times, while others described more explicit expressions of stigma in physical and verbal encounters. Given many participants described a range of ongoing mental and physical health concerns that, at times, required hospital care, the discrimination reported here is especially significant.

Interpersonal encounters

Many of those interviewed described negotiating distrustful and discourteous encounters with hospital staff. Some recount being questioned about their motivations for accessing treatment or the seriousness of their health concerns. Overall, participants often described mixed experiences in which they felt they were treated well by some staff but poorly by others. Angela (F, age 60, alcohol), who planned to seek care for mental health concerns upon exiting inpatient withdrawal management, described her past experiences in a public hospital in this way:

[Some staff] treat you like you're just nothing. I felt that's the way. Some of the nurses were really good, but some of them were really mean, you know [...] The way they speak to you, you know, like you're less than nothing [it's] terrible. Terrible [...] it had a bad effect on me.

Angela explained further that she stopped attending this particular hospital after a number of these experiences.

Well, I haven't been back there for a while now. Yeah, that's when I started drinking and smoking pot. It really hit me [...] Yeah, it had a bad effect on me [...] I just don't go [to the hospital any more].

Seth (M, age 49, alcohol) reported similar experiences:

Some doctors [at the hospital] were brilliant and some had that judgment thing. [Their attitude was] 'Oh, you're back here again. Oh, you've been drinking again' [...] It makes me feel that they don't understand, they don't understand.

Pippa (F, age 36, heroin) recounted a situation where the needle and syringe vending machine located next to a public hospital was empty. When she entered the Emergency Department of the hospital to ask the staff for injecting equipment, she felt she was not treated respectfully. On another occasion, according to Pippa, paramedics treated her roughly:

When I was first taken to Emergency when I had my psychotic episode, the ambulance drivers said, 'Why didn't you catch a bus?' and my friend tried to explain to them, 'She's paranoid schizophrenic, she's freaking out,' [and] 'she can't catch the bus, like, she needs you to take her'. They were doing my blood pressure and stuff [and] they were really rough with me and things like that. Then, when I got to emergency, they said, 'You just have to sit in the [crowded waiting room],' and, like, there were people everywhere [...] And then when they took me into the [psychiatric emergency] unit, that's when they said, like, you know, 'She's not well' [...] and they go, 'Well, she should be taking her medication then' [...] [I felt I was treated like this] because I was a drug addict [...] And they knew I was a drug addict because I don't lie.

Pippa also described that, because she felt 'judged' by psychologists at a hospital mental health service, she eventually stopped seeking their services.

There are three or four different mental health workers [at the service], the psychologists there. [Because of] the way they look at me and things like that, I shut down. I think you've

already judged me before I've even opened my mouth. So, I won't even bother and, like, that's how it went for a long time [...] Not wanting to go and see another psychologist because I thought, 'You're all going to be the same.' [...] Why pick this profession if you're not going to help? [...] I stopped taking my medication again and started, like, smoking more pot.

While William (M, age 53, alcohol) planned to seek mental health support more consistently after exiting inpatient withdrawal management, he also described past difficulties attracting hospital staff attention, and enduring long wait times. These experiences were interpreted by him as a form of, or evidence of, stigma. For example, he described being relegated to the 'back of the line' when he raised his history of mental and drug-related health issues:

Oh mate, the [hospital staff] make me wait, and as soon as you [explain that] you have got a mental problem or a health problem with previous drugs and all that, they, sort of, let you go to the back of the line. [This is] just the way you can just slip through the system [...] I used to love the place [hospital] too, you know my kids were born there and all that.

William explained that these kinds of experiences affected his engagement with hospitals. For example, on 'five or six' occasions he had 'walked to hospital instead of calling an ambulance'. As he explained, 'I didn't think they would believe me [about my anxiety]'. Additionally, experiences of not being treated like a 'human being' discouraged him from seeking hospital care: 'Well it stops me from going mainly, you know what I mean'.

Reflecting other research, the drug consumption stigma reported here overlaps with other forms of stigma – in this instance, stigma associated with mental health problems (Evans-Lacko & Thornicroft, 2010; Hartwell, 2004). While it would not make sense to offer clean-cut distinctions between forms of stigma operating concurrently, these accounts indicate that experiences of stigma can have a significant impact on attitudes towards healthcare settings, discourage

efforts to access healthcare among people who consume drugs (Lloyd, 2013), and act as a structural barrier to healthcare more generally (Evans-Lacko & Thornicroft, 2010).

Viewed together, these accounts suggest that hospitals are not always experienced as welcoming public institutions offering the care SWSLHD Drug Health Service users need. Rather, participants often experience them as sites of implicit and explicit judgment and discrimination. These dynamics at times limited access to healthcare for participants, even in cases of extremely serious need. While issues such as wait times may be indicative of broader challenges including funding or staff shortages, their impact on people with histories of alcohol and other drug use can be greater than for the general community. These patients may have higher needs, and past experiences of stigma and discrimination can position them as undeserving of care (Paterson, Hirsch & Andres, 2013). For many Drug Health Services users, past experiences with SWSLHD hospitals colour their expectations of care more generally. As a result, it is insufficient for service assessment to operate according to whether staff and processes do or do not explicitly stigmatise patients who consume alcohol and other drugs. Service delivery for Drug Health Services users, many of whom experience multiple layers of disadvantage, requires sustained attention to stigma, and unless services take steps to overcome it, it may be reproduced regardless of staff intent.

3. Experiences of stigma in healthcare: General practice

Many of our participants talked about their relationships with general practitioners (GPs), and their experiences of GP care. These data indicate that general practice services located in the district could also be experienced as stigmatising for participants in this research. While positive encounters with GPs were described at times (see Positive experiences with healthcare and health professionals, pp.12–13.), negative or stigmatising experiences were also described.

Judgmental encounters

Many participants remarked that GPs did not demonstrate a strong commitment to their healthcare. Rather, they spoke about feeling ‘judged’ by GPs. Larry (M, age 43, alcohol), for example, described a number of negative experiences at a local medical centre.

At the time [when I went to the GP], I didn't feel that anyone cared. It was just like [...] they were telling me to] just go away and try and deal with [my drinking myself] – get better and see how you go from there. [I felt] judged and put into a box [...] Basically, as soon as the word alcohol was raised, it was like, ‘Okay.’ It was like you were put into that box, and I felt like an addict and undesirable. That’s as blunt, yeah, as I’m trying to get those words out.

These issues continued for Larry after leaving the inpatient withdrawal management service. Initially he found the GP he was referred to by the service ‘really good’, but also explained that he felt too ashamed and unwanted to arrange another appointment with her after he had missed some due to work commitments:

I felt ashamed. And [although] I felt like coming back, I just couldn't, so I didn't [...] Because I never got a phone message or even a letter in the mail or just a text to say, ‘Hey, is everything all right, because you had this date and this date and this date. Is there something else we can do or what’s happening?’ [...] Yeah. I didn't think that they wanted to see me.

Similar comments about feeling judged were made by other participants. Peter (M, age 49, methamphetamine) for example stated, ‘I find private doctors, I find them to be judgmental’.

Importantly, he explained that his primary strategy for negotiating this kind of stigma was to avoid their services:

If I have got strategies [for managing stigma at GPs], they're not real good ones; it's stay away from them. I only go there if I have to [...] So that's been my strategy [...] I only go to the doctor's if I really, really have to.

While Pippa (F, age 36, heroin) was following her plan to visit the GP regularly following inpatient withdrawal management, she also explained that a previous GP's approach, which was not understanding of her drug consumption, had led her avoid seeing GPs altogether for some time:

[My past doctor] was a bit not as nice about the drug use [...] Just the way he used to go, ‘Oh, you're here again,’ like, you know, and things like that, and he'd say, ‘Oh, you're smoking pot again,’ [...] I didn't want to go to the doctor any more [...] Like, I thought every time I come here [I have to listen to] ‘Oh, you're still on Suboxone. You're still smoking pot,’ like, you know.

Similarly, Angela (F, age 60, alcohol) was ‘nervous’ about seeing her GP upon exiting the inpatient withdrawal management service. According to her, the GP had not been understanding in the past and had given her ‘attitude’. While Angela planned to find another GP if her experience did not improve, she felt she would have to look outside her local area to do so.

Suspicion and distrust

Contributing to participants’ concerns about GP commitment to their care were experiences where GPs questioned their motivations for accessing healthcare. Stacey (F, age 45, methamphetamine) who had to leave inpatient withdrawal management early

due to a family emergency, reported that she was not referred to a new GP when she exited the service because she 'actually [already] had one'. However, she clarified that she plans to seek care from this GP only 'when [she] really need[s] to'. This hesitancy was informed by past negative experiences, such as when she had gone to her GP after being violently assaulted in a home invasion. On showing her facial injuries to the GP, she felt that 'he didn't care' and 'was just pissed off to be at work'. Like Larry and Peter, Stacey felt judged when she visited the GP:

Automatically, there's that judgment. I feel that judgment instantly, and any hope of speaking and sharing and looking for a little empathy goes straight out the door. They look at me, 'she's a junkie. I'm not giving her nothing except a bloody lecture' [...] I think he could've been more comprehensive in his examination and the possible ramifications of what we've been through and been more medically empathetic and willing and understanding.

Importantly, Stacey described having limited options for care, arguing '[it] makes me look like a doctor shopper [...] if I go to another doctor'. Based on her past experiences, Stacey felt that there is 'no point' making appointments and generally prefers to 'fix herself up' if she has a health problem.

Tracey (F, age 48, methamphetamine), who had recently left the rehab service to which she had been referred by the inpatient withdrawal service, recounted similar experiences with GPs:

I did go and see a doctor in [South Western Sydney] and I explained to him what was going on. Like, I couldn't sleep, I was agitated all the time [...] and I asked him if there is anything he could prescribe for me. Because I told him my history of ice problems, he just looked at me like I just wanted to get off my face on anything that I could grab my hand on, but that was not the case.

After trying to see another GP but having no more luck, Tracey decided to avoid GPs altogether:

I went and seen another doctor up here, but they just gave me the same [response]: 'you just want to get off your face', and that's it. I am done with doctors because all they think is that I want to get off my face on tablets, but I don't.

This dynamic can have significant implications. For example, after a series of experiences such as these, Tracey (F, age 48, methamphetamine) 'gave up' seeking care and continues to experience pain.

My friend that used to stay with me, he was going to [a] doctor [close to my house] and he said 'He is pretty good, he won't judge you or anything like that'. I went and seen him and [he was] giving me the same look and everything as the other doctor. So I gave up and I put up with pain and the swelling and everything like that. But it's coming to a point where [the pain is] hindering me. I can't run after my boy because my knees will just [...] give out.

According to William (M, age 53, alcohol), not enough GPs are willing to treat patients with alcohol and other drug problems.

The [number of] understanding GPs that will see a drug user, I think is getting smaller, you know. The tolerance of [the] profession I think is getting smaller. There are less places, you know, you can go to, to feel more comfortable like you used to be able to.

These accounts demonstrate the ways in which general practices were not always experienced as welcoming for the participants in this project. Rather, GP encounters could be coloured by suspicion, distrust and judgment such that effective therapeutic relationships are hard to establish. These dynamics have a range of important implications. They are concerning in that some participants planned to seek care for a range of physical and mental health concerns upon exiting inpatient withdrawal management, yet they are discouraged from accessing health services considered standard for

other members of the community. In Stacey's case, she felt unable to access quality GP healthcare elsewhere because doing so would, she thought, position her as a 'doctor shopper'. As a result she withdrew from GP care altogether. This sequence of events highlights a circular dynamic, also identified elsewhere, in which structural disadvantage shapes patient behaviour, but this behaviour is interpreted as characteristic of the patient rather than the system, in turn disadvantaging those patients further (see Fraser, 2006).

4. Judgment and stigma among consumers

Reflecting dynamics identified in other studies (for example, Simmonds & Coomber 2009; Radcliffe & Stevens 2008), our participants also expressed views about drug use, and other drug users, that themselves can be characterised as judgmental and stigmatising. The perspectives offered in this section correspond in some ways with the views expressed by health professionals throughout this report.

Alexa (F, age 23, cannabis), who planned to attend a day rehab program upon exiting inpatient withdrawal management, contrasted her own cannabis consumption with injecting drug consumption, positioning the latter as worse.

I'm against [injecting drug use]. Junkies are ones that use needles and rob people, hurt their family, blah, blah, blah, blah. Me, I find myself as just a weed user. I just smoke weed [to help me] cope with this person who I am.

This stigmatising dynamic impacted on Alexa's access to alcohol and other drug treatment. For example, in the past she delayed accessing residential drug treatment because she did not want to be in the company of people who inject drugs:

I don't like alcohol. I don't like ice. I don't like heroin. I don't like none of it. It's been hard to be with these people, especially fucking heroin users and needle users. And track marks scare me. So that's what put me off being at [a residential drug treatment service].

Other participants, such as Charlotte (F, age 46, heroin), recounted experiences of stigma in alcohol and other drug treatment settings, and in some cases these experiences originated from other consumers. For example, Charlotte was participating in a Narcotics Anonymous group session when another member began insulting her:

[He said...] Yeah, 'you are nothing but a junkie scumbag' [...] I said, 'Listen here brother, I've been off methadone for seven years. If I can do that, anybody can do anything'.

These stigmatising dynamics also arose within families (see Stigma within families, p.21). For example, while Jasar (M, age 42, methamphetamine) stated that his uncle was the 'only [relative] that [he] could open up to' about his life and drug consumption, he also spoke about him pejoratively.

I just don't want [my daughter] to see her dad like I've seen my uncle. Like, my uncle to me is a junkie – he passed away God bless him – but he was the only one that I could open up to [...] He used everything, anything that he could shoot up his arm or smoke [...] Like, when I turn around and I tell people, '[name] was my uncle' the first thing they say to me is 'he is nothing but a thief, he is nothing but a junkie dog' [...] I don't want people to say that about me.

These views shaped Jasar's engagement with health services. For example, he argued that he did not see the point of seeing a GP or attending Narcotic Anonymous, partly because he wanted to avoid the company of other people who consume drugs (see, also, Radcliffe & Stevens, 2008).

Me coming to see a GP or me going to NA [Narcotics Anonymous] meetings, like, I don't see the point in it. Me standing up [saying] 'G'day everyone, my name is Jasar, I am a recovering addict', like how are they going to help me? I don't know. You, you don't know me [so] how are you going to help me? [...] At the end of the day, who you hang with is what you are going to do. You lay with dogs, you get fleas, that's the saying you know. Also, you are who you hang with, if you are a junkie, I am going to be a junkie, at the end of the day, it's, as I said, you are who you hang with.

Similarly, while Peter (M, age 49, methamphetamine) expressed frustration about the stigma he encountered in a range of settings, he also said that he looks down on people who, like him, consume drugs:

If I was, you know, a do-gooder and worked all my life and paid taxes all my life and had my

car broken into and all that sort of stuff, I would look down on drug addicts myself. And in a way, I do even now, myself.

As explored in other research, these accounts demonstrate that involvement in drug consumption does not necessarily inform attitudes about drug use or beliefs about people who consume drugs (see, for example, Cama et al., 2016; Simmonds & Coomber, 2009; Radcliffe & Stevens, 2008). As with other groups in the community, the views of consumers vary significantly. While some reject and resist the negative judgments attached to their drug use (also see, for example, Fraser et al., 2017; AIVL, 2011, 2015), others accept and agree with them. As such, stigma shapes consumers' understandings of themselves and others in ways that can reflect and reproduce the negative judgments and discrimination they experience in encounters with healthcare professionals (for example, Simmonds & Coomber, 2009). In this way, forms of structural discrimination can be reproduced within stigmatised social groups, reinforcing dynamics such as those experienced by the participants in this research. In this sense the many participants who had completed inpatient withdrawal management, or planned to access further alcohol and other drug treatment after leaving the service, must negotiate a complex context in which attitudes to drug consumption vary in important ways. This variety emphasises that the challenge of reducing alcohol and other drug-related stigma and discrimination requires prioritising consumer insights and experiences without making assumptions or generalisations about these insights and experiences (see Recommendation 5).

5. Stigma within families

As explored in other research, families can also act as sites of stigmatisation for consumers (Earnshaw, Smith & Copenhaver, 2013; Fraser, et al., 2017). Some of our participants experienced stigmatising judgments and accusations from family members. At times, these experiences limited their ability to speak with their families about their health problems and healthcare needs. Jasar (M, age 42, methamphetamine), for example, explained that he was ‘shattered’ when his mother called him a ‘junkie’:

[If] someone that [I care about says something] to me [...] it's going to hit me in the heart, you know what I mean. Like what hit me [...] was when the word 'junkie' came out of my mum's mouth towards me, all right. When my mum turned around and said, 'You look like a junkie', that shattered me [...] To me a junkie is a guy that sticks a needle in his arm and leaves shit lying around.

According to Pippa (F, age 36, heroin), her parents gave her an ultimatum to either stop smoking cannabis or move out of the family home:

I was smoking a bowl every four days and, like, it was just ridiculous. My parents found out and they basically said to me, 'You need to clean yourself up or you've got to get out,' because I lived with my parents [at the time].

A related dynamic was reported by Peter (M, age 49, methamphetamine), who said he felt like an ‘outcast’ from his family:

My mum and dad, like, I'm still welcome in their house, but I'm an outcast. I could never go back and live with my parents. They wouldn't let me [...] Even if I was drug-free, that wouldn't be good enough for them. You know, they would just assume that, 'You might be drug-free now, but in two months' time, you're not going to be', you know.

Claire (F, age 25, methamphetamine) explained that

the stigma within her family limited her ability to seek healthcare from her GP:

You don't want to tell your doctor [about drug issues], especially when you are from the same family practice. [It's] like, 'Oh, you are on drugs', and then because my mother or my sister also go [to the same practice] you don't want that and it's embarrassing. I hid it from my family, from everyone, for a very long time that I was on drugs because of the shame, and I didn't want them to know. It's embarrassing and I didn't want them to look down at me. And look at me now. I don't even speak to them anymore, they don't want nothing to do with me.

Most research exploring stigma in the families of people who consume alcohol and other drugs focusses on stigma stemming from outside the family unit (see, for example, Souza-Formigoni, 2007; Templeton et al., 2016). However, the accounts our participants gave demonstrate that stigma can take shape within families and between family members (Ahern, Stuber & Galea, 2007; Earnshaw et al., 2013). While some participants had family members who were invested in their inpatient withdrawal management, completing alcohol and other drug-treatment – including withdrawal management – did not have a consistent effect on reducing stigmatising beliefs and actions. This form of stigma has a number of implications, such as housing insecurity in the case of Pippa. Most importantly for the aims of this project, stigma within families compromised interpersonal relationships and social supports in ways that limited some of our participants' ability to communicate their health needs. Beyond this, research suggests that this dynamic can undermine participation in alcohol and other drug treatment (Gerra et al. 2003). Further, it has been found to be a particularly distressing form of stigma for people who consume alcohol and other drugs (Earnshaw et al., 2013).

6. Primed for stigma: Encounters in healthcare

Unsurprisingly, the participants in this research were well aware of the stigmatisation of their consumption practices. As in other research on alcohol and other drug stigma (see, for example, Fraser et al., 2017), some recounted expecting or being primed for, negative judgments and encounters. In this sense, their extensive experiences of stigma and discrimination were a reason to be particularly sensitive to the comportment of healthcare professionals.

Alcohol and other drug services were key settings in which this priming seemed to operate, with some participants highly sensitised to signs of stigma. For example, Charlotte (F, age 46, heroin) who, after completing her stay, planned to move interstate and then attend counselling and Narcotics Anonymous, recalled a time when she spoke to a staff member from the service she used to access methadone, and received a negative response:

I went in to do a meeting [at the service] and [a nurse] turned around and she said to me, 'You won't be able to get off methadone, you won't be able to do this, you won't be able to do that' and I said, 'Well you just watch me'. That's how I feel, they judge you, and they're methadone nurses, like, they should be putting me in a room and encouraging me.

While it is possible that the nurse's intention was to offer Charlotte helpful advice, for example, that she take time to reduce her methadone dose, the encounter was experienced as discouraging and disrespectful series of judgments.

Speaking about another context, this time an inpatient withdrawal management service, Georgie (F, age 50, alcohol) offered a different example with a similar dynamic. While she was generally positive about the service, she explained that she was very offended when a staff member asked her whether she had been smoking cigarettes in her room:

I highly recommend [the service] to everyone. The only issue I had was on the last day when [a staff member] come out and she said, '[Georgie] I can smell the smoke in your room' and I said, 'For a start, I've been bludging

[cigarettes] off [of another patient]', because I was out of smokes. Then I said, 'You've really, really offended me' [...] so I left there [exited the service] with the shits [...] I think she thought I was bullshitting, so that's the part that really hurt me.

While this incident might not appear especially serious to an outsider, for Georgie, the accusation of lying carried great significance. This was a stigmatising encounter in which she was not believed, and as a result exited a service – a service she otherwise liked and was benefitting from.

Priming for stigma also related to some professions more than others. For example, Pippa (F, age 36, heroin), was seeing a psychologist but was also looking for a suitable psychiatrist, saying she expected to encounter stigmatising attitudes from psychologists.

[My current psychologist is] excellent. I've been through so many [psychologists] that I couldn't talk to. Sometimes I just sat there and said nothing [to them]. It's just a vibe I got off them.

Peter (M, age 49, methamphetamine), who was awaiting an opening at a residential rehabilitation service following his stay in the inpatient withdrawal management unit, made a similar point, but also highlighted the possibility that his past experiences may have led him to make assumptions:

Most of what I've got [from my psychologist] has been pretty good, pretty good. I think, at the end of the day, it probably is a little bit judging, but he doesn't show it. He's very professional [in] the way he conducts himself [...] I suppose that's more of [my own] assumption, you know. I expect that from general society.

While Pippa and Peter described being generally satisfied with their current psychologists, they both also described a history of poor experiences and, as a result, being primed for encountering stigma.

Overall, the participants in our project needed to

access a range of different healthcare services upon exiting the inpatient withdrawal management service, due to the need to attend to often complex health issues, and stigma arose repeatedly as an obstacle or burden. Their accounts indicate ways in which the stigma that shapes the fabric of everyday life for our participants can prime them to see it across the health system, including in the healthcare services they need to access upon exiting inpatient withdrawal management. This is not to question these accounts, or suggest the stigma identified is imaginary. Instead, it is to emphasise the complexity of stigma related to alcohol and other drugs, and the ways in which broader contexts of healthcare encounters, including negative and judgmental encounters, can inform the meaning of professional practices, regardless of intent.

Those who experience multiple forms of disadvantage and discrimination alongside drug consumption stigma, like the participants in this research, must negotiate particularly complex and potentially taxing professional encounters with a range of social services. These dynamics encourage many people who consume drugs to be particularly sensitive to professional practices that others may simply dismiss as minor. The exploration of stigma in our project, and in the body of academic research on the topic (for review, see Lancaster, Seear & Ritter, 2017; Lloyd, 2013) suggests that drug consumption stigma governs the meanings of healthcare encounters and how interpersonal interactions play out.

This is an issue that health professionals, who often have access to the histories of their patients, need to be aware of and actively work to alleviate. While a context in which gestures, feelings or 'vibes' may constitute stigma is a challenging one to manage, health professionals and people who consume drugs need to be aware of this dynamic in order to begin to shift it, and to allow consumers to benefit from the services that are their right.

Unless health services endeavour to properly address stigma and the interpersonal encounters it produces, they may inadvertently reproduce the kinds of experiences and barriers to care identified in this report. The life experiences of service users and the broader cultural context that produce stigma cannot be ignored, and these need to inform professional

practice. Without such initiatives, stigma can be understood as a form of service failure reproduced by the very services designed to cater for people who consume alcohol and other drugs.

7. Inpatient withdrawal management discharge plans

In the preceding sections we have reported on how stigma and discrimination shape participants' views on and experiences of healthcare. These effects can be seen in both their pre-treatment and post-treatment experiences. This final section has a different focus. Here we describe participant healthcare plans for the period immediately after leaving the service, exploring their knowledge of and preparation for accessing healthcare services after treatment. Importantly, while many participants spoke of having a discharge plan, they often struggled to articulate it clearly and generally offered vague descriptions of plans for accessing healthcare. As shown throughout this report, people accessing the inpatient withdrawal management unit in SWSLHD often face stigma and discrimination in ways that make following up on referrals, keeping or reorganising appointments and inquiring and re-inquiring about health service availability more challenging than for other members of the community.

On admission to the facility, staff advise service users about the proposed duration of their admission and make enquiries regarding their expected plans after discharge. In addition to the service user's physical and mental health, the initial clinician's assessment considers their social circumstances, and this also informs early discharge planning.

Discharge plans may include referral back to the service user's general practitioner or other healthcare practitioner for ongoing care; referral to a drug and alcohol counsellor; admission to a day or residential rehabilitation program; or transfer to another component of DHS (for example, assertive case management and/or outpatient follow-up). In some cases, the service user may speak with by phone, or meet with in person, their future counsellor, rehabilitation service representative, or clinician from the case management team.

On some occasions, discharge plans may not be clear, due to the service user's circumstances or for other reasons. And a significant minority of service users admitted to the unit discharge themselves before completing their treatment; attempts are usually made to contact such clients a short time later to discuss their wellbeing as well as options for follow-up.

The primary written record of the service user's admission and their discharge plan is a succinct transfer of care summary, which is sent to the service user's general practitioner or other healthcare practitioner, with the person's consent.

Lack of clarity around discharge plans

While all service users exiting inpatient withdrawal management are expected to leave with a discharge plan as described, our research found many participants were unable to articulate a clear course of action for accessing healthcare after leaving the service. Charlotte (F, age 46, heroin), did describe future plans for accessing services, but only in very general terms, and in a new geographical location. As she explained, after moving interstate she would 'do counselling, NA meetings and all that sort of stuff and have a better life for myself'. Duc (M, age 39, heroin) said only that he planned to 'stay clean and get a job straight away'.

Other participants also had family responsibilities that affected the making of plans and the forms of care they accessed upon leaving the inpatient withdrawal management. Due to a family emergency, for instance, Stacey (F, age 45, methamphetamine) had to leave the service early, and explained that the staff had to 'hurry' her plan. As such, her plan was primarily to 'get counselling'. Jordan (M, age 45, alcohol) was about to follow his plan of entering residential rehabilitation but was concerned that his family and financial commitments would mean he would not be able to complete his stay there. In these two cases, family and financial obligations emerge as potential obstacles to following discharge plans. These cases indicate the need to take into account the circumstances of service users in creating viable discharge plans, especially where economic disadvantage and other forms of marginalisation are relevant.

That said, other participants offered more detail about their plans. Angela (F, age 60, alcohol), for example, had begun accessing the mental health support she had planned for while she was a patient. She stated that her planning process had been 'thorough and good', and that she had an 'actual plan for outside rehab'. Importantly, she had begun to access the mental health services she had envisaged.

Notably, she remained 'nervous' about accessing the GP in her plan, with whom she had had negative experiences the past (see, Experiences of stigma in healthcare: General practice, pp.16–18).

Pippa's (F, age 36, heroin) need to spend time with her children meant that her original plan of entering a residential rehab service did not work out. Otherwise, as she explained:

'I see a psychologist [at the inpatient withdrawal management service] [...] once a week. I [planned to] go see my GP and I'm doing that ... I'm trying to find a psychiatrist because [I need] to stabilise my meds and everything, and I'm going to try and find another psychologist as well'.

Finally, while Amelia (F, age 34, heroin) initially said that she had left the service without a plan, upon reflection she stated that her plan had been to enter a residential rehab. Plans had changed, however, as she felt she could not leave her friend who had 'stuck by' her while she was in a violent relationship. While her plans had changed on leaving, she also said she could have benefitted from more advice on 'putting [...] plans in action'.

In previous sections of this report, the role of stigma as a profoundly important and socially productive force shaping healthcare access for people in South Western Sydney was described. In this section, the focus turned to specific arrangements for discharge plans. This is because such plans are intended to offer direct pathways into ongoing healthcare, and to avoid losing those who have left the service 'through the cracks'. As our participants' comments suggest, however, these plans may not be detailed enough, or clearly enough set out for them. They may not adequately take into account other responsibilities such as family, and may not recognise financial hardship and the need to work instead of attend time-consuming services. Importantly, while discharge plans were usually put together before exiting the inpatient withdrawal management, participants were generally unable to offer a detailed account of their contents and how they would, or had, carried them out. Given the stigma, discrimination

and marginalisation explored throughout this report, people accessing the inpatient withdrawal management unit may need more thoroughly integrated mechanisms to assist them in consistently accessing healthcare in the district. Recognising the challenges and forms of exclusion they face is essential for inclusive, non-stigmatising healthcare.

Conclusion and recommendations

This report details findings and recommendations from a targeted qualitative research project on the healthcare encounters of people accessing the inpatient withdrawal management service in SWSLHD. The findings and recommendations reported here are based on interviews with 20 people who had accessed the service in the last 12 months. The interviews focussed on experiences with alcohol and other drug consumption, attitudes to different healthcare services, experiences with healthcare, experiences of stigma and strategies for negotiating it, health issues and plans for the immediate future. Service users reported a range of different forces that shaped their lives including, family issues, health problems including mental health, financial hardship, employment concerns and housing instability. Within this complex context, stigma and discrimination were found to be profoundly important for their experiences of and access to healthcare.

The experiences of stigma and discrimination reported here chime closely with the large body of existing alcohol and other drug research (see, for example, Anstice, Strike & Brands, 2009; Earnshaw, Smith & Copenhaver, 2013; Fraser et al., 2017; Lloyd, 2013; Olsen et al., 2003; Paquette, Syvertsen & Pollini, 2018; Paterson et al., 2013; Simmonds & Cooper, 2009). A number of Australian studies have produced reports on related issues, looking in general at the experiences of alcohol and other drug consumers (for example, AIVL, 2011, 2015; Lancaster, Seear & Ritter, 2018; Lubman et al., 2014; Pienaar et al., 2017). This project had a more specific focus – access to healthcare services after completing inpatient withdrawal management, and the role of stigma in this. As such it investigated the stigma dynamics shaping healthcare access for these service users. Our findings have relevance both to specific circumstances before and after entering inpatient withdrawal management, and also to healthcare access for consumers of alcohol and other drugs in general in South Western Sydney. To develop recommendations from these findings, we drew on existing research, alongside our own approach to stigma, aiming to orient them specifically to the SWSLHD context. These recommendations are

organised into three categories: (1) recommendations to tackle stigma within SWSLHD health services; (2) recommendations to improve healthcare experiences and; (3) recommendations to improve healthcare access following inpatient withdrawal management:

Recommendations to tackle stigma within SWSLHD health services

1. Conduct analysis of staff attitudes to alcohol and other drug-related health issues in SWSLHD health services
2. Conduct anti-stigma training across SWSLHD health services
3. Audit complaints processes across SWSLHD health services

Recommendations to improve healthcare experiences

4. Work with peer representative organisations to train and employ peer workers in healthcare settings accessed by people who consume alcohol and other drugs in SWSLHD
5. Work with peer representative organisations to develop and conduct consumer rights training in SWSLHD Drug Health Services
6. Support families of those accessing SWSLHD inpatient withdrawal management services to negotiate with other health services, and to understand alcohol and other drug issues

Recommendations to improve healthcare access following inpatient withdrawal management

7. Develop greater coordination between SWSLHD inpatient withdrawal management services and other health services
8. Establish greater continuity of care for clients accessing SWSLHD inpatient withdrawal management services
9. Increase follow-up of service users after exiting SWSLHD Drug Health Services facilities such as inpatient withdrawal management
10. Ensure discharge plans are robust and service users are confident about how to implement them

Recommendations to tackle stigma within SWSLHD health services

1. Conduct analysis of staff attitudes to alcohol and other drug-related health issues in SWSLHD health services

Developing deeper insight into the perspectives of health professionals working in SWSLHD will allow recognition of the strengths available as well as areas for improvement, and inform tailored responses to the forms of stigma and discrimination that take shape in this context. This analysis should include quantitative measures of attitudes and qualitative analyses of health professional practice and healthcare encounters with people who consume drugs.

As stigma does not simply emerge from staff attitudes but can inhere in procedures, systems and processes (Paterson, Hirsch & Andres, 2013), we recommend an audit of workforce practices in relation to stigma and discrimination across targeted SWSLHD services (see, also, AIVL, 2011). For example, while wait times at first might be positioned as an unfortunate but ultimately apolitical result of funding or staff constraints, the inconsistent mobilisation of waiting can amount to an enactment of stigma and discrimination. All practices that reproduce stigma should be adjusted to make SWSLHD less distressing and allow easier access to care for people seeking help for alcohol and other drug problems.

2. Conduct anti-stigma training across SWSLHD health services

As recommended in other reports, healthcare experiences of, and outcomes for, people who consume alcohol and other drugs may be improved by changes in health professional attitudes and practices (Lancaster, Seear & Ritter, 2018; Pienaar et al., 2017). Regular anti-stigma initiatives should be a central part of workforce training and professional development for all staff working in SWSLHD. Such training would need to incorporate research-based approaches alongside skills building exercises. Examples of anti-stigma programs that could be adapted for SWSLHD can be found in research (see, for example, Corrigan et al., 2012; Livingston et al., 2012; Pretorius et al., 2016; French et al., 2015).

3. Audit complaints processes across SWSLHD health services

When stigma is encountered, SWSLHD Drug Health Services users need an accessible and effective avenue of reporting and complaint. Echoing Lancaster, Seear and Ritter's (2018) recommendation for state-wide audit of complaints mechanisms in Queensland healthcare settings, we recommend an audit of these mechanisms within SWSLHD. As set out by Lancaster, Seear and Ritter (2018), p. 94 a complaints mechanism must be:

- A** available;
- B** easy to access (even for people with low literacy, or internalised stigma);
- C** publicly and openly advertised;
- D** and non-stigmatising (for example, the potential for anonymity when making a complaint is especially important for individuals who use illicit drugs, or for those who are in precarious living conditions and for whom healthcare access is essential).

While essential for better healthcare experiences for service users, a robust complaints mechanism will also provide insights into issues particular to the SWSLHD and to specific services within it.

Recommendations to improve healthcare experiences

4. Work with peer representative organisations to train and employ peer workers in healthcare settings accessed by people who consume alcohol and other drugs in SWSLHD

Much research stresses the importance of peers and peer organisations in addressing the healthcare-related stigma experienced by people who consume alcohol and other drugs (see, for example, AIVL, 2011; Lancaster, Seear & Ritter, 2018). Indeed, many of the participants in this research expressed similar views. Given the barriers individuals face in advocating for themselves when facing discrimination, and the extra challenges of doing so while feeling unwell and vulnerable in a healthcare setting, service users could benefit from extra support when accessing healthcare. Peer organisations such as the NSW Users and AIDS Association (NUAA) or the Australian Injecting

and Illicit Drug Users League (AIVL) have relevant expertise to help SWSLHD Drug Health Services develop a workforce of peer workers to assist people who consume drugs when accessing healthcare in the district. The audit of healthcare settings (Recommendation 1) could be used to develop priority settings in which peer workers would be most helpful. Peer workers could be trained in the policy and procedures of the healthcare services, as well as in consumer rights, to improve healthcare access and negotiate potentially unfamiliar procedures.

5. Work with peer representative organisations to develop and conduct consumer rights training

Having a stronger sense of the own rights, and the responsibilities of healthcare professionals, may help service users develop more confidence in accessing healthcare, and better strategies to negotiate stigma where it does occur (see, also, AIVL, 2008; Lancaster, Seear & Ritter, 2018). Importantly, this training should focus as much on the responsibilities of the district and health professionals to deliver good quality care as on service users' strategies to negotiate these settings. Again, peer organisations including NUAA and AIVL have the expertise to help develop and conduct consumer rights training.

6. Support families of those accessing SWSLHD Drug Health Services to negotiate district health services and understand alcohol and other drug issues

The families of SWSLHD Drug Health Services users should be supported in two ways:

- A** to communicate in non-stigmatising ways with family members of those accessing SWSLHD Drug Health Services and;
- B** to navigate the health services available in SWSLHD.

Families of people who consume drugs can struggle to engage productively with relatives' alcohol and other drug-related health issues and may require additional support (McCann & Lubman, 2018). As our interviews suggest, and other research has also shown, there is an urgent need to support families of people who consume drugs via education and information

resources (see, also, Lancaster, Seear & Ritter, 2018). Education efforts should emphasise the negative effects of stigma and discrimination on the capacity of people who consume alcohol and other drugs to communicate both within families and outside them, such as when attempting to access healthcare. These efforts should also offer specific resources that support family members in communicating effectively, and also provide information on available services.

Families should also be supported to navigate the health services available in SWSLHD. Assisting families this way will create extra resources for services users to engage with Drug Health Services and the other healthcare services available in the district. With extra support, families may be better equipped to support service users to access appropriate healthcare. Organisations such as Family Drug Support Australia may have the expertise to collaborate on an initiative of this kind.

Recommendations to improve healthcare access following inpatient withdrawal management

7. Develop greater coordination between SWSLHD inpatient withdrawal management services and other health services

As much research demonstrates, alcohol and other drug-related health issues are often intertwined with other health issues and life challenges (see, for example, Fraser et al., 2007; Rhodes et al., 2003). Therefore, greater coordination among health services could allow a more collaborative approach to care. This process should ensure clients have access to representatives from a range of services they may wish to access upon completing their stay at the inpatient withdrawal management facility. This should include access to harm reduction services and peer organisations such as NUAA. For example, greater communication between the inpatient withdrawal management service and local GPs could ensure follow-ups are conducted with patients who may not have accessed the care they planned for upon exiting the service. Additionally, greater communication between the service and other drug treatment services, such as residential treatment services, could ensure

follow-ups are conducted with patients who leave residential care early. One option could be to request the service user's permission to share discharge plans with all the relevant healthcare services to allow for coordinated follow-up and continuity of care.

8. Establish greater continuity of care for clients accessing SWSLHD inpatient withdrawal management services

As research indicates, continuity of care is a necessary aspect of alcohol and other drug treatment (Lubman et al., 2014). The exiting inpatient withdrawal management service users in our project often had a range of healthcare needs, some related to alcohol and other drug consumption and some not. Experiences of stigma and discrimination shaped, and often impeded, their access to the healthcare services identified as necessary when exiting inpatient withdrawal management. Service users should be directly supported to access different forms of healthcare, especially in the period immediately following treatment.

9. Increase follow-up of service users after exiting SWSLHD Drug Health Services facilities such as inpatient withdrawal management

People accessing the inpatient withdrawal management services in SWSLHD report a complex collection of healthcare and other needs. These different needs can conflict with each other in ways that make following through with referrals, attending appointments and inquiring and re-inquiring about health service availability difficult. As such, service users need follow-up to promote continuity and engagement with the healthcare services they need (see also, Lubman et al., 2014). For example, service users may benefit from a series of follow-up phone calls in the months after exiting the service. These calls could follow up whether the service user was able to access the care they needed, impediments they faced (if any) and whether any new issues had recently emerged.

10. Ensure discharge plans are robust and service users are confident about how to implement them

People accessing the inpatient withdrawal management service in SWSLHD often offered only

vague accounts of their plans to access healthcare upon leaving the service. To properly support people to access ongoing healthcare, discharge plans need to be clearly set out and viable. It may be that these plans need to be provided to the service user in a number of ways, including in hard copy at exit, sent to their postal address, and emailed or downloaded onto their mobile phone. Additionally, multiple plans may be needed in case the original plan does not work upon exit. For example, staff and service users could develop a 'plan A' and a 'plan B' before exit. Follow-up by telephone may be required to ensure viability of the plans upon exiting. Plans that appear workable while in treatment may need to be re-evaluated once the service user has begun engaging with everyday responsibilities after treatment.

In developing the 'plan A' and 'plan B' approach, care needs to be taken to focus on strengthening the planning process and ensuring those exiting have a greater range of options to support their care and changing needs. Plans need to take into account the individual circumstances of the service user and therefore work with daily obligations such as family or employment responsibilities. Service users may also need follow-up appointments to re-work aspects of plans that they have not been able to enact or that are no longer appropriate due to changed circumstances.

Importantly, plans should focus on service users' agency, capacities, assets and expertise. Plans can build on these assets and strengths in order to develop positive post-treatment health goals. Overall, acknowledging and countering the stigma and discrimination faced by people who use alcohol and other drugs may require additional strategies and forms of support. In the absence of these extra supports, stigma and discrimination may be reproduced.

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Appendix 1:

Table of participants

Gender	
Male	10
Female	10

Age	
20-29 years	3
30-39 years	4
40-49 years	9
50 years and over	4

Sexuality	
Heterosexual	17
Bi-sexual	3

Cultural and ethnic background*	
Australian	11
Australian Aboriginal	3
North African and Middle Eastern	2
Southern and Eastern European	2
South East Asian	1
Southern and Central Asian	1

Educational level	
Incomplete secondary	14
Complete secondary	4
Certificate/Diploma	2

Employment status	
Unemployed	18
Full-time	2

*Reporting of cultural and ethnic background follows the Australian Standard Classification of Cultural and Ethnic Groups, developed by the Australian Bureau of Statistics. Cultural and ethnic background was classified according to a combination of self-reported group identification with particular cultural or ethnic groups, the participant's birthplace and their parents' birthplaces.

Appendix 2:

Participant information sheet/consent form

Non-Interventional Study – Adult providing own consent

Drug Health Services

Title: Lived experiences of stigma and discrimination among SWSLHD DHS service users: A qualitative study

Short Title: Lived experiences of stigma: A qualitative study

Protocol Number: 178661

Coordinating Principal Investigator/ Principal Investigator: Professor Suzanne Fraser, National Drug Research Institute, Curtin University / Dr Adrian Farrugia, National Drug Research Institute, Curtin University

Location: Details removed to preserve anonymity.

Part 1: What does my participation involve?

Introduction

You are invited to take part in this research project, Lived experiences of stigma: A qualitative study. This is because you have exited a detox service in the last 12 months and have important insights to offer about Drug Health Services in South Western Sydney. The research project is aiming to explore people's experiences accessing healthcare after exiting an inpatient withdrawal management service in South Western Sydney. We want to explore how people are treated when they try to access healthcare, for example when they see a GP, and hear about potential issues including stigma and discrimination.

This Participant Information Sheet/Consent Form tells you about the research project. It explains the research involved. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative or friend.

Participation in this research is voluntary. If you don't wish to take part, you don't have to.

If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

- ▶ Understand what you have read
- ▶ Consent to take part in the research project
- ▶ Consent to the research that is described
- ▶ Consent to the use of your personal and health information as described.

You will be given a copy of this Participation Information Sheet to keep.

What is the purpose of this research?

This project aims to understand people's experiences accessing healthcare after they have exited a detox service. The project is especially focussed on experiences of stigma and discrimination and how they may affect people's healthcare access.

Although stigma is a known issue for people who have experiences of alcohol or other drug consumption, much less is known how this affects their access to healthcare. This project investigates this issue focussing on South Western Sydney in particular.

Your contribution has the potential to inform how people are treated in healthcare settings in South Western Sydney.

This research has been funded by the South Western Sydney Local Health District.

This research is being conducted by a team of researchers from Curtin University: Professor Suzanne Fraser and Dr Adrian Farrugia and South Western Sydney Local Health District: Dr Michael Edwards, Medical Director, Drug Health Service and Ms Stephanie Hocking, Acting General Manager, Drug Health Services

What do I have to do?

If you decide to participate in this research you must give us your 'consent'. This means that you have freely chosen to be involved and that you give us your permission to interview you.

If you choose to give us your consent and participate, you will take part in an audio-recorded semi-structured face to face interview of about 45 to 60 minutes duration. The focus of the interview will be on your experiences accessing healthcare, interactions with healthcare professionals (such as GPs) and potential issues such as stigma and discrimination. If you are not comfortable answering any question you can refuse to do so. You can also withdraw from the interview at any time without any negative consequences.

This project will run for about three to four months.

You will only be committed to your interview and will not be required to do anything else.

Importantly, you're interview will be audio-recorded.

This research project has been designed to make sure the researchers interpret the results in a fair and appropriate way.

There are no costs associated with participating in this research project. If you do choose to participate you will be compensated \$50 to cover your time and any expenses in taking part.

Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

If you do decide to take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your ability to access health services in the future or your relationship with Drug Health Services.

What are the possible benefits of taking part?

We cannot guarantee or promise that you will receive any benefits from this research, however, possible benefits may include the opportunity to express your opinions about the provision of healthcare for people who have experiences consuming alcohol and other drugs. Your opinions may inform public understandings of the issues.

What are the possible risks and disadvantages of taking part?

When reporting research findings we will refer to you by a false name so there is little risk that your identity will be discovered through the research reporting process.

Only the principal investigator and research team for this project will have access to the project's raw data. Other bona fide researchers approved by the principal investigator may be given access to the data, but only in its de-identified form.

Everything you say in the interview will be kept confidential. Any information gathered in the interview will be protected in order to protect your identity.

Your contribution to the research would be disclosed outside the research team ONLY if required by a court subpoena. In this unlikely event the research team may have to divulge the identities of participants.

What if I withdraw from this research project?

Your participation is voluntary so it's completely up to you to decide if you want to be involved.

You may refuse to answer any question you do not wish to answer.

If you decide to withdraw from this research project, please notify a member of the research that you want to withdraw.

If you decide to withdraw, we will destroy any information connected to you. For example, we will destroy your interview recording and transcript.

What happens when the research project ends?

We will send you a copy of the research report if you are interested.

Part 2: How is the research project being conducted?

What will happen to information about me?

We will use this information to understand the potential barriers faced by people with histories of alcohol and other drug consumption when accessing healthcare in South Western Sydney.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified.

All data will be stored on a password protect secure University laptop and database.

Any hard copy transcripts will be kept in a securely locked cabinet accessible only to the researchers in our research office in Fitzroy, Melbourne, Victoria. The second project Chief Investigator, Dr Adrian Farrugia will have the key. Audio recordings and electronic copies of transcripts will be kept in a password protected folder on a secure University computer. Basic participant demographic information will be stored on a password protected spreadsheet itself stored on a secure University computer. Your signed consent form will also be stored as a password protected pdf document on a secure University computer. The material will be kept for seven years after the research has been published, and then destroyed.

If you become upset or distressed as a result of your participation in the research, the interviewer will be able to offer information for counselling or other support. Any counselling or support will be provided by qualified staff who are not members of the research project team.

Who is organising and funding the research

The research is being organised and conducted by Professor Suzanne Fraser and Dr Adrian Farrugia, Curtin University with funding from South Western Sydney Local Health District.

Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this research project have been approved

by the HREC of Curtin University.

This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007). This statement has been developed to protect the interests of people who agree to participate in human research studies.

Further information and who to contact

If you want any further information concerning this project, you can contact the principal investigator on Dr Adrian Farrugia **03 9079 2205 / 0448 167 534** or adrian.farrugia@curtin.edu.au.

Complaints contact person

This study has been approved by the South Western Sydney Local Health District Human Research Ethics Committee. Any person with concerns or complaints about the conduct of this study should contact the Research and Ethics Office, Locked Bag 7103, LIVERPOOL BC NSW 1871
ph: 02 8738 8304 / fax: 02 8738 8310
email research.support@sswahs.nsw.gov.au,
<http://www.swslhd.nsw.gov.au/ethics/default.html>
and quote **[HE18/205]**.

Thank you for taking the time to consider this study. If you wish to take part in it, please sign the attached consent form.

This information sheet is for you to keep.

Consent form

Lived experiences of stigma and discrimination among SWSLHD DHS service users: A qualitative study

1 I,

of

2 agree to participate in the study described in the participant information statement set out above.

3 I acknowledge that I have read the participant information statement, which explains why I have been selected, the aims of the study and the nature and the possible risks of the investigation, and the statement has been explained to me to my satisfaction.

4 Before signing this consent form, I have been given the opportunity of asking any questions relating to any possible harm I might suffer as a result of my participation and I have received satisfactory answers.

5 I understand that I can withdraw from the study at any time without prejudice to my relationship with the [details removed to preserve anonymity].

6 I agree that research data gathered from the results of the study may be published, provided that I cannot be identified.

7 I understand that if I have any questions relating to my participation in this research, I may contact Dr Adrian Farrugia on telephone 03 9079 2205 / 0448 167 534, who will be happy to answer them.

8 I acknowledge receipt of a copy of this Consent Form and the Participant Information Statement.

Signature of participant

Please PRINT name

Date

Signature of investigator

Please PRINT name

Date

Appendix 3:

Interview guide

Lived experiences of stigma and discrimination among SWSLHD DHS service users: A qualitative study

Semi-structured interview guide

Opening information for participants:

- ▶ *This project explores experiences of accessing GPs and health services after exiting an inpatient withdrawal management ('detox') in South Western Sydney.*
- ▶ *Participation is voluntary and how you answer the questions is up to you. You don't have to talk about anything you feel uncomfortable about or answer any questions you don't want to answer.*
- ▶ *Everything you say is kept confidential and a range of strategies will be used to protect your identity if you are quoted (as outlined in the consent form you have signed).*
- ▶ *To protect your identity, try to avoid using names of people and places. If you do mention these details, however, we will change or remove them to protect your privacy.*
- ▶ *The interview can be terminated at any time you choose. Please let me know if you would like a break or to stop completely.*

Opening questions

- ▶ Can you tell me why you were interested in participating in this study/why you thought this study was relevant to you?

Experiences of alcohol and other drugs

- ▶ Can you tell me about your experiences of alcohol and other drug use?
Prompts: Can you tell me about when you first came into contact with drugs, which one(s) you have most often, and when?

Experiences of inpatient withdrawal management

- ▶ Can you tell me about your experience at the service ('detox')?
Prompt: How did you find the inpatient withdrawal management service overall?

Discharge plans

- ▶ Have you been developing a discharge plan with the staff at the service ('detox')?
- ▶ What your plan overall?
Prompts: What's the kind of the advice you've been given when putting together the discharge plan? Have you got any specific plans to see a certain GP? Which one? Why? Did the staff recommend this GP? Did you already know them? What kinds of healthcare or support do you think you may need once you leave [service name]? Do you feel your plan will help you with those?

Experiences with general practice

- ▶ Were you referred to a GP when you left the inpatient withdrawal management service?
- ▶ Have you tried to see/have you seen a GP since you left?
 - ▶ [If yes] Can you tell me about the experience seeing the GP?
Prompts: Was it helpful/unhelpful? What was positive about the experience? What was negative about the experience? Did this experience impact how you think about your health and well-being?
- ▶ **[If they have not seen a GP]** Have you had any reason to see a GP since leaving the inpatient withdrawal management ('detox')?
- ▶ **[If yes]** Why haven't you tried to see a GP about these issues?
- ▶ How do you feel about the ways that you have been treated when you've seen a GP in South Western Sydney?

Non AOD-related health issues

- ▶ Do you have any ongoing health issues that require you to see doctors, specialists etc.? (E.g. Hep C, chronic pain)
- ▶ How do you feel speaking about X issue with your GP?
- ▶ Can you tell me about an experience of discussing X issue with a GP?

Prompts: Was the conversation helpful/unhelpful? Did you feel comfortable/uncomfortable? What was the outcome of the conversation? Have these experiences affected your use of GPs or other health services at all?

Perspectives on general practice

- ▶ Do you speak about your alcohol or other drug use with healthcare professionals? How do you feel talking about it with healthcare professionals?
- ▶ How do you feel talking about it with GPs specifically?

Prompts: Can you tell me about an experience of discussing your X use with a GP? Why did you discuss your X use? Was the conversation helpful/unhelpful? Did you feel comfortable/uncomfortable? What was the outcome of the conversation? How would you rate your experience with GPs overall? What has been positive about your experiences with GPs? What has been negative about these experiences?

Stigma and discrimination

- ▶ How do you find the attitudes of others towards your X use and the use of X more generally?
Prompts: Have you spent much time talking about your experiences with others and if so, what sort of views have you encountered? How do you think other people see your use of X? How do you negotiate or deal with judgmental attitudes when you encounter them?
- ▶ Do you think you have ever experienced stigma or discrimination when you have seen a GP in South Western Sydney?
- ▶ Can you take me through a specific time that you've experienced stigma? What happened? Who were you speaking to? What was the reason you needed to visit the GP?

Prompts: referral, injury/illness, medication, family member etc. Where were you? [Waiting room, consultation room etc.] Were you able to address the problem you visited the service for?

- ▶ How did this make you feel? Was this a significant experience for you?
- ▶ When you think about other times you think you've been treated differently, or experienced stigma or discrimination, where have those interactions taken place?
- ▶ Have these experiences affected your use of GPs or other health services at all?

Negotiating stigma

NOTE: Only relevant if the participant reports experiences of stigma and discrimination

- ▶ Do you have any specific strategies to manage any negative attitudes to your X use?
- ▶ Do you have any strategies to manage any negative attitudes of health professionals such as GPs?
Prompts: Speaking with friends/family, getting recommendations from friends/family, wearing certain clothes, taking someone with you, disclosing/not disclosing certain information, avoiding particular GPs/practices)
- ▶ Do these experiences affect how you feel about going to see a GP? (e.g. hesitant, nervous, reserved, avoidant)
- ▶ **[If not already covered]** Do these experiences affect the kinds of things you will discuss with the GP?

Experiences of health service access after leaving inpatient withdrawal management

- ▶ Have you used any other health services since leaving the inpatient withdrawal management ('detox')?
Prompts: If so, what kind of health service did you use? (Pharmacy, AOD services, NSPs etc.)
- ▶ Why did you go to X service? (Referral, specific health concern, to access other services etc.)
- ▶ Can you tell me about the experience?
Prompts: What was positive about the experience? What was negative about the experience?

Final thoughts

- ▶ This project is about exploring people experiences of healthcare and potential stigma and discrimination in order to inform future practices in this areas and ultimately improve healthcare for people exiting withdrawal management services and with experiences of drug consumption more generally. Given these aims, is there anything else we should have talked about but didn't? Are there any other important issues that we haven't discussed?
- ▶ From your experiences, is there anything about healthcare and GP clinics that could be changed to better address your needs?

Well that brings to the end of the interview. I just want to say thanks again for taking the time speak with me today. Your input is extremely important and helps greatly with our research and how different people are treated when they access healthcare.

Appendix 4:

Analytical code list for NVivo

1. Criminal justice system

- ▶ Prison/release from prison
- ▶ Interactions with police
- ▶ Forensic drug treatment

2. Experiences of drug consumption

- ▶ Consumption prior to entering [service name]
- ▶ Consumption after leaving [service name]

3. Inpatient withdrawal management

- ▶ Experiences of Inpatient withdrawal management
- ▶ Attitudes to Inpatient withdrawal management

A. Discharge plans

- ▶ Discharge plans

B. Referrals

- ▶ Healthcare referrals at discharge

4. GPs

- ▶ Experiences of GPs

A. Access

- ▶ Impediments to access

B. Attitudes towards GPs

- ▶ Positive
- ▶ Negative
- ▶ Concerns
- ▶ Confidence

C. Negative experiences of GPs

- ▶ Specific negative encounters
- ▶ Unpleasant attitudes
- ▶ Unpleasant practices

D. Positive experiences of GPs

- ▶ Specific positive encounters
- ▶ Pleasant attitudes
- ▶ Pleasant practices

Health after inpatient withdrawal management ('detox')

- ▶ Health issues immediately preceding discharge

5. Health problems

- ▶ Health issues overall
- ▶ Chronic illness (except hepatitis C)

6. Hep C

- ▶ Experiences of hep C
- ▶ Diagnosis
- ▶ Testing
- ▶ Related health problems
- ▶ Disclosure
- ▶ Social relationships

7. Hep C treatment

- ▶ Experiences of hep C treatment
- ▶ Interferon
- ▶ Direct acting anti-viral treatments
- ▶ Access
- ▶ Disclosure
- ▶ Social relationships

8. Other drug treatment

- ▶ Rehabs
- ▶ Pharmacotherapy
- ▶ Other inpatient withdrawal management services (detoxes)

9. Other healthcare settings

- ▶ Hospitals
- ▶ Pharmacies
- ▶ Alcohol and other drug services

10. Stigma

A. Experiences of stigma

- ▶ Settings of stigma
- ▶ In healthcare
- ▶ Effect on healthcare access and practices
- ▶ Attitudes towards other opioid consumers
- ▶ Daily life
- ▶ Family and friends

B. Strategies to manage stigma

- ▶ Speaking with friends/family, getting recommendations from friends/family
- ▶ Wearing certain clothes/managing presentation
- ▶ Attending the appoint with someone else
- ▶ Disclosing/not disclosing certain information
- ▶ Avoiding particular GPs/practices

11. Systemic issues

- ▶ Service availability e.g. not enough beds/waiting times
- ▶ Institutional requirements
- ▶ Cost
- ▶ [service name] practices

12. Social relationships

- ▶ Family / friends
- ▶ Obligations
- ▶ Care
- ▶ Sharing information
- ▶ Relationships with other patients/clients