



What helps and what hurts: perspectives on clinical care from people who use drugs and alcohol in NSW

A report prepared for the NSW Health Centre of Alcohol and Other Drugs by the NSW Users and AIDS Association. Mary Ellen Harrod was the lead author of the report with additional support by Justin McKee and Tony Iltis.

Acknowledgements:

NUAA Community Acknowledgement:

NUAA is a peer based, community-controlled drug user organisation. We represent the voices and needs of drug using communities in NSW. NUAA and the community of people who inject drugs were instrumental in averting the HIV epidemic and we remain central to improving the health and human rights of drug users in NSW. We would like to take this opportunity to acknowledge the legacy of the peers who went before us and reaffirm our commitment to fighting the effects of stigma and criminalisation in all their manifestations.

We would also like to thank and acknowledge the peers who gave their time and energy to taking part in this project. The bravery, dignity and insight of the people who participated is evident in every page. Their input has made an invaluable contribution to our ongoing advocacy for people who use drugs in NSW and it is our fervent hope that this report will support efforts aimed at reducing the stigma our community experiences when accessing health services.

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Happy families are all alike; every unhappy family is unhappy in its own way

Tolstoy

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1. Executive Summary

Purpose of the research project

The Centre for Alcohol and Other Drugs (CAOD) is working to improve consumer experience and health outcomes by reducing the stigma and discrimination experienced when people present with issues associated with alcohol and other drug use in the NSW Health system.

To support this work and provide a consumer perspective to the project, NUAA was commissioned to undertake a small research project to consolidate understanding of consumer experiences and provide insights into potential solutions relating to stigma and discrimination. Participants in the project included Aboriginal people, young people, older people, pregnant women, LGBTQI+ people, people living with a disability, people who have had contact with the criminal justice system, people living in remote and rural areas, people who experience mental health issues and culturally and linguistically diverse people.

Themes examined included factors that create positive and negative health interactions, health care settings and recommendations to improve care and social care interactions for people who experience harm from alcohol or other drugs use.

NUAA interviewed 38 people drawn from community networks.

Overview of findings

Most people interviewed had experienced what they considered poor health care. By and large, they accepted a poor outcome, poor service and/or stigma and discrimination without complaining or challenging the service provider. Instead, people sought out relationships with health professionals who they perceive as 'good' – people who listened, focused on the medical issue without judgement, were accessible (physically and financially), and were competent and caring.

Many of our participants identified poor experiences with personal factors, such as drug use or belonging to the LGBTQI+ community. They were at times belittled and made to feel inferior by health care practitioners and experienced overt discrimination, had been refused treatment, or had felt like they had no control in the clinical situation and were not provided with person-centred care. A high number of participants had difficulty accessing adequate pain relief. Participants described many incidents when seeking treatment that were dangerous to their health and either could have or did result in long-term complications, that they attributed directly to stigma.

Outcomes

Specific interventions to reduce stigma are well-described in the literature. However, to meaningfully shift what people who use drugs experience in the health system, we must address stigma at a broad, population level. Regarding stigma experienced in health care settings, the case for change needs to be made as forcefully as possible by quantifying the harms and establishing stigma reduction as a key priority. Interventions must be inclusive of all staff and examine structural stigma. And finally, we need to empower our community to actively participate in systems change – as complainers, as contributors, as people who are able to advocate for themselves.

2. About this report

The experiences described by the people who agreed to be interviewed for this project were sometimes the most difficult and deeply humiliating experiences of their lives. This report tries to honour the courage, strength and generosity demonstrated by our community by including as many of their words as possible. Some of the experiences described in this report are confronting and may be triggering for people reading it.

Participant stories are largely unfiltered. At time minor changes or omissions have been made to increase clarity as indicated in the text by either (parentheses) indicating rephrasing or three dots (...) indicating some content has been omitted.

The people interviewed as part of this project are referred to as either participants or people who took part in the project. When we refer to “community” we are using the term in a broad sense of anyone who has experienced issues associated with illicit drug use and/or alcohol use. The phrases “community” and “people who use drugs” are employed whether the experiences of everyone interviewed are current or in the past, and whether they are seeking or receiving treatment for these issues or not. We recognise that there are many diverse communities of people who use drugs in NSW but also that there are common experiences that bind us together.

When we are describing the clinical interaction we have used the terms “clinician,” “health care worker” or the specific professional designation of the health care provider. When we are discussing what happened within a clinical encounter we have frequently used “patient”. When we are talking about people as service users we use the term “service user” or people.

2.1 Abbreviations used in this report

AIVL	Australian Injecting and Illicit Drug Users League
AOD	Alcohol and other drugs
CAOD	Centre for Alcohol and Other Drugs
HETI	Health Education Training Institute
LGBTQI+	Lesbian, Gay, Bisexual, Trans, Queer, Intersex
NUAA	NSW Users and AIDS Association
OAT	Opioid agonist therapy
OTP	Opioid treatment program
PWUD	People who use drugs

3. Introduction

The Centre for Alcohol and Other Drugs (CAOD) is working to improve consumer experience and health outcomes by reducing the stigma and discrimination experienced when people with issues associated with alcohol and other drug (AOD) use present for care in the NSW Health system. To support this work and provide a consumer perspective to the project, CAOD commissioned the NSW Users and AIDS Association (NUAA) to undertake research to consolidate understanding of current consumer experiences of stigma and discrimination and provide insights into potential solutions relating to stigma and discrimination.

NUAA is a peer based, community-controlled drug user organization that represents drug using communities in NSW. We aim to elevate the voices of people with lived or living experience of drug use and advocate for the health, human rights and dignity of our community. We recognise that drug use is a continuum, and our community includes all people whose lives have been affected by stigma and criminalisation whether their drug use is current or in the past. A central focus of our work is improving the experiences of people with lived or living experience of drug use when interacting with health services.

Core to meeting our mission is working to reduce the level of stigma and discrimination that our community experiences when interacting with health services. We have delivered training to health care professionals for many years, both within the AIVL “Putting Together the Puzzle” Framework and through our own models developed in consultation with clinicians and peers. We have worked with HETI to develop online training for NSW Health employees. Our flagship publication, *Users News*, highlights the stories of our community and help us to recognise and overcome our own internalised stigma and advocate for ourselves. We also contribute to NSW policy and procedures through bringing the voice of our community to the table. Combatting stigma is woven into all the work we undertake whether it is explicitly identified or not.

For this report, we asked our participants to describe positive and negative experiences that they had in seeking health care in any clinical setting. The encounters were not limited to seeking treatment for drug use. Each participant had a story of how they had experienced poor care, often within the NSW Health system but also in GP and other settings and very often the experience could be either directly attributed to or was apparently related to stigma based on previous or current drug use. Some of these stories are confronting, many are heart breaking. We acknowledge the honesty and courage of all the people who were interviewed for this report and thank them for their participation in this work.

4. Methodology

4.1 Ethical considerations

This project was intended to provide peer intelligence of people's experience of stigma and discrimination and therefore formal ethical approval was not sought for this project as it was not intended as a research project. This work was conducted in accordance with standard NUAA practices when working with community. Participants were advised of the aims of the study, what would happen with their data and who would have access. Because participants were recruited from people known to NUAA employees, they were able to specify NUAA employees that would not have access to their data. Interviewers regularly checked in with participants throughout the interviews to ensure that they were happy to continue. Participants were reimbursed \$80 for their time and expertise that was given to the project. Participants will be given the opportunity to provide feedback on the report and ensure that they are comfortable with the content they provided and provide feedback on any recommendations. This feedback has been incorporated into the report.

4.2 Participants

A total of 38 people with lived experience of alcohol and other drug issues in NSW participated in this project. Participants were recruited from NUAA networks and included community members, volunteers, work colleagues, friends, family members and referrals. Participants also referred other participants to the project. All participants were advised of the purpose of the research and that they were able to discontinue participation at any time with no financial penalty and without risking their relationship with NUAA as an organisation or with the interviewer.

Each participant was initially identified as belonging to one of the priority populations identified by COAD in commissioning the work (Aboriginal people, young people, older people, pregnant women, LGBTQI+ people, people living with a disability, people who have had contact with the criminal justice system, people living in remote and rural areas, people who experience mental health issues and culturally and linguistically diverse people). Another category that a number of participants fit into emerged from the interviews: people living with a chronic illness.

Eleven (33%) of participants had been in touch with the criminal justice system. Eight of these identified as belonging to this priority population as they had served time in prison and two because they had laid charges for domestic violence against a former partner in criminal court. One

participant identified for both reasons. Young people ranged in age from 21 to 24. There was significant overlap between the groups (see Table 1), with many participants identifying with more than one group.

As seen in Table 2, priority populations identified by CAOD are well represented. It was apparent in writing this report that people inject drugs, or whose injecting history is evident either in bodily scars or in medical records, experience more extreme manifestations of stigma and “history of injecting drug use” was added as a category in Table 1

Table 1: Priority populations represented by participants with category representation. Aboriginal = Aboriginal and/or Torres Strait Islander; Alcohol = people who have identified issues with alcohol use; CJ System = people with experience of the criminal justice system; CALD = people from culturally and linguistically diverse backgrounds; Disability = people with a disability; LGBTQI+ = people who identify with the queer community; MH = people who have identified mental health challenges; Older = people aged over 55; Parents = people who have children or who have recently given birth; Rural = people living in rural or remote areas of NSW; Young = people who identify as young; Comorbid = people with a significant co-morbid health condition.

Participant	ABORIGINAL	ALCOHOL	CJ SYSTEM	CALD	DISABILITY	LGBTQI+	MH	55+	PARENT	RURAL	YOUNG	PWID/OTP	COMORBID
1													
2												OTP	
3													
4													
5													
6													
7													
8													
9													
10													
11													
12												OTP	
13													
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27													
28													
29												OTP	
30													
31													
32													
33													
34													
35													
36												OTP	
37													
38													
TOTALS	4	8	9	4	8	10	9	6	7	8	7		

4.3 Data Collection

Data for this project was collected via in-depth interviews. The interviews were conducted by two NUAA peer employees with interviewing experience. Thirty-six participants were invited to participate through a one-on-one, in-depth interview process. Interviews lasted for an average of 40 minutes with interviews taking place between Monday 5 November 2021 and Monday 6 December 2021. Two additional interviews were conducted to gain further insight on the topic of pregnancy and parenting. One participant requested to participate by email because of their personal circumstances. After receipt, these data were judged to be appropriate for analysis and were included in the findings.

Participants were asked open-ended questions¹ that were not limited to experiences accessing AOD services but instead asked participants to reflect on any positive and negative experiences. Participants were asked broad questions that encouraged them to explore their experiences with the health care system and reflect on what creates positive and negative interactions with health care providers. Follow up questions focussed on settings in which consumers have had previous negative and positive experiences and what could be done to improve consumers experience of health care. (see Appendix 1 for interview guide)

Interviews were conducted over the phone and were recorded for analysis. The content of the interviews was at times distressing, and consent was active and ongoing with interviewers actively checking in on the welfare of participants. Participants were offered the opportunity to seek counselling, if necessary, supported by NUAA. Some participants expressed gratitude for the chance to speak about their experiences and indicated that the process was helpful while others were committed to improving the system and saw their participation in the project as a chance to make a difference.

Interviews were conducted until no new themes/material was being uncovered. When necessary and when the study team felt that they needed additional perspectives to explore particular themes, the study team expanded the recruitment target for that group.

¹<https://methods.sagepub.com/book/collecting-qualitative-data/i510.xml>

Transcriptions were completed internally and through an external service. Internal transcriptions were initially done through Otter.ai and were then checked for accuracy. Verbal pauses (“ums”) were not transcribed. All participants were assigned gender-neutral pseudonyms in the reporting of this project.

4.4 Data coding and analysis

Interviews were coded into major themes with two raters independently agreeing on major themes. All participants had the opportunity to review the report and their contributions as well as the opportunity to have input into the recommendations through an emailed survey.

5. Results

The aim of this work was to explore both good and bad experiences of health care. The analysis identified five main factors related to good experiences: listening, a focus on the medical issue rather than drug or alcohol use, service accessibility, clinical competence and caring. The negative experiences described by participants were more complex. There were broad general themes and several specific experiences related to specific clinical interactions that emerged. There were four general themes that emerged from participant experiences of poor health care: stigma and overt discrimination, medical gaslighting/treatment refusals, power imbalances or lack of control in clinical interactions and inadequate pain management. A number of other significant issues were raised by participants including poor disabled access, having or being threatened with the authorities being called, and being mis-gendered. The results also examine issues specific to identified priority populations.

Although people who do or have injected drugs was not a target group, issues around injecting drug use and pharmacotherapy for opioid dependence emerged strongly. Participants were recruited from NUAA networks which, given the nature of the organisation and our focus on harm reduction and needle and syringe program services, include a high proportion of people who inject drugs. However, it is inescapable that this group is subject to higher levels of stigma and discrimination when accessing health care because of the visible markers of drug use on

their medical records and on their bodies (see for example Cheetham et al 2022). This stigma in turn makes involvement with an organisation like NUAA more likely.

5.1 What does good health care look like?

There is growing body of literature and discussion about stigma and the resulting discrimination in health care as it relates to diverse communities,^{2 3} but we less often examine what good care looks like for patients, particularly for people who use drugs.

The six dimensions of health care quality are that it is safe, effective, patient or person-centred, timely, efficient and equitable.⁴ Person-centred care is described as caring for the whole person and going beyond a focus on a person's condition or disability through flexible, strengths-based services.^{5 6} Good health care for people who use drugs and alcohol, as described by our participants, was aligned with these dimensions of quality and is much the same as for the rest of the community.

The qualities valued by participants in this project were a genuine exchange of information and mutual respect without judgement, competence, a focus on health issues and accessibility – all qualities that are recognised in quality frameworks. For people who use drugs, good health care is also free of judgement, stigma and discrimination. While judgement-free care is implicit in definitions of person-centred care, the people we interviewed identified a willingness to provide treatment without negative judgements as a feature of positive experiences.

² Cheetham, Picco, Barnett, Lubman, Nielsen (2022) The Impact of Stigma on People with Opioid Use Disorder, Opioid Treatment, and Policy. *Substance Abuse and Rehabilitation* 2022:13 1–12

³ Nyblade, Stockton, Giger, Bond, Ekstrand, McLean, Mitchell, Nelson, Sapag, Siraprapasiri, Turan, Wouters (2019) Stigma in health facilities: why it matters and how we can change it. *BMC Public Health* (17)

⁴ Institute of Medicine accessed via ahrq.gov

⁵ NSW Health Clinical Excellence Commission (<https://www.cec.health.nsw.gov.au/improve-quality/teamwork-culture-pcc/person-centred-care> accessed Feb 2022)

⁶ NSW Health “What is a person-centred approach?” (<https://www.health.nsw.gov.au/mentalhealth/psychosocial/principles/Pages/person-centred.aspx> accessed Feb 2022)

5.1.1 Listening

“Being listened to” was central to good care cited for most of the participants in this project.

“Being listened to” had tangible and intangible features that marked these interactions as a genuine two-way exchange of information: *“(The GP) was just caring. He was listening to what I said. Anything I said, he could, you know, sort of reflect back to me and that was helpful.” (Sam)*

Other characteristics of good listening were eye contact *“they’re looking at you, making eye contact but they don’t sound condescending... they’re not just filling in the hours” (Skyler)*, and two-way exchange of information, including taking in and accepting information provided by the patient at face value, and asking questions. Being asked questions was key for many participants: *“rather than the doctor being the lord over ‘I’m the expert’ kind of position, which they often are, here it feels like a collaboration, and that the reality of my situation is respected and okay” (Gerry).*

Listening often resulted in positive outcomes for the participants who, as a group, had very few positive health care experiences:

Oh okay. Well, that (identifying a good experience) would be a hard one. Okay. Yes. I've got one. Yeah. It was about eight, nine years ago. And it was a female doctor. And I had depression and anxiety and that, and I've never had it addressed before. Even though I was molested as a child, and had drug addict parents and all that, but I've never really had anyone help me with it. She got me on medication for it, which I'm still on now. Which helps me. But she was great... that was the only time I ever had a doctor that actually helped me ... She actually sat down and spoke to me... I was talking to her about a few things. And she just listened to a few things that I said and approached me with it and asked me all the questions and then went into full detail of what I've been through and all the rest of it. And she said, 'I think medication would help you.' And I said, 'I'm willing to try it.' And a month later, I was great. I was so good (Casey)

Listening also indicated that clinicians cared about the health and well-being of their patients – another important aspect of good care to many participants. Other participants described listening as a *“willingness to pause” (Kim)* or giving people space *“she will genuinely, first off the bat, ask how I’m going and will actually stay silent and let me answer the question... (I receive) the question as about my well-being and not just a ‘what are you here for?’ (Tommie)*

Participants identified that ‘being listened to’ is also the antecedent to any possibility that the person seeking treatment for alcohol and other drug related issues will:

- have their health issue assessed and receive appropriate treatment
- receive ongoing treatment where necessary
- place any level of trust in the person delivering the service, and return to that health professional
- be treated like a valuable member of society.

Being listened to, and the appreciation participants felt when they were listened to, was often connected to previous experiences of being dismissed. Participants often described feeling disconnected from health services and providers whereas the feeling of being listened to was a sense of connection that was difficult to put into words but was clear in their clinical interactions and that made a significant difference to the quality of their experiences. Participants linked “successfully being listened to” with “being taken at face value” or “believed”.

“Being listened to” was associated with a participant having their health issue put first and a consultation continuing to be about their health issue and not their AOD consumption. *“They put my health issue first, not my drug taking.” (Jordan)* An implicit or explicit assumption in these conversations was stigma being absent.

“When they listened to me and focused on my health issue, they didn’t treat me like a junkie.” (Gerry)

“...asking a couple of questions about your life or being friendly. Even things like, I guess going through your history maybe, or asking questions or like responding with more active listening, like ‘It sounds like you’ve already tried this and it isn’t working, so maybe we can try this’ rather than kind of feeling like they already know exactly what you haven’t been doing.” (Colin)

“Well, listening, communication, obviously, is the major thing when it comes to healthcare. People just want to feel heard. When you’re terrified that something’s wrong or you’re injured or something, being listened to and taken seriously and any sort of symptoms acted on is important.” (Cole)

“Over the last 10 or 15 years, I’ve presented to hospital a few times because of an accident or an incident or whatever. And I’ve found the service to be exemplary every single time because there were people who were actually paying attention to what’s going on.” (Quinn)

“I think it’s the time she takes, definitely, and I think the fact that she listens and she gives me time to answer and actually responds to what I’m saying, she’s not just kind of ticking a mental box, doing a flowchart in her head like, ‘Oh, yes, this thing, this is what Tommie said, this means this thing or this means another.’ ... She kind of meets me where I’m at. I’ve never felt berated or embarrassed just

because I've come to her being like, 'Ah, I need a referral. I'm fucked. I've been drinking heavily and not seen a psychologist for four months'". (Tommie)

These established relationships were particularly important when accessing pain medication.

"I've been going through an increase in my daily pain from living with endometriosis and adenomyosis... And I was telling (my doctor) about how I'm really exhausted from not being able to talk about pain relief with doctors, because I have always experienced so much stigma and denial of pain medication, having had opioid dependence on my record that has followed me around... And we had a really great conversation about it. And she ended up prescribing me Panadeine Forte, which is kind of unheard of, in my experience. Just having her trust my experience, have a real conversation about it and her being like, 'pain relief is important, you shouldn't be denied that and let's also get you in with a specialist, but in the time being, let's reduce your pain.' And that was just like very refreshing." (Tatum)

5.1.2 Lack of judgement/focus on the medical issue:

"Mate we're not here to judge you. We're just here to fix you."

Participants valued a matter of fact and judgement free approach. One participant described a recent experience at Canterbury-Bankstown Emergency Department:

"I recently fractured my hand punching a wall ... the ER doctor who looked at it was just incredibly non-judgemental. It was like 'how did you do this' and I'm like 'I punched the wall' and he was like, 'Oh, yep, I've done that before. Broke this knuckle.' He then talked about the circumstances, and I said that I was drunk and he just kind of checked how much I'd been drinking... That was towards the end of August, it was the second month of lockdown and it was just nightmarish. And he just went 'yup, I understand you're drinking a lot. I was drinking a lot too. But that's a bit much to do for a long time but if that's what you need to cope, that's okay just make sure it doesn't continue forever.' And that made me feel so at ease... And the same with the x-ray tech, she also said that she's punched a wall. I don't know if people at Canterbury-Bankstown Hospital are taught to tell people that they've done the same thing to make everyone feel comfortable or it's just staffed by people who are really into angry wall punching. Fuck, it made me feel at ease." (Tommie)

A focus on the medical issue incorporates aspects of other markers of good care identified by participants, such as listening and competence. Medical care for people who disclose drug and alcohol use is often marked by a lack of professionalism in treating clinicians. It should be redundant to say good care requires a focus on the issues that resulted in a person seeking care, but it isn't for people who use drugs:

“So (substance use) comes up, but very much at my initiative, and it’s never met with any sort of judgement or concern. It’s just like, the drug use isn’t the problem. Whatever I say is the problem is the problem.” (Tommie)

Lack of judgement was also crucial to being able to engage in care. Lack of judgement had several features including an ability to be open and frankly discuss issues, particularly AOD issues.

Sometimes a lack of judgement just involved listening without necessarily trying to fix the problem. *“You can talk to them about things where there’ll be no judgement and no dramatic action taken necessarily – they’re there to support you.” (Harper).*

5.1.3 Accessibility

Accessibility was an important factor in maintaining a consistent relationship with a general practitioner. Quinn, describing a long-term relationship with a GP: *“I can walk in there, I don’t have to make an appointment. I don’t have to wait... He doesn’t over service... He’s very engaged in not overcharging people ... so he bulk bills and refers to people who bulk bill.”* Several participants believed that the ability to pay was a crucial factor in being able to access good healthcare:

A key part of (my positive experience) is that I go to a private practice, like I pay a gap payment. I deliberately shopped around and went to find a doctor who I heard was good, and kind of good with women’s health stuff. And that has been a massive uptick in my experiences.” (Tommie)

Accessibility was not just about short waiting times and affordability. Other patients mentioned the language used by clinicians as important to their sense of safety and quality. *“They put it in a way that I could understand it. They simplified it for me rather than using technical and scientific terms... Being able to actually relate to it properly, knowing what exactly I have to do to have the best benefit for me, made it so much better.” (Harper)*

5.1.4 Competence

Clinical competence is multi-faceted with participant descriptions varying. Being knowledgeable and therefore capable of addressing the patient’s needs was frequently mentioned by participants as the sign of a good clinician. Other factors that participants noted as contributing

to good experiences were being a good diagnostician, appropriately referring to specialists, being factual, and following up outside of scheduled appointments to notify patients of test results.

5.1.5 Caring

Health providers investing in therapeutic relationships was valued by participants. Trust and connection were improved by a two-way relationship where participants felt they could relate to the health care provider. Often a sense of care was found in the context of relationships with GPs but, as Tommie's experience in the Emergency Department shows, caring and empathy can be demonstrated in short term interactions.

Often the relationships with general practitioners where participants felt listened to were long-standing. At times these relationships went beyond the purely professional to where there was a sense of genuine caring. These relationships were often with general practitioners and were characterised by trust and connection.

"I've just come to trust him over time." (Quinn)

"I walked in the doctor's surgery, and I've just seen this smile on his face, like that recognition. Like, I know who you are. Mum still goes there. And that's the only time I've actually been given a script for my pain medication, for Endone, with 12 or 24 in the packet and been able to walk out of the doctor's surgery with a script and then the chemist with some pain medications that actually works." (Shae)

"I don't know. I guess it was just his persona. I guess, knowing that he had daughters, a wife. Not only that, it was just the way he spoke to me about my problems. He didn't disregard my feelings in any way, like usually any other doctor would. They'd just be like, 'yep, yep. Okay. Okay. Okay,' and put their head back in the book and blah, blah." (Billie)

I think it was just we got to the point where we're just friends — Well, I think we're friends, but it's still professional. She was like "I already knew". Like, you don't stay with somebody, you don't go back to somebody... She was very open about it but still professional at same time. But the main issue wasn't the drug use, the main issue was the violence. (Adrian)

For some participants, particularly the most highly marginalised, a genuine sense of caring and being understood was crucial to them being able to open up to a health care practitioner. Billie was a young Aboriginal woman with mental health and alcohol issues. Her initial attempts at 17 to get help were unsuccessful. *“The counsellor that I was talking to always pissed me off in a way, because every time I tried to talk, she shut me down, and would just try to relate from the book, instead of trying to actually understand me for me”*. The transformative experience for Billie was meeting a clinician who went above and beyond and who did not maintain clinical distance *“He actually sat there and took time to understand me and actually try to relate to me. And it was, to the point where I could see him crying. I guess that's why I could trust him because he felt emotion towards me as well.”* Billie’s relationship with this clinician went beyond normal boundaries during the many challenges she faced including a cancer diagnosis, abusive relationships, two pregnancies and the recurring threat of having her children removed. Ultimately, the relationship with this clinician was enough to keep Billie’s children from being removed and set her on the path to success.

5.1.6 Other factors associated with positive health care experiences

What makes good health care is well understood and is the same for people who use drugs as anyone else. What was striking in this report was how infrequently participants identified having experienced good health care and how it was often, but not always, tied to finding the right clinician.

Specialist services were identified as important and places where participants had experienced good care. The Kirketon Road Centre was mentioned by several participants as a great health service.

“It's the specialized nature of the service, which makes all the difference for me. So that if it's sort of queer friendly, if it's like, for instance, Sydney Sexual Health Centre, yeah, for me, is the ultimate way to go. Because they've been there, they've done, that's what it's for. And they deal primarily with, you know, men in my situation, or men or women, whatever, in my situation. And, you know, the whole sex and drugs thing, is quite common, and I deal with that. And that's sort of their expertise.”
(Rene)

Some issues were raised by very few or only one participant, but are significant and merit inclusion in this report.

Respecting boundaries will be explored in more depth when power imbalances are examined, as it is a significant issue when clinicians don't respect boundaries. Clinicians respecting patient privacy – physical and otherwise – was mentioned as a facet of good care. River described one component of good care as, *“They're conscious about your body and boundaries. My physio always leaves the room and then knocks on the door when I take off my shirt for a massage so then I can just be lying on the bed, I'm comfortable, I'm ok with being seen.”*

Pain Management will be discussed in more depth later in the report but receiving adequate pain management is a novel and remarkable experience for many participants.

Queer Doctors: Gay or queer clinicians were mentioned by several participants for being easier to work with on health issues. In describing stigma experienced once a health care professional realises there is a history of injecting drug use, Angel said *“the funny thing is, if it's a queer nurse it doesn't happen. I don't experience that type of change of attitude or anything”*. Jessie described a long-standing relationship with a GP as *“He's great, he's also a gay man and he and I have been working together for over ten years, and I'm comfortable to talk about all aspects of my health. That includes drug use, psychotic episodes, everything that's related to the chemsex scene,”* while Rene said, *“It is really quite amazing the difference of going to a, for lack of a better expression, gay friendly, queer-friendly practice ... I felt like I could be much more honest about my medical history, about my drug use.. and I found it really empowering.*

5.1.7 Summary

Very few of the experiences described by participants as positive can be described as clinicians going “above and beyond”. For the most part, the examples of care that contributed to a positive experience can be characterised as respectful, competent health care. Frequently this respectful and competent care occurred in the context of long-term relationships with general practitioners but did also occur in hospitals and emergency departments.

5.2 What does poor health care look like?

Each participant had experienced poor quality care which they believed was related to their drug and/or alcohol use. Poor quality care happens when people presenting for medical

concerns are not listened to by the clinician. People who use drugs are experts on their own bodies and health care needs but are often dismissed or ignored by health care professionals. The trauma felt by participants in this project through these experiences was often visceral. At times they described experiences where their health was severely compromised.

Examples of poor health care service will be examined in more depth below, but the people participating in this project identified stigma related to drug use:

- being judged,
- being refused treatment,
- unprofessional or poorly prepared clinicians,
- being treated like a billing opportunity,
- being mis-gendered,
- sexism,
- poor pain management,
- coming in for health care and either having or being threatened with services (DCJ/police) being called,
- poor access for people with a disability, and
- attending multiple appointments with no diagnosis and the frustration of successive referrals with no outcome and no assistance.

The experiences of people with a visible history of injecting were notably worse than those who were not identifiable as drug users (who “passed” as non-drug users) or who were not injecting drug users.

Several participants thought that their ability to “pass” or their own privilege – whether it was financial or related to their personal characteristics – meant that they were able to access better quality care. Most people that we spoke to were not particularly motivated to complain, and often the reason cited was because *“it wouldn’t make any difference”*.

5.2.1 Stigma and overt discrimination

“I was made to feel like a worthless piece of shit.” (Robbie)

“The minute I sense judgement, my sense of self identity changes... I feel childlike, messy, grubby, dirty. And I’m specifically using those words – I feel physically dirty, incompetent. And as that feeling wells up in me of being a problematic child, a pain in the ass... my behaviours change to be more and more like that.” (Gerry)

Participants identified many incidents of either overt discrimination or poor treatment that they perceived as fuelled by stigma. Discrimination based upon stigma is here considered as behaviours and language that participants believed occurred in response to actual or perceived drug and alcohol use or another personal characteristic such as gender, sexuality or mental health.

Stigma is humiliating and demeaning. Many people we interviewed described it as painful. One participant, whose mother had just died, missed a plane and rang her doctor to ask him to re-organise her dosing. The doctor then spoke down to her *“His answer was... patronizing... like a father talking down to his child: ‘How could you possibly miss your plane? That’s ridiculous, who misses a plane?’”* The participant described waiting in stunned silence while the doctor continued: *“Well, now that your mother’s died someone’s got to tell you’ ... I bet he never says that to his Potts Point la-di-dah patients”* (Gerry).

Stigma results in a number of forms of discrimination which are discussed in more depth below. The participants often described immediately knowing that they were being judged through changes in listening or even ‘atmospheric’ changes that could not be defined when they were being judged.

Many participants felt that being identified as an injecting drug user (through being on the opioid treatment program, overdose, current or past hepatitis C, or track marks) resulted in discrimination that followed people presenting as patients for years:

“Once they... have my file in their hand that shows my drug history or whatever. Because look, I’ve been taken to the emergency room for an overdose... So it’s in there then they don’t want to give me pain relief, I’ve been escorted to the toilet to make sure I’m not in there to shoot up, as if to say I’m only there to score drugs, and when the reality is I’m there because I’m actually having a problem...and sometimes the problem has nothing to do with them needing to give me morphine or anything like that. But they still treat me like that’s why I’m there.” (Alex)

One participant described a policy at a Sydney hospital that prohibits anyone with a record of injecting drug use from leaving the hospital with a cannula in place. This discriminatory policy does⁷ not consider the individual circumstances of the patients and that what might be a reasonable risk mitigation measure for a small number of patients

⁷ The participant described recent experiences but we have not followed up with RPAH to determine whether this policy is currently in place.

(for example, people with prior admissions for injecting related injuries, history of femoral injecting) does not make sense for all injecting drug users.

“They refused to allow me to leave the emergency ward, even to go outside to get fresh air. And they said it’s because of the risk of having IV drug user with a cannula outside of the emergency ward. Because, yeah, I’m going to go and inject something into my cannula when I’m sick enough to be in an emergency ward. But yeah, that’s happened to me before and it was quite distressing. (They said) ‘if you leave the hospital we will call the police’.” (Kris)

The application of this policy required Kris to have a new cannula each day for outpatient antibiotic treatment when under normal circumstances the cannula would remain in:

But with me, they specifically said, ‘We’re not actually allowing that to happen with you.’ Because of the fact that I was an IVDU. And once again, that was at RPA. So it’s been consistently applied, that whatever policy they have there has been consistently applied across two different departments.

The readers of this report are likely to be abundantly familiar with stigma and discrimination in health care settings and further examples may not be needed but some of the stories we heard while compiling this report demand to be told. Multiple people who we spoke to reported their privacy being violated by clinicians who exposed their injecting history to other patients:

“He walked in, he opened the curtain (I was in a room with other people), he’s pointing at me with these doctors around saying, ‘See her track marks here’ and telling everybody else in the room my history and I just thought ‘That’s not right!’. And the other mothers, the way they were looking at me, I felt so low! I told my son’s father, and that’s why we got the other doctor from the hospital, the other drug and alcohol doctor. Because my son’s father came in and I was crying. I had to be hospitalised before I had my son because it was so high risk — it was dangerous for me to be walking around. And I was in tears. My son’s father’s like, ‘This can’t be good for the baby’. But just the way he walked in and open the curtain and showed everyone and he’s pointing at me, and he’s making me put my arms out so he could look for track marks. It’s just it wasn’t good Wasn’t good at all.... Just the way I had my shirt up and that and he’s opened the curtain. And I’m half dressed and he’s opened the curtain. And pointing at me, ‘See her track marks there, it’s gonna be hard to get a line in because...’ And he just kept going on with it. And to me, him doing that as a doctor. You’re not ... I didn’t think you were allowed to do stuff like that.” (Casey)

These repeated experiences mean people avoid care: *“Put it this way, I don’t even like going to the hospital anymore. I’ve got something wrong with my heart at the moment... Everything was*

going good up until the point when they wanted to get blood. Then they could see my old using marks and it was downhill from there. So I ended up signing myself out.” (Robbie) When Robbie was asked what changed he said the care taken by the person taking blood changed: *“He got sloppier and it hurt more”*. Robbie was not the only participant to describe experiences where apparently less-than-normal care was taken in drawing blood.

5.2.2 Medical gaslighting and denial of care

Gaslighting has been defined as a phenomenon where “perpetrators mobilise gender-based stereotypes and structural and institutional inequalities against victims to manipulate their realities.”⁸ This view of gaslighting places it squarely in a social context where it is enacted through existing power imbalances based on gender, race, socio-economic status and other structural inequalities. One of these structural inequalities is the power imbalance inherent in doctor-patient relationships that are exacerbated for people who use drugs when seeking treatment, particularly in the context of opioid agonist treatment. Medical gaslighting has been described in a variety of contexts including women’s health^{9,10} and Long COVID.¹¹

This phenomenon, which can include dismissing or diminishing concerns raised by patients in the context of clinical consultations, can result in lower standards of clinical care and misdiagnosis. Misdiagnosis based on sex, race and socio-economic status is a documented phenomenon.¹² Participants in this project frequently reported that their medical concerns were dismissed or diminished: *“(I was using methamphetamine and had noticed changes in my skin.) I could see from that point on, she did not take my skin complaint seriously. And the more I tried to explain it, the more insane I felt I sounded and I had such a moment of, I can’t tell you, my heart broke”*. (Gerry)

⁸ Sweet, P (2019). The sociology of gaslighting. *American Sociological Review* 84(5), 851-875.

⁹ Fielding-Singh P, Dmowska A (In Press). Obstetric gaslighting and the denial of mothers’ realities. *Social Science & Medicine*, accessed online 4 April 2022.

¹⁰ De León-Menjivar, C. (2021). Understanding the Dialogical Experiences of Puerto Rican Women With Fibromyalgia: An Intersectional Analysis. *Hispanic Health Care International*, 15404153211064608.

¹¹ Rubin R (2020) As their numbers grow, COVID-19 “Long Haulers” Stump Experts. *JAMA* 324(14): 1381-1383.

¹² Newman, -Toker DE, Moy E, Valente E, Coffey R, Hines AL (2014). Missed diagnosis of stroke in the emergency department: a cross-sectional analysis of a large population-based sample. *Diagnosis*, 1(2), 155-166.

It can be difficult to differentiate brushing off legitimate concerns from incompetence. For Jude, it took three visits to the GP before they were referred to a diagnostic procedure for extreme pain. The first doctor *“walked around a few times just saying, ‘I don’t know, I don’t know, I don’t know’ and gave me a script for Panadeine Forte. That was it... I went back a week later, it was getting worse...(and another clinician said) ‘Mate you’re all hunched up. You look stressed’... He came me a script for Valium and said ‘see you later’.”* Jude was eventually diagnosed with an infection in his neck that had damaged a vertebra and could have left him a quadriplegic.

Some of the most concerning instances of people with legitimate medical issues being dismissed happened to pregnant women, these will be discussed separately below.

Another common experience for the people who participated in these consultations was being refused service. Sometimes these refusals were face-to-face and overt in other cases they took place through restrictions on access to treatment or having genuine medical concerns that were not picked up or dismissed because of a lack of investment and energy by clinicians.

Overt refusal of pain medication was a common experience, mentioned by many participants – many people with a record of drug use don’t bother to ask for pain medication because of previous experiences creating another very common mechanism for reduced or no access to health services: giving up or not trying.

Tatum described attending a pain specialist who pre-empted any discussion declaring *“I won’t be prescribing you any opiates ... he sent a letter to my doctor and all it pretty much said was ‘this is what is going on today. Do not prescribe opiates’.”* Tatum eloquently described the feeling of giving up on seeking assistance from health care providers after previous overt denials of care:

My actual health issue and the way that has been impacting my life, and my emotional experience in chronic pain and all of the ways that this bleeds out into every other area: in relationships, it affects work – none of that is actually being cared for or witnessed in that dialogue, when it becomes about: ‘You are a drug-seeking person. That becomes the entire focus of a conversation like that. And that experience is really upsetting, and hurtful and de-humanising, and makes me feel like my really hard ongoing and day to day experiences of being chronically ill are in some way an elaborate guise for me to get high, (it’s) so humiliating and so just not okay...

And the feeling of giving up or essentially becoming exhausted by being communicated to in that way or framed in that way comes from losing the stamina to not internalize that kind of shit. That that is who I am and that is what’s going on. Because, like you

said, that repeated experience totally detracts from the validity and weight of what's actually going on, which is that most of my life I have been denied adequate health care, because even outside of this kind of conversation of 'you're a drug seeking person', I have already experienced so much minimising, invalidation, deflection or this kind of 'your experience isn't real' — I've been experiencing that my whole life and the drug element is just a way to package that up and completely dismiss you. It's kind of like that's the chance for doctors who have consistently been getting it wrong already, to just be like, 'Oh, that's what it is! Cool, I don't need to engage at all. I'm gonna completely dismiss this complex history of your health and your negative experiences of complex healthcare dynamics and treatment, and just package it up in this really simple: I don't have to engage because it checks a box of drug seeking behaviour.' And it's humiliating, so humiliating."

Denial of treatment took other forms. Frankie described an experience they witnessed *"(One person I know) that was on ice lost his license because he went to the GP to seek help. He goes 'I need help. I need something. I don't want to do this any more. I want to get off.' What does the GP do straight away? An hour later, his license was cancelled."* Quinn described an experience where he had been in an automobile accident with multiple people injured, including children. The health care workers at the emergency department *"treated me like I was evil... They didn't listen to me, they took blood because they needed to breathalyse me, then they basically choofed me out the door... I said 'I'm just not right, there's something wrong' and they still ignored me. And eventually, when I almost passed out and kind of collapsed, they started taking me seriously. It turned out that I'd fractured my spine... Nobody said anything. I was clearly treated differently to the others. That judgement ultimately led to nobody checking to see if I was okay properly and missing something really significant."*

Leslie had a similar experience where, after a gastroenterologist had recommended surgery to remove a serious blockage a registrar looked at the clinical notes, saw that Leslie was on OTP and refused the surgery. After years of ongoing problems with her bowels, Leslie was required to undergo an emergency cesarean where the problem was evident and that the issues were due to adhesions from a previous cesarean section. As Leslie put it: *"Yeah, if they'd done any further exploration years early on when I was there, they would have found (the scarring)"*

Evan described delayed surgery because of the concerns of a registrar around injecting drug use *"I don't think he believed me when I said 'Look, I'm being abstinent now. I've been abstinent for a while, I've been on treatment' ... He said 'Look, if you're using and we do this operation it could*

possibly lead to infection’.” The surgery still has not taken place, with COVID a complicating factor, but Evan has been asked repeatedly about his using by his clinicians.

More than one person who took part in this project and was an injecting drug user mentioned issues getting injection related injuries treated:

“One when I went to see a specialist about my leg when I had cellulitis and I had ulcers on either leg. I was in agony. I was in so much pain, I was suicidal. But the doctor didn't mention to me that what you can have done is you can have skin grafts, and once they've done skin grafts on either ulcer, the pain dissipates virtually immediately. Because what happens with ulcers is that eventually they're so deep that your nerves are exposed. He didn't mention that you could do a skin graft, it was only when I saw someone else. And I never understood that, because I had private health insurance, so it wasn't that I wasn't covered or he was going to have to do it on Medicare or anything. So I don't know what that was about.” (Sam)

5.2.3 Power imbalances/loss of control

Power imbalances between a doctor and a patient are present in many interactions, and in many of the interactions already described in this report. Participants reported clinicians using inaccessible language, not attending to, or dismissing, information provided by the patient, disregard of boundaries, public disclosure of personal information – all markers of relationships where there is an imbalance of power. The experiences described by participants varied but they often had a common theme of a lack of care by clinicians and a lack of regard for the patient as an autonomous human being deserving of respect. The people reporting these experiences felt like they had no control over the situation.

We have seen in the section on what good practice looks like that health care practitioners who have read your notes and are prepared, contribute to a positive experience. The converse experience, when patients have to repeat information again and again, is disempowering. One person participating in this project described an experience with a doctor who wouldn't pay attention to anything on file: *“I had to reintroduce myself, my entire history, to somebody who should have access to that information already but doesn't bother to read about it before they actually talk to me... It was re-addressing my entire life story to one person, which I don't think is appropriate or should have to happen”* (Harper). This experience felt negative because of a lack

of control – Harper felt they had no choice but to go through the uncomfortable experience of repeating their history in order to receive the required care.

Tommie described being “*chewed out*” by a psychologist that continuously brought up drug use at the start of the session and whose advice was frequently impractical: “*I got tired of explaining what it’s like to be a poor, queer migrant. Like some of the stuff she was saying was just not accessible.*” Eventually Tommie moved to a clinician who gave them control of the conversation: “*If I bring it up then we talk about it.*”

A lack of information also makes people feel like they have no control over a situation. Jessie described an experience when they were taken to an ED.

“I wasn’t informed. I definitely wasn’t informed. I didn’t know what the process would look like. I was not advised on what would happen to me. And I guess they were trying to make sure that I don’t try to kill myself again on that spot, I suppose... I was laying outside for four hours and then was inside for another three hours and they still wouldn’t let me go. My brother was already there with me.”

Power imbalances created through a lack of information and a lack of care by clinicians resulted in very poor care. Tommie described a situation in which not being given adequate information resulted in a contraceptive device being inserted incorrectly.

“I think my final straw with the Newtown practice was when I went there for the insertion of Depo Provera... You are meant to get that inserted at a certain point in your cycle. No one told me that. And the woman asked me ‘are you at this point in your cycle?’ I said no. And she was like, ‘oh well’ and inserted it anyway and it fucked up my cycle for like three months and then I got it pulled out. There was just no explanation of anything, no particular care for my experience as a person. They were just like a meat slab is here for insertion of thing.”

River described how clinicians not listening or discounting the experience of their patients – when they are in a vulnerable state because of physical or mental pain – leads to a loss of control and an inability to speak up in the moment. The privileging of medical knowledge over lived experience is inbuilt into the current system

“I’m not trying to discount (clinical knowledge) but ... because rationality and facts are associated with masculinity, they tend to be given more weight than lived experience that’s been expressed in subjective terms, but the only way you can express your lived experience is in subjective terms, so it feels like a built-in power imbalance.”

5.2.4 No or inadequate pain management

Although we did not specifically ask participants about pain, of the 38 people who took part in this study, 24 (63%) specifically mentioned difficulty obtaining adequate pain relief. Many of the participants experienced significant levels of pain.

Several participants told us that they do not routinely ask for pain medication as they believe that they will be refused with several participants also saying that they sourced their own pain medication.

I'm always mindful that if they don't offer (pain medication) I don't really tend to push for it because otherwise, I think they think that you're just there looking for pain medication. I'm always really careful about that... Yeah, I usually just handle it myself. (Sam)

Quite a few other participants were not given adequate pain relief, even in situations where pain relief is quite normal including childbirth and dentistry. *"Some dentists, they don't put enough of that stuff in the needle in your mouth, so it's just pain, pain, pain" (Robbie)*

When I had my baby... the pain management at Wollongong Hospital, because I had a caesarean, was woefully inadequate. Like I said, allergic to paracetamol, they can't give me Nurofen because it's a blood thinner, and I was postoperative, so they didn't want to thin my blood. The only option was Endone, which I got a tablet a day or you know, and then another extended release one at night-time. And for me, as a current user with previous opioid dependency, one Endone tablet was just not going to cut it for me post major surgery. And even when I requested it lying there withering in pain, they still wouldn't give me any more pain medication. And I find that it's actually gotten worse over the years, over the last 20-25 years, trying to get adequate pain medication is just so really, really difficult. (Shae)

5.3 Specific issues pertaining to priority and other groups

There was significant overlap in the experiences described by all participants however there were some findings that were specific to priority and other groups. It is worth bearing in mind that groups tended to be small (less than ten people) and these findings may not be generalisable. Not all priority populations are mentioned here as they were only included if clear patterns emerged.

5.3.1 Young people

The group of five young people interviewed for this project were quite diverse and had experienced significant challenges including disability, mental health challenges, incarceration and cancer. The young participants interviewed for this project had similar views on what they considered to be good care:

“They told me exactly what I needed to know and made sure I understood it.” (Harper)

“He listens to me as if I’m just talking about myself like a normal person.” (Axel)

“It was fast and to the point. I mean, she was very professional, but also talking to me, going through the procedure. I got everything done... there was no shame or judgement or anything.” (Charlie)

“They half cared about my well-being.. they talk to you like they should talk to... a person.” (Jace)

These participants also valued having their expertise on their own bodies and health listened to and taken into consideration by clinicians. In discussing good care, Axel said *“I feel listened to and respected. I think the fact that someone is willing to hear me out, and also understand that I understand my own body, and that I understand what my issues are.”* This sentiment was echoed by several other young participants.

One striking common theme is the lack of care that some these participants experienced when presenting for emergency treatment. Charlie was taken to an Emergency Department and was left for five or six hours waiting for a psychiatrist before they could get approval to leave. When the psychiatrist arrived, the assessment lasted for about three minutes:

“I didn’t want to go back there after because there was no care. It was meant to be a safe space that I was taken to and I didn’t feel safe. I felt rejected and left. The fact that I thought my life was ending, I was having a panic attack I think, I thought my life was ending and they plopped me in a room waiting for someone to talk to me and then essentially just let me go, like just ‘Bye’ ... she literally sounded like she didn’t want to talk to me. And it’s like ‘I come here looking for help and you can’t even be arsed asking how I’m doing, what’s the matter, what’s wrong.’”

Axel described a similar experience that happened to a friend when they were both 16: *“He was passed out face-down in the gutter in the middle of a suburb ... and they called an ambulance for him because he’d obviously take a lot of M and then drunk a whole heap of alcohol and then passed out... they took him to RPA... and basically, as soon as he woke up, they discharged him*

from RPA and kicked him out and he wandered by himself up to my house. He was obviously in a position where he needed help and he would have been 16 or 17 at the time.”

Jace was recently incarcerated and described his experiences trying to access health care while inside correctional services. Jace experienced both gaslighting and denial of care:

“At places like Parklea and Silverwater.. they don’t really care, they just leave you there.... One of my teeth was knocked out. And then, like over two days, that spread to my ear, and then I ended up getting a toothache and ear infection. And then I pretty much asked them ‘can I go down and see a nurse or a doctor or something?’ And they said ‘Yeah alright’ like they sort of just lie to your face. ‘Yeah, no, no worries, we’ll put you in the clinic list for the morning.’ And the next day would come – nothing. So then I wait and wait because the nurses come around at night and give people their pills. I wouldn’t see her face to face, but I’d talk out my cell window and say ‘Oh look Miss, I’ve got green pus coming out of my ears. Like is there anything you can do to help me?’ and they go ‘Oh, yeah, don’t worry. I’ll put you on a clinic list for tomorrow morning’ and that literally happened for two weeks and I was sitting there... in the worst amount of pain I’ve ever had in my life... You could see one of my ears had doubled in size with full on green puss coming out of my ears. They just keep saying ‘Yeah, no, no worries, we’ll get you down there’ but literally two weeks nothing happened. I never even ended up getting down and getting on antibiotics, it just went away by itself.” (Jace)

It's uncertain whether Jace's experience was due to his age but it is strikingly similar to the experiences of Charlie and what Axel witnessed his friend go through.

Finally, another theme that emerged with younger participants was a particularly sensitivity to non-verbal cues indicating that they were being judged *“(You can tell someone is judgemental) their face might tense up, there might be a different inflection.” (Axel)*. Axel's sensitivity to subtle cues was similar to Harper's view of clinicians. *“It hasn’t been a flatline judgement. It’s just the hesitation and, I guess, the silence of it sometimes... It’s not saying ‘oh you’re an idiot, no, don’t do that’ but you still get that aspect of they don’t agree.”* Billie also described *“a sixth sense towards people like I can sense whether they are genuine or not.”*

5.3.2 Aboriginal People

Several of the Aboriginal People who participated in this project described being threatened with, or having, external agencies called in while they were seeking health care. Of the Aboriginal people participating, half had experienced this threat. Robbie described seeking assistance from a doctor while hanging out after saying that he wanted to stop using:

“I'd been in the scene for a while. I was always told it was healthy to relapse. This doctor didn't think so! Not at all. The Christian doctors seem to be the worst. She had to ring the police on me because I was asking for some Valium, just to help me sleep because I was hanging out. I just couldn't understand that. I wasn't threatening or anything.” (Jamie)

Billie, the young Aboriginal woman described above, was reported to authorities both times she gave birth. She attributed the report to the fact that her ex-partner showed up at the delivery ward:

“And that was only because my son's father decided to rock up at the labour. Like we were separated, I had an AVO, but I said, ‘Your son's going to be born, your first son, do you want to be there for the labour?’ And I said, ‘look, but you have to be sober.’ He came there off his face on heroin, going on the nod in front of me in the labour room. So I went through it all on my own. And the nurses are sitting there looking at me looking at him, and I'm like, ‘Can you get him out of here?’ And I believe that, because of that, they put a report against me, you know, without even actually asking me or talking to me.

The next time Billie gave birth, she left hospital early to avoid being reported:

“They tried to sit there and say to me because I was a victim of physical and sexual assault for nearly 10 years of my life in the foster homes and I've never done therapy or counselling for it, that I'm a threat to my own child because I might snap at him one day and take it out on him or treat him the same way I was raised. I said, ‘like bullshit.’ I said, ‘You took me from my mom because she was an alcoholic and youse put me with a convicted paedophile and an alcoholic who abused my brother and me on a daily basis. So you're telling me you're gonna take my son for me and put him in the same situation? I don't think so.’

Being threatened did not exclusively occur with Aboriginal people who participated in the project (two other participants described being threatened with police for refusing to comply with instructions) but it did appear to occur more frequently.

5.3.3 Pregnancy and parenting

All the mums interviewed for this project had traumatic birth experiences. They identified occasions when their health concerns around their pregnancies or their children were dismissed. These experiences involved clinicians not looking at what were in fact serious issues and would be investigated – instead they were dismissed or attributed to drug use or drug treatment. Other experiences were blatantly discriminatory.

One participant, Blake, asked her GP for pre-pregnancy counselling because of her drug use only to find that she had been referred to a termination clinic rather than receiving a referral to an OBGYN or women's hospital after the GP had chided her for "allowing herself to get pregnant". Blake started methadone while she was pregnant after being told that her child would be removed if she was not on methadone when she delivered. Throughout her pregnancy, Blake experienced severe vomiting – daily until the end of her pregnancy. Her GP told her that the vomiting was due to the methadone without further investigation, giving her vomit bags. She was not given any assistance by her methadone clinic such as allowing her to split the dose. A lack of movement by the baby was also dismissed as methadone as were any other health concerns raised during the pregnancy.

The baby was three weeks overdue when Blake went to the hospital to say she was concerned, and she was induced. At this point, there was no amniotic fluid surrounding the baby because of the vomiting and Blake's baby was delivered by forceps (it was the doctors first delivery). Blake felt that the staff at the hospital did not make an effort to explain the best options to ensure a safe delivery and instead underwent a traumatic delivery. Her child has grown up with multiple disabilities which may be able to be attributed to the heavy use of forceps. Blake describes herself as "angry with herself that she trusted them to do the right thing."

Another mother we interviewed, Casey, described the birth of her child as "the most horrific experience of my life":

"Yet, this man from the clinic, because he knew me from years before, had a preconceived idea of what I was and what I was about. So he just treated me like crap. And then, when I actually had an emergency C section. And they, because of my back, they kept trying to get epidural in but it only numbed my legs. And when I woke up out of surgery, because they had to put me under. I woke up and the lady was rolling me over to put pads under me because you still bleed. And she was rolling the top half of my body, but not the bottom half. And because the bottom half was completely dead and numb from the epidural, it was tearing the stitches and that and I was screaming in so much pain. And I said, 'Please give me something for the pain.' She wouldn't. She said, 'Oh no, it's your anxiety.' And I'm like, 'I've just had major surgery, and she's tearing at me stitches and I'm crying and she's telling me it's anxiety.' My son's father finally said 'No, it's not. So she gave me ketamine.' But she thought, 'oh, we'll I'll get her.' She gave me this massive dose of ketamine that was way too much. I had out of body experience. I couldn't breathe, I forgot how to breathe. It was worse than the pain. And I said to her: 'Don't do that again. Don't do that.' And she realized, 'Oh, well she must be in pain.' So she put me on a drip. Like giving birth is supposed to be the most beautiful experience ever. It was the most horrific experience of my life. Like

hands down I've never experienced anything so painful and so scary and just horrific it was yeah ...not right

Casey was publicly shamed by a doctor who pointed out her track marks to a crowded room. *"The way he walked in and opened the curtain and showed everyone and I'm half dressed. I didn't think you were allowed to do stuff like that."* Casey was also threatened by a clinic staff member: *"I'm going to have to ring DOCs and they're probably going to take your kid because you haven't gotten a referral, you haven't gotten an appointment,"* when there was, in fact, a referral on file. Casey's child was born with Down's syndrome and has been to hospital on a number of occasions and still, clinical staff do not listen to her concerns: *"'no he's fine' and the next he'd be on life support"*. Casey's describes her son:

"It's ... how my son is to me. He laughs and then we laugh. He does something funny and we laugh. It's just so infectious that you just can't help but want to be happy because they are so happy. And I think that that's so beautiful, and what the world needs so much more. And that's why it breaks my heart when people look at people with disabilities and treat them like they less a person when they're not. My son is more of a person than a lot of people I know. Like, he's got so much resilience, like, he came off life support and started to wake up and he just smiled, just from seeing me and his dad there. Even at his sickest, he just smiles at you. Yeah, it's so beautiful. Like, I mean, I wish I had that."

Another participant, Shannon, described going to hospital while miscarrying and being discharged without any follow up. She was told that *"normally we would do an ultrasound or curette but it sounds like everything has passed so we won't"* and from there had no follow up. Shannon described how she then had a second miscarriage as the foetus was still present: *"It fell into my knickers"*. Shannon attributes this treatment to having "methadone patient" recorded on her record.

Billie was a young Aboriginal mother with cancer when she gave birth:

"I had an appointment to be induced due to my son getting sick because of the cancer and all that stuff. And so was I, so we had to get him out sooner. And I never knew anything about being induced is 10 times harder and more painful than normal labour. And like they didn't give me a heads up or nothing. They just put the blue needle in my arm and walked out and I'm starting to get all this excruciating pain. I'm like, 'What the hell'. They didn't even give me any time to work up for it or anything. Like, yeah, I really, really hated my first experience giving birth. It really scared me. I didn't want kids ever again because of that experience. Yeah, I truly didn't. And like, I was petrified."

And like, they just left me in the room the whole time to go through everything on my own. Those nurses. You know, like, it's my first time I've given birth, and I've got cancer. And you're going to sit there, out there and listen to me screaming in pain and not come in and help me? I've never given this before and you're not even going to tell me how to do it, how to breathe, how to calm myself down. I said, 'Look, I don't know what the hell I'm doing.'" (Billie)

While only Aboriginal participants described having authorities called on them, several of the mothers interviewed described the profound impacts of having the threat of services being called.

Sometimes seemingly throwaway comments were made to participants that have had profound impacts. On participant, Blake, lived in fear, avoided authorities, and never claimed child tax rebates because of fear of her child being removed after her doctor casually advised her that would be the case if she did not go on methadone. She has been unable to exit the program for twenty years. When Shannon went into RPAH to give birth a doctor made the comment *"I suppose it's like three different Dads?"*

These experiences persisted for participants as their children grew up. Robbie described his experiences as an OTP patient at Lithgow Hospital as *"not being seen"* because clinical staff assume you are there to dose. When his former partner took their sick child to the hospital the advice was that she was *"freaking out over nothing"* when in reality the child was seriously ill. Robbie believes that *"the same people (that have discriminated against him) are starting to take it out on my kids"* and that his children *"feel it when they get treated differently and it's because of me"*.

5.3.4 LGBTQI+

One theme emerging from our interviews with LGBTQI+ participants was a clear preference for "queer friendly services" that is described in Section 4.1.6. Several participants described experiences with GPs, even GPs with whom they had an established relationship as "judgemental" when there was a lack of understanding of their choices. Rene described an encounter with his established GP who asked him *"Why the hell would you do that?"* Rene describes the experience: *"It really upset me after having such a good relationship with him. And then I thought 'you know what? I'm pushing shit up a hill... he's just not going to get it.' And that is when I decided to go to a more queer-friendly GP"*. As noted, there was a marked preference

for services that “get it” with all participants stating that they currently had access to these services either via specialist GPs or Sydney Sexual Health Centre.

One trans participant described being deliberately and repeatedly mis-gendered, describing these experiences as traumatic:

“I’ll have definite issues where they’ll continue to call me she or her. Even though I am a bearded man. Like, I sound like a man, I look like a man unless you pull my pants down. I correct them, but it doesn’t matter... With some of them it does. Yeah. I’ve had, again, queer nurses pull other people up about it... I suffer traumatic trauma, way more with that than I do with the drug stuff... I’m sitting there, and there’s other people around, and, like I said, I look like a man and they’re addressing me as ‘she’ or ‘her’ or ‘miss’... All these people can see who they’re talking to, like, I’m sitting in a waiting room. You know what I mean?”

This experience occurred in a general service setting.

5.3.5 People seeking treatment for alcohol use

Many of the participants in this project have had negative experiences in Emergency Department that have been detailed throughout this report. In contrast, people who visited Emergency Departments for alcohol use did not appear to experience the same issues. Tommie’s positive experience after attending Canterbury ED after an injury caused by drunken wall-punching was reported in section 5.1.2. Similarly, Cole describes the staff at RPAH as “helpful, patient and non-judgemental”. While acknowledging the wait times as excessive and that her positive treatment is largely due to the privilege of being “well-educated, well-off, white... I’ve always had great experiences because honestly, I think I’m just so excited. I’m always very friendly with the doctor and I’ve sobered up enough that I’m not snappy or anything, I’m more just ‘let’s get this done, let’s get the hell out of here’”.

Axel described a recent ED presentation brought on by bad reaction to alcohol

“They seemed to be there to make sure that I was all right... I was in a fair amount of pain in my oesophagus from acid reflux or something, and they seemed to be... they were understanding, and they didn’t seem judgemental when I told them what was happening, or the issues that I was presenting. It wasn’t like, ‘Oh he’s had too much to drink.’”

5.3.6 People with Disabilities/Disabled access

The group of people with disabilities interviewed for this project was quite diverse and it is difficult to draw conclusions beyond those that have already been discussed – accessing ongoing and appropriate pain management is very difficult for anyone with a history of drug use in their medical record and this disproportionately has an impact on people living with a disability.

One issue to note is access, particularly in relation to OTP clinics. Two participants mentioned that disabled access at these treatment services is poor and, at the time of the experiences described in this report, clinics do not afford any flexibility to people with physical challenges. Blake discussed being reluctant to have her child via caesarean (a safer option given the complications she experienced during pregnancy) because she did not know how she would cope with daily dosing. NUAA has been told of people being required to attend daily dosing in very challenging circumstances such as cancer treatment. One participant in particular has numerous challenges because of a disability:

*“I’m disabled. So I use a wheelchair... I’m on methadone, not because of my drug use, but because of pain management. So I turned up to this doctor with a letter from the hospital, asking that he be my prescriber and explaining why then I’m in chronic pain, that I don’t want to continue to be using MS Contin... He refuses to give me takeaways because I cannot access his toilet (to do urines) because it is not wheelchair accessible.”
(Angel)*

Angel goes on to describe another experience at his dosing clinic:

“One time where he asked absolutely insisted that I had to give him a cup of urine, I had to get people, to help me hop on, one (person at each) leg.. and I dropped the fucking cup into the toilet. And it was sealed. But it had water on it. And it got a little cold from the cold water in the toilet. And he assumed that I was trying to do something dodgy and so refused to accept the urine. Like if it’s really fucked up. He just is really horrible with people who are either on methadone or because he sees them as drug users.”

5.3.7 People with involvement in the criminal justice system

Jace’s experience, or lack of experience with health care in a correctional setting was described in section 5.3.1. Other participants consistently reported similar issues with health services in prison including Bo who said:

“Getting health stuff in jail is horrific. Honestly... There’s just not enough nurses or doctors or whatever for the jails when you go in. So unless you literally have an emergency, you don’t get to see someone for a week. If you have a toothache, if you get to see someone in under a month, you’re lucky. But you’re inside, and, according to them, you have no rights.”

5.3.8 Injecting drug use

People who have a history of injecting recorded on their medical records or bodies (through scarring) experience particularly virulent forms of stigma and discrimination. Loss of control and power imbalances are heightened in the relationships they have with their medical providers. Many of the participants in this study described how injecting drug use reduced their access to care and very frequently resulted in stigma and discrimination, particularly in health care settings. These experiences are described throughout this report, but specific issues are highlighted here.

A number of participants have described how distressing venepuncture can be and how they believe there is a perceived lack of care when hospital staff realise that they have a history injecting drug use.

“I suffer really badly from cellulitis... I went in on a Saturday morning to have 7 nurses have a go at getting a cannula into me to give me antibiotics. Three times. So you know, by the end of this... they had all had a go, they know I need to be there, I know I need to be there, but I walk out, because I just couldn't take any more jabbing.

These people either weren't serious about it, or they were the most awful registrar's and practitioners that I have come across. I got rounded up by security in the carpark and asked to come back to emergency, which I did. I negotiated that they get one more go. I got taken up to the ward and settled in up there and (the person who was going to have the final attempt at inserting a cannula) arrived at 11 o'clock. And he looked at my arm, said 'there we go' and got it in straightaway. So I felt very pin-cushioned that morning. And I think they did deliberately, because they'd seen me before.” (Bo)

Multiple participants described painful and humiliating venepuncture experiences and “being jabbed” with clinical staff disregarding their advice on venous access. These experiences centred around hospitals and mainstream settings.

Another form of discrimination injecting drug users described repeatedly was the disclosure of personal information. These disclosures were distressing and led to participants feeling they had no control in the situation.

“I spent three months in that hospital and every morning when they did the rounds, the nurses would go around all the time and they would announce for everyone in the room to hear ‘Oh and Jordan is an IVDU’. Like every morning. So you’d never feel totally in control.”

The impact of the disclosure of personal information was particularly damaging when it occurred in the context of childbirth. These experiences are described in more detail below and in other places in this report.

Finally, many participants described experiences of the “temperature in the room” changing when they or their records disclosed injecting drug use:

“You can see that they’re talking about you to the next person they talk to you because it’s whisper, whisper, then turn and looking at you. It’s horrible! Put it this way, I don’t even like going to the hospital anymore. I’ve got something wrong with my heart at the moment and I had to go to the hospital at the weekend. I just felt wrong the whole time I was there because I’m hard to get blood out of because of using. Everything was going good up until the point where they wanted to get blood. Then they could see my old using marks and it was downhill from there. So I ended up signing myself out.” (Robbie)

“The way they speak about me. Or once they get like, they have my file in their hand that shows my drug history or whatever. Because look, I’ve been taken to the emergency room for an overdose before, you know, yeah, and stuff like that. So it’s in there then they don’t want to give me pain relief, I’ve been escorted to the toilet to make sure I’m not in there to shoot up as if to say I’m only there to score drugs, and when the reality is I’m there because I’m actually having a problem... And sometimes the problem has nothing to do with them needing to give me morphine or anything like that. But they still treat me like that’s why I’m there.” (Angel)

5.3.9 Being on the opioid treatment program

Loss of control for people on the opioid treatment program is particularly acute. People on OAT experience many overt measures of control such as daily dosing and urine drug screens that are imposed regardless of patient circumstances or fact-based risk assessments. This sense of loss of control can have significant impacts on the people receiving this treatment.

One way the public dosing system diminishes the sense of agency of people on the OTP is the way prescribing is done. Often patients do not see their prescribing doctor.

“You’re lucky to see the same doctor twice. So you never actually know what doctor you’re going to see, it’s generally always a student... (One) public holiday, I went in to

the chemist to get my six takeaways. And my pharmacist went, 'Oh, hang on, come back. There's a public holiday next week on the day you usually pick up. So let me just double check your script'. And for the last two or three scripts in a row. Previously, I had been able to get the extra one for the public holiday. Right? Well, whoever had written my script, this time, had not looked at the previous script. They've never seen me before. And throughout COVID, all of the doctor's appointments have been done by nurses at the clinic. That just gives you a phone call and say, 'hello, is everything the same? Yes. Okay, goodbye.'

And whoever wrote the new script had left the public holiday provision off. So even now, like two months down the track, I'm still going in on a different day, because I ended up having to get five takeaways instead of six. Yeah, then I had to go back in on a different day. And then I tried to balance it so that I could go back to the original day. But it didn't work out. So you know what I mean? Like, you're kind of in the situation where you're at the mercy of someone you've never met before. Who hasn't even read the file. It's frustrating to say the least ... If you had more direct contact with the person who was actually writing the script, that would make more sense... You have a discussion. They talk about what the possible medications are, you make a choice, and they write the script. In this situation, you're talking to somebody on the phone, who's not even the doctor, who's asking you a handful of questions. They then go back and tell someone else and that person then writes it down. And then they write the script. And then – you know what I mean? – it's like, a three-person process. You're not talking directly to the person who's in control of your dose.” (Leslie)

Just as many participants described having a consistent relationship with a GP as positive, the lack of continuity of care means that the quality of the care is diminished. Leslie went on to say that the lack of continuity in the clinic means that *“the likelihood of them using anything you say against you is quite high... That’s the difference between my GP who I feel like I can trust and be open and honest with and the clinic where you’re not even seeing the same person each time and so therefore it’s hard for you to know how that person you’re talking to will even interpret what you’ve told them.”*

Often for people on OAT, the power imbalance means staying in a setting where they have felt belittled. Gerry, who felt “broken-hearted” by her treatment by a prescriber describes the reason described the reason for staying with this prescriber as *“a strategic decision... he’s an easy doctor to have. And I weighed up, you know, what I would be losing and what I would be gaining. And I thought, bugger it, it’s easy, easy, easy... I don’t like him with any part of my body but nah, I’ll stay”*

6. Discussion

We're not hard to reach we're hiding.

The conversations we had with the people that participated in this project illustrate the phrase “stigma kills” and go some way to illuminating the mechanisms on the ways it kills people who use drugs. The experiences described by participants in this project were challenging – challenging for the participants to discuss and challenging to hear, organise and write about. For some participants, the question becomes not one of “why is it difficult for people who use drugs to access health care” but “why would you subject yourself to that?”

The UN Single Convention on Psychotropic Substances, 1971¹³ declared recognised “that addiction to narcotic drugs constitutes a serious evil for the individual and is fraught with social and economic danger to mankind” language that is not applied to slavery, apartheid nor torture.¹⁴ People who use drugs are not protected by anti-discrimination legislation and indeed, a common rationale for treating people who use drugs poorly is that “it’s good for them.”¹⁵

While there is a heightened awareness of stigma following years of advocacy by community groups it appears that many clinicians, even specialist clinicians, have only a superficial understanding of what it is and how it is expressed. This assumption is based on the belief that the clinicians described in this report were not intentionally inflicting harm where that was the outcome for their patients.

Discrimination is the action that follows from the stigmatising belief. It is often not overt, but the impacts are profound. Some of the incidents described in the results (hospital cannula policy, being held for extended periods of time when there is a risk of self-harm) are the result of poorly thought-out policy or poorly implemented policies because of resource constraints. Discrimination resulting from structural stigma is still stigma and still felt as keenly, with the same impacts in terms of accessing health care, as interpersonal stigma.

¹³ United Nations (1971) Convention on Psychotropic Substances.
https://www.unodc.org/pdf/convention_1971_en.pdf (Accessed Feb 2022)

¹⁴ Lines, R (2010). Deliver us from evil? The Single Convention on Narcotic Drugs, 50 years on. International Journal on Human Rights and Drug Policy vol 1.

¹⁵ AIVL (2011) Why wouldn't I discriminate against all of them?

Often participants had internalised the stigma they experienced accessing services, saying that they knew that many people did try to hit up services for pain medication but that had not been the case for them. Only one participant described engaging in “doctor shopping” or attending multiple prescribers in specifically to obtain drugs in the past. Most of the participants described genuine and long-lasting pain.

Health system costs

There are clear costs to the health system described by participants in this report. Often these involved injecting related injuries which were dismissed, not treated, or where people avoided seeking treatment because of previous discrimination. Admissions for these injuries can last for months at a time in acute care settings and they can, for the most part, be prevented with early intervention.

The experiences of women giving birth are also concerning. Inadequate health care, which has clearly been the case for some of the mothers participating in this project, can have impacts lasting for the life of the child as well as the mother. Of equal concern are the young participants being denied care or turned away from services, particularly Emergency Departments, in situations that may have long-term consequences for their health.

Inappropriate risk mitigation

Those policies that were/are in place specifically addressing drug use, particularly intravenous drug use, in mainstream settings are clearly inadequate and poorly thought out. There was only one incident of a clear organisational policy pertaining to IV drug use – the description of hospital policy preventing anyone with prior IV drug use leaving the premises with a cannula in place fails to consider the drug of choice or prior evidence of injecting. The policy, which is a blanket ban, is poorly conceived and discriminatory. It is possible that the two participants who described being “left” after being taken to Emergency following suspected suicide attempts may have been the result of hospital policy, it is equally possible that resourcing was an issue.

Power Imbalances

Power imbalances are an inherent feature of health care. Clinical practice is highly specialised and requires extensive training. There is a degree of expert knowledge that cannot be shared. These imbalances are hugely exacerbated in situations where people requiring health care are

highly dependent on services such as pregnancy and childbirth and the OTP. The experiences of our participants often demonstrated power being exercised in a casual manner that could result in serious complications for their patients. For the most part, these power imbalances resulted in feelings of pain and humiliation and resulted in an avoidance of a specific clinician or healthcare in general. At other times the imbalances resulted in what can be interpreted as serious harm to the patient.

The people who participated in this study were acutely aware of judgement and power imbalances in clinical relationships and these negative experiences at times had significant and long-lasting impacts on their lives. Conversely, positive experiences had profound impacts with respectful treatment by health care professionals increasing participant's sense of self-worth.

Trusting clinical relationships

Several participants felt more comfortable with clinicians that they could identify with. This identification helped establish trust for people who had previously had negative experiences with health care. Two of the participants that articulated the benefits of connection were Billie and Rene. Rene discussed feeling more comfortable in "queer friendly services" that had "been there and done that" there was a level of relating, and of peer knowledge around gay men's health, assumed in dealing with these services. Highly specialised services were often mentioned as being preferred. Billie described needing to have a basis for understanding and trust before establishing an open relationship with a clinician "*if I'm going to tell you my deepest, darkest secrets throughout my entire life. And I need to know something about you, too.*"

Complaining

Very few participants complained after negative experiences. For most it "just wasn't worth the fuss". People who had lodged complaints did not feel there was a satisfactory outcome. It is possible that many of the behaviours exhibited by clinicians that participants have recounted here could be dismissed or explained away if investigated. The feelings of hurt are real but, in many instances, based on subjective judgements. The lack of access to care or denial of care is rarely a straight-out refusal but is more frequently a reassuring "don't worry about it". The complaints system in place does not work for our community.

Pain

Unsurprisingly, people who use and are dependent on opioids including illicit opioids frequently have chronic pain issues¹⁶. The transition of people with chronic non-cancer pain including peri-operative pain from prescribed to illicit opioids has been well described in the USA¹⁷ It is currently the case in NSW that people with chronic pain are being referred to opioid treatment programs rather than pain clinics¹⁸ potentially setting them up for later issues in hospital settings. Pain patients also frequently draw a distinction between “real” pain patients and “addicts”. The accelerating drive by the Commonwealth Government to reduce access to opioids through levers like up scheduling codeine products and prescription monitoring must be accompanied by an investment in greater accessibility to pain management, including for people with a history of illicit drug use. The lack of understanding around these complex issues means that many people must suffer needlessly. We need to start looking at this situation as a violation of the basic human right to quality health care.

Priority populations

This project was asked to examine issues for 10 priority populations: people with a disability, LGBTQI+ people, people with experience of the criminal justice system, Aboriginal people, young people, parents, people in rural and remote settings, people whose primary concern is alcohol, Culturally and Linguistically Diverse people, people with mental health concerns and older people. Given the time and budgetary constraints it was not possible to do an in-depth analysis of issues facing each group however some interesting patterns and notable findings emerged as described in previous sections.

¹⁶ Campbell G, Nielsen S, Larance B, Bruno R, Mattick R, Hall W, Lintzeris N, Cohen M, Smith K, Deghardt L (2015). Pharmaceutical Opioid Use and Dependence among People Living with Chronic Pain: Associations Observed within the Pain and Opioids in Treatment (POINT) Cohort. *Pain Medicine* 16(9) 1745-1758.

¹⁷ Vadivelu N, Kai A, Kodumudi V, Stramcik J, Kaye A (2018). The opioid crisis: a comprehensive overview. *Current Pain and Headache Reports* 22(16).

¹⁸ See work around Real Time Prescription Monitoring and current recommendations

7. Recommendations

This report was compiled in a spirit of collaboration with the participants of this project. While we have attempted to draw out common themes, we have, as much as possible, brought out their experiences and descriptions of those experiences with as little filtering as possible. In this spirit we have asked for and received feedback from the participant group which has now been incorporated into this report

There is a substantial body of literature on stigma, and effective interventions have been outlined elsewhere. The Zest report commissioned by the Ministry presents a set of recommendations tailored to particular “types” of clinicians. The recommendations in this report are in line with previous research¹⁹. There are several interventions that have been demonstrated to work to change attitudes.

However, the problem is substantial and persistent. Clearly, stigma is a system-wide issue and addressing it will need to tackle systemic change. Health services also operate within broader society and the people working within them reflect commonly held and acceptable views. One of the recommendations of the Special Inquiry into the Drug “Ice” has recommended a broad public campaign but it is arguable whether such a campaign should be a government-led initiative. First both NSW and Commonwealth governments have regularly produced stigmatising marketing campaigns. The second issue with such a campaign being led by government is that it would necessarily be time limited. Challenging these deeply held and ingrained views is long-term work. It is a commonly held belief that the criminalisation of drug use is responsible for the degree of stigma we are subjected to, but it is difficult to believe that the legal framework will change without first broadly changing hearts and minds.

It should be possible to challenge stigma within the public health system without a broad community campaign. It is clear from the experiences described in this report that there are substantial and long-term costs to the health system from poor quality care that are based on

¹⁹ See for example Cheetham A, Picco L, Barnett A, Lubman DI, Nielsen S. (2022). The Impact of Stigma on People with Opioid Use Disorder, Opioid Treatment, and Policy. *Subst Abuse Rehabil* 13(1): 1-12

stigmatising beliefs and expressed as discrimination. Quantifying these costs would support meaningful action on this issue. For example, the costs of preventable injecting-related injuries and whether these can be effectively prevented through GP education or more accessible harm reduction could galvanise action. Two- and three-month ICU admissions are costly to the system and preventable.

The experiences of the parents in our participant group are also striking. They were repeatedly told “she’ll be right” and to not worry about their pressing medical concerns leading to serious complications that had a potentially long-term impact on their children. Not only were mothers and fathers turned away, the children of people who use drugs were turned away. It should be common practice in examining serious adverse events that occur in hospitals whether stigma – not necessarily limited to but certainly including stigma against people who use drugs – played a role.

Assuming that there is an appetite to tackle stigma and findings available from the Zest report and previous literature on possible interventions with different groups of clinicians, any future intervention should focus on settings where an issue has been identified either through this report or further community intelligence gathering. Two possible settings would be RPAH and Lithgow Hospital. The intervention should be wholistic, not be limited to clinical staff, and examine structural stigma such as policies and facilities.

Finally, the issues described in this report will not shift until the affected community is able to advocate for themselves. The power imbalances experienced by this patient group are significant. The importance of community building, and community empowerment, must be recognised. The voice of lived experience is not well represented in AOD services in NSW at least in part because the work of capacity building is not at present valued or funded. The work of developing the capacity of clinicians to provide high quality of care is important and must be done but even more important is the work of supporting the affected community to demand the basic human right of health care equal with any other member of the community.

Appendix 1: Interview process and question

Overview, confidentiality, and ethics

Interviewer: Seeking consent

We would like to record the audio of the interview to help us gather accurate data.

This will not be accessible to anyone that is not part of the project team and the file will not be made available to the NSW Ministry of Health.

Are you OK to proceed?

If Yes, start recording audio.

If No, record notes by hand.

Interviewer: Once you have hit the record button open with this line:

“Thanks for giving consent to record the audio of this interview. I will now go over the overview of the project.

NUAA is conducting research about the experience of consumers of alcohol and a range of other drugs who present with health issues associated in NSW.

The purpose of the research is to help us understand consumer experiences of services in the NSW Health system and provide insights into what changes to health care delivery might improve experiences for people with lived experience of AOD use. The research is being conducted on behalf of the NSW Ministry for Health’s Centre for Alcohol and Other Drugs’ (CAOD).

NUAA is reaching out to a broad range of people to take part in a 60 minute, one-on-one interview as part of this work.

The information collected from the interviews will be used to construct a report for the NSW Ministry of Health. Your name will not appear within this report, including next to any of the answers that you may provide. Your answers will be compiled along with those from 30-40 individuals.

Participants will receive a \$60 reimbursement either as:

- a cash deposit into their account (processed out of NUAA’s bank account on the next Tuesday after their interview, and should be received within 48 hours from the Tuesday)
- an electronic gift card which can be processed within the hour.

During the interview, you will be asked some questions about your experiences interacting with health professionals (doctor, nurse, specialist, physio etc) in public and private settings such as surgeries, hospitals, or specialist clinics.

Discussing these experiences may be upsetting for some people and you can withdraw at any time. If you withdraw you will still receive the full reimbursement for your time and your

relationship with NUAA will not be affected in any way. Your decision to withdraw, like the content of your interview, will remain anonymous.

If after the interview you would like to speak to someone, NUAA can arrange for support.

Interviewer: Do you have any questions?

Interviewer: Are you OK to commence the interview?

Questions:

- Can you tell me a bit about yourself? What is your background?
- Can you tell me about a time where you went to a doctor and had a great experience?
- Can you tell me about a time where you went to a doctor and had a not-so-great experience?
- What about hospitals? Have you been to the hospital and if so, what was that like?
- If you think about how your (primary Health Care Professional) speaks to you what makes feel like you're been listened to/respected? Do you ever feel like they aren't listening or aren't respecting you?
- What makes you feel like a doctor or nurse is listening to you and cares about you?
- What makes you feel in control of your treatment?
- What makes you feel uncertain/out of control?
- If you don't agree with something your doctor is saying or doing, what is your response?
- Do you speak up? If not, why not?
- Have you been in a situation where you felt like you should complain? Did you complain? If not why not? If you did, what happened?
- If yes, what is the result?
- **Is there anything that you would like to share that you have not had the opportunity to speak about?**

**Interviewer: Are you happy with what we have done here?
Are you comfortable with this interview and the recording?**