

# LIVES of **substance**



## **Experiences of alcohol and other drug addiction, dependence or habit in Australia:**

Findings and recommendations  
from a national qualitative study

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# Executive summary

This report presents findings and recommendations from a national qualitative research project on experiences of alcohol and other drug addiction, dependence or habit in Australia, undertaken between 2014 and 2016. Drawing on in-depth qualitative interviews, the study was designed to collect and analyse the personal accounts of people who describe themselves as having an alcohol and other drug addiction, dependence or habit.

It aimed to generate much-needed new insights into the range of experiences that make up life for people with drug use experiences of this kind. Interviews were conducted with 60 people from diverse backgrounds living in cities and regional areas of Victoria and New South Wales, Australia. Interview questions addressed participants' experiences of living with addiction, including how consumption fits into daily life, coping with stigma and discrimination, experiences of treatment, and views on the idea of recovery. **The report details the study's findings on these key themes and, where appropriate, recommendations for improving policy and service provision.**

A major output of the project is a new website, [livesofsubstance.org](http://livesofsubstance.org), which presents the personal accounts collected using video re-enactments, original audio recordings and written extracts from the interviews. Planned and designed with the help of a large national advisory panel, the website was launched publicly in October 2016 and evaluated via an online survey of website visitors. This report also outlines the findings of the evaluation, which indicate that the site is reaching its target audiences; the personal stories are considered helpful and informative; and visitors overwhelmingly indicate they will recommend the site to others.

## The main findings and recommendations of this research are that:

- ▶ A highly diverse range of people see themselves as affected by addiction issues and their individual circumstances and experiences of consumption are equally varied. **An awareness of diversity among affected individuals must be integrated into policy development and service delivery.** Policies and treatment practices need to be responsive to individual needs and sufficiently flexible to enable tailored care.
- ▶ Issues with alcohol and other drugs are not the only challenges people face. Indeed, as previous research (Fraser et al.; 2007; Galea, Nandi & Vlahov, 2004; Rhodes et al., 2003) has documented, alcohol and other drug-related issues may be as much an outcome of other problems as a source of them. **Greater coordination between alcohol and other drug services and other agencies is needed so that collaborative approaches to the care of clients can be enhanced.**
- ▶ Addiction is commonly viewed as a disastrous state, associated with decline, misery and loss of control. Our participants' accounts challenge this view: they show that many people who see themselves as affected by addiction cope and lead rich, full lives. Moreover, their experiences can be understood in ways other than the usual reductive narratives. These findings point to **a pressing need to see people who live under the sign of 'addiction' as whole people, rather than as a series of problems. Strengths-based approaches focusing on whole people with skills and assets may be appropriate for many.**
- ▶ People who identify as experiencing addiction often report carefully regulating their consumption, actively managing the risks of heavy use and looking after their health. For many, regular alcohol or other drug consumption is experienced as able to enhance health as well as diminish it. These findings support the need identified in past research (e.g. Duff, 2015; Race, 2008) for **more nuanced, effective responses that do not treat consumption as necessarily harmful to health.** Policy and practice should provide more resources that support people who regularly consume alcohol and other drugs to maintain their health and well-being.
- ▶ A key concern for many is coping with the **stigma associated with addiction and drug use.** Many participants described encountering stigma in the

health system, with several commenting that they feel healthcare professionals ‘look down on’ them or judge them more harshly than other patients. These findings are consistent with past research documenting the persistence of stigma in the health system (e.g. Anstice et al., 2009; Henderson et al., 2008; Van Boekel et al., 2013). To address stigma in the health sector,

**stigma and discrimination training should be a core part of workforce training for healthcare professionals.**

- ▶ Also connected to addiction-related stigma were concerns about deciding whether to tell family and friends, as well as employers or colleagues, about alcohol or other drug consumption. Our findings point to a **need to educate the public about the stigma associated with illicit drug use and addiction**. Education efforts should emphasise the fact that people affected by addiction are not a homogeneous group. They are individuals with diverse experiences, who share recognisable concerns and challenges, and who do best when contact with family and friends is not lost. Given the issues related to disclosure, education should also cover the importance of preserving confidentiality and recognising the individual right to decide when and to whom they disclose.
- ▶ The **role of the media in creating and reinforcing stigma and discrimination** was also cited as a significant issue. Many noted that media coverage can be sensationalist, exaggerating the harms of drugs and relying on misinformation and negative stereotypes. As identified in past research (Blood & McCallum, 2005; Hughes et al., 2010), there is a **need for media training on how to report sensitively and in an informed way on drug use and addiction issues. We recommend that a set of guidelines governing media coverage of drug use and addiction be developed**. As with the Australian guidelines for *Reporting on suicide and mental illness* (Hunter Mental Health Institute, 2014) which were developed in collaboration with peak media bodies, mental health organisations and consumer networks, these guidelines should be informed by best practice and made publicly available.
- ▶ Criminalisation was seen as a key driver of the stigma surrounding drug consumption, and many policing measures intended to reduce consumption were considered ineffective or unnecessarily invasive (for example, sniffer dogs, random drug testing for drivers). Measures that treat stigma as an individual issue to be tackled solely through education and interaction with stigmatised individuals ignore broader social structural and institutional influences. There is therefore a **need to address the relationship between stigma and legal arrangements by heeding increasing calls for decriminalisation of drug use** (see e.g. Douglas & McDonald, 2012; Hughes et al., 2016; Macintosh, 2006; Ritter, 2012; Wodak, 2012).
- ▶ Language and terminology emerged as important issues for some participants concerned about stigma. The terms ‘dependence’, ‘addiction’ and ‘recovery,’ were considered stigmatising for some. These participants pointed to a **need for alternative ways of framing regular, heavy alcohol and other drug use without pathologising it as ‘addiction’**.
- ▶ Most of our participants were working or studying and stressed the need to strike a balance between their commitments and their alcohol or other drug consumption. Some cited the value of formal treatment programs, especially opioid pharmacotherapy treatment (OPT), in helping them to fit their consumption around their other commitments. However, others observed that the common expectation that dosing be delivered daily under supervised conditions disrupts work commitments. As identified in past research (Fraser et al., 2007, Treloar, Fraser & valentine, 2007), **there is a continuing need for more flexible OPT**. Another issue related to OPT participants identified is cost, with dispensing fees presenting a significant financial burden for some. This finding concurs with previous research (Fraser et al., 2007; Lea, Sheridan & Winstock, 2008; Lord et al., 2014; Shepherd, Parella & Hattingh, 2014) and suggests a **need to reduce or waive OPT dispensing fees, particularly for clients on fixed incomes or welfare support**.

- ▶ People who see themselves as affected by addiction initiate and maintain change using a variety of formal and informal strategies. Some of these changes occur without any particular plan or effort, and others are part of broader changes to lifestyle and individual circumstances. Moving to a new location can prompt change by shaping access to treatment services, social networks and other informal resources that support people to create and maintain new consumption patterns. Transitions into and out of residential treatment and custody are particularly important in this regard, emphasising the need observed in past research (e.g. Binswanger et al., 2012; Griswold et al., 2008; Taylor, Thompson & Davis, 2010) to ensure effective post-treatment and post-release care. In order to ensure genuinely responsive care for those in need of it, **policy and service provision must recognise and support the range of ways in which people change their patterns of consumption, without assuming that the reduction or cessation of use are the most legitimate means of change. Access to services, resources and care for those in need of it should be maintained when individuals relocate and/or their living arrangements change.**
- ▶ Connected to experiences of change through relocation, some of those with experience of residential treatment reported a lack of follow-up care, while others observed that the institutional environments of residential centres can make it difficult to resume everyday responsibilities upon returning home. These comments underscore **the need identified in past research** (Berends *et al.*, 2004; Griswold, et al., 2008; NSW Health, 2007; Taylor, Thompson & Davis, 2010) **to improve continuity of care, including aftercare and support for those undergoing treatment in residential settings.**
- ▶ Many participants identified unmet demand for treatment in Victoria and New South Wales, and reported **difficulty accessing treatment** and long waiting times. These issues have been identified in the past by researchers (Diguisto & Treloar, 2007; Fraser et al., 2007, Ritter *et al.*, 2014) and point to an **ongoing need for increased funding for treatment in both states.**

## A note on terminology

Ideas about addiction vary across time and place, and experts and others disagree on what addiction is and what causes it. In medical and public health circles in Australia and some other countries, the term **'dependence'** is preferred as it is considered to be less stigmatising than 'addiction'. In everyday conversation terms such as **'habit'**, **'drug problem'** or **'compulsion'** are also used. Our participant accounts reflect this range of ideas and terms. Some of those interviewed use the word 'addiction', while others prefer the term 'dependence'. A number of people opt for the word 'habit'. Several resist all these terms and describe their consumption in other ways, for example as part of their lifestyle, or as a regular activity that they organise around other activities and commitments. **This report does not rely upon one definition or term over another;** instead an effort has been made to use the terms chosen by our participants, or, where general statements are made, all three terms are sometimes used. More often the term 'addiction' is used, mainly due to its recognisability. Overall, the aim is to ensure the content is as clear and understandable as possible, to avoid reproducing unhelpful ideas, but also to speak in language most meaningful and relevant to our participants and to the target audiences of this report: researchers, service providers, user group members, health professionals and policymakers. The aim is also to **encourage reflection on the meaning of 'addiction'** as readers encounter experiences rarely associated with the term.

# Background and aims

Despite decades of research, policymaking and service provision, much remains unknown about lived experiences of alcohol and other drug addiction or dependence in Australia. For example, little systematically developed knowledge exists on the range of people currently affected by addiction issues, how they cope and manage drug use in their lives, how they initiate change where necessary and what ideas of well-being or recovery mean to them. A small body of research can be identified that does address these issues. Much of this work is based in concepts and methods from psychology, with some exploring how experiences of addiction impact on individual sense of self, with various implications for treatment (e.g. Larkin & Griffiths, 2002; Shinebourne & Smith, 2009). Other work draws on concepts from behavioural psychology to theorise addiction as a behavioural pattern produced through conditioning and social learning (e.g. Newton *et al.*, 2009; Wise & Koob, 2014). While these studies describe individual experiences of addiction, they tend to treat it as either a dysfunctional response to unconscious emotional needs or an irrational, compulsive behavioural pattern (Karasaki *et al.*, 2013). Beyond these tendencies to construct addiction in pathologising terms, these approaches are unable to tell us much about how addiction takes shape through everyday experiences and practices.

Critical social science on alcohol and other drugs goes some way toward addressing this issue by offering detailed analyses of alcohol and other drug consumption in specific geographic and cultural contexts. Employing sociological and anthropological methods, such research is often based on years of ethnographic fieldwork and offers richly textured accounts of the meanings, social settings and practices of consumption (e.g. Bourgois & Schonberg, 2009; Garcia, 2010). However, only a small portion of this social science literature treats addiction as an object of inquiry, much of it preferring to avoid this fraught concept as an explanation for behaviour (Weinberg, 2011). Those studies that do explicitly use addiction as an interpretive concept emphasise the role of social and cultural forces in shaping it (e.g. Boshears, Boeri & Harbry, 2011; Singer, 2006;

Weinberg, 2005). However, despite its important insights into addiction as a socially and historically contingent concept, social research of this kind tends to focus on particular drug cultures or communities and is therefore unable to offer an analysis of experiences and understandings of addiction in their diversity. Further, some studies reiterate unhelpful assumptions about addiction by depicting it as a compulsive attachment to drugs, characterised by irrational 'drug-seeking' behaviours and loss of control. By extension, as critical social research has shown, those seen as affected by addiction are presented in these accounts as chaotic, disordered and incapable of exercising agency (Fraser & Moore, 2008; Seddon, 2007). Depictions such as these serve to reinforce the damaging stereotypes that circulate freely in the media and public discourse, contributing to stigma and discrimination.

Critical scholarship on drug use and addiction challenges these stereotypes by demonstrating how the equation of addiction with compulsion and loss of control is socially and culturally constituted, rather than natural or inevitable (e.g. Berridge, 2013; Room, 2003; Weinberg, 2002). Building on this socio-cultural research, other scholars have tracked how addiction functions as a powerful mechanism of social control to classify and discipline subjects (Fraser, 2006; Fraser & valentine, 2008; Netherland, 2011; Smith, 2010). Still others have analysed addiction as the product of particular policy and treatment structures, charting how it emerges through our interventions, rather than as a precursor to them (e.g. Carr, 2011; Keane, 2013; Moore & Fraser, 2013). A recent study that extends this critical tradition is the work of Fraser, Moore and Keane in their 2014 book *Habits: Remaking Addiction*. With reference to a diverse range of empirical data, Fraser *et al.* (2014) challenge conventional understandings of addiction, which treat it as an established medical fact. Instead they theorise addiction as an unstable phenomenon made in practice, including through our efforts to define, understand and address it. Importantly, for our purposes, they argue that the process of 'making addiction and the addicted' (p. 236) is an active, ongoing one that should become

the object of scholarly investigation. This body of critical literature offers valuable insights into the social production of addiction but it leaves open the question of **how addiction takes shape through personal experiences of regular drug use and the meanings people attach to these.**

## Aims

Responding to these gaps in research and publicly accessible information, this project aimed to **generate much-needed new insights into the lived experiences of people who see themselves as affected by addiction, with a view to promoting more effective community responses.** Drawing on in-depth qualitative interviews, it aimed to produce new knowledge on how people:

- 1 Experience and give meaning to addiction;
- 2 Cope with the stigma associated with drug use and addiction;
- 3 Manage regular consumption and create change where necessary; and
- 4 Make decisions about and experience treatment.

This newly generated knowledge was used to develop an innovative online resource – [livesofsubstance.org](http://livesofsubstance.org) – that presents these personal experiences in people's own words using anonymised video re-enactments, original audio recordings and written extracts from the interviews. [Livesofsubstance.org](http://Livesofsubstance.org) aims to support people who consider themselves to have an alcohol or other drug addiction, dependence or habit, and inform members of the public, health workers and policymakers by sharing personal stories of these experiences.

## Method

The research project on which this report draws used a research methodology developed by Oxford University's Health Experiences Research Group (HERG, 2014). Following this methodology, purposive recruitment and in-depth qualitative interviewing were used to collect personal accounts from 60 people who responded to a recruitment flyer that opened with the question: 'Do you consider yourself to have a drug habit, dependence or addiction?' The flyer was circulated through alcohol and other drug treatment services, drug user organisations, community noticeboards and on social media. Those who responded were screened to ensure we recruited participants with a current or past pattern of alcohol and other drug consumption that would qualify them for a diagnosis of 'substance use disorder' or 'dependence syndrome', the terms for 'addiction' in two influential diagnostic models, namely the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) (American Psychiatric Association, 2013) and the International Classification of Diseases (ICD-10) (World Health Organization, 1992). They were also screened to ensure variation in gender, age, drug type(s) and treatment experiences. The 60 eligible participants comprised 35 men and 25 women, aged between 19 and 59. All described ongoing (n=47) or past regular (n=13) use of a range of licit and illicit drugs including alcohol, cannabis, methamphetamine, heroin, prescription and over-the-counter drugs, and 'party drugs' (e.g. MDMA, GHB). More information on the participants is presented in Appendix 1.

The study was approved by Curtin University's Human Research Ethics Committee (Approval number HR 55/2014). All participants provided informed written consent. Following an open-ended invitation to 'tell us their story', they were asked about their experiences of living with an alcohol or other drug habit, dependence or addiction, including how consumption fits into daily life, managing health and well-being, experiences of treatment and future plans. The opening invitation and relatively unstructured interview guide reflected our intention to approach participants as whole, complex people with rich lives. Interviews took place in urban and regional Victoria and New South Wales, Australia, and were audio-recorded and transcribed verbatim. To protect participant identities, each was given a

pseudonym and all identifying details were removed from the transcripts.

The interviews were analysed using an iterative inductive approach in which a preliminary list of codes was drawn up based on themes emerging from the data, as well as knowledge of key debates and past research. This list was refined in consultation with the research team. The project advisory panel, comprising representatives from policy, service provision and consumer advocacy groups (see full list in the acknowledgments), also advised on the theme list and on other aspects of the research, including participant recruitment, data collection and analysis, dissemination of findings and quality assurance of the material presented on the website. Once the list of thematic codes was finalised, the data were coded with the aid of the NVivo qualitative data management software. In order to elucidate key aspects of the findings, quotations from participants are included in the sections that follow. Accompanying each quotation is basic information about the participant quoted. Presented in brackets after their pseudonym, this information includes their **gender, age, employment status and main preferred drug**, e.g. 'Louise (**F, 19, studying, cannabis**)'. In this format, only the person's preferred drug is reported, but in many cases our participants consumed more than one drug at a time or across time.



# Findings and recommendations

In the sections that follow we discuss the study's **key findings and recommendations** (including recommendations derived from the unique analyses in the articles presented in Appendix A). Our observations are organised under the following headings, which reflect the focus of the interviews on the everyday lives of our participants:

- 1 Relationships, confidentiality and telling others
- 2 Work, study and managing money
- 3 Dealing with stigma and discrimination
- 4 Creating change: treatment, self-help and other responses
- 5 What is 'recovery' and how important is it?
- 6 Messages for health professionals and policymakers
- 7 Narrating lived experiences and challenging addiction stereotypes

All of the material is presented more extensively on the [Lives of Substance](#) website. We encourage readers looking for more detail on any of the topics presented here to visit the [website](#).

# 1. Relationships, confidentiality and telling others

The main focus of the interviews was to explore everyday life for people who identify as having a drug habit, dependence or addiction. Participants were asked how their alcohol or other drug consumption fits in with other activities, such as going to work, studying or spending time with friends and family. This section presents participants' accounts of how **consuming their preferred drug(s) affects their relationships** and **whether they are open about it or keep it confidential**.

## Telling family, friends and intimate partners

A key concern for many of those interviewed was deciding whether to tell others about their consumption. Some recounted how telling loved ones that they were experiencing issues related to their consumption helped them to cut down, stop or otherwise vary their consumption patterns. Others indicated that their family and friends had expressed concern about their consumption and suggested they seek treatment, cut down or stop altogether. Concern expressed by loved ones, in some cases, introduced or confirmed the idea that they had an issue, as the following account from Anika (F, 19, studying, cannabis) illustrates:

*[Once my dad found out I was smoking weed] I think [he and my mum] just had to sit me down and go, 'Do you do this?' [...] and I fully just had to say, 'Yeah, yeah, yeah, I'm pretty addicted'. And he actually asked me, 'Do you need to see a counsellor or do you need to get help?' And that was actually quite nice for my parents to, like, support me and ask if I needed help.*

By contrast, some indicated that because they do not see their consumption as an issue, they do not need to raise it with others. As Angelo (M, 35, works in the construction industry, alcohol) put it:

*I guess [I didn't discuss my drinking] because I always kind of felt I had it under control, and I didn't want to kind of identify myself with having an issue.*

**Being open about their consumption with partners, family and friends** was important to many of our participants, some of whom described how telling others helped to strengthen their relationships, build trust and establish a support network. For example, Scarlett (F, 29, works in finance, ice) explained how being open with her partner about her crystal methamphetamine (ice) consumption improved their relationship:

*Being honest with your partner [about your drug use] works the best. I found our relationship improved a lot because I wouldn't hide things from him. When I first [...] injected drugs, I didn't tell him. He found out that same day because he knows me too well. He picked it up straight away [...] I wasn't in a good state [...] so he asked me, 'Have you shot up this weekend?' And I straight away just said, 'Yes' [...] He's someone who I know I can trust.*

However, others reported **encountering negative attitudes** and, in some cases, these experiences prompted them to avoid consuming in the presence of certain family and friends, or talking about it. Pauline (F, 51, works in administration, cannabis) offered an example of this in relation to her previous partner whom she described as 'very judgmental' about her cannabis consumption:

*I came out of a relationship [a few years ago...] with another woman who was very judgmental about my pot [use]. I guess I played it down a bit at first, but it was a real problem in the relationship [...] Somehow in that time I was with her, I was aware that [...] my pot use changed. So if I was at home before her from work, which was quite common [...] I'd have one [joint and then] I would start thinking things like, 'Do I quickly have time to rush and have that second one before she gets home?' You know, like, hiding it.*

While many of those interviewed were open about their consumption with family and friends, some were not and gave a range of **reasons for choosing to**

**keep it confidential.** These included not wanting to cause worry or anxiety, feeling embarrassed or ashamed, and being concerned that they will be judged or stigmatised. For example, Lucy (F, 34, works in retail, cannabis) avoids telling some of her friends about her cannabis consumption because she thinks they will judge her:

*I kind of have two sets of friends: ones who have been there and done all that, and they are way past [drug use] and the others who still like to have a smoke. I tend to hang out with them more to be honest because I know they're still on my level. And they're not judging me for it [...] But then there's the other friends who are the more judgmental types, who I would try and keep [my marijuana use] from [...] I'm not going to go to great lengths to hide it. But if I tell them, I know that they're, like, judging me for it.*

Concern about being a 'bad role model' meant some avoided telling their children:

*No [my children] haven't brought it up and I don't want to bring it up really. Just try to make sure that they don't see [me smoking] or know about it [...] When they come over, nothing's around [...]because] I don't want to be a bad role model. I would hate for them to start smoking, thinking, 'It's okay because Dad did it'. Because in the long run, it's not a good thing to do. (Matthew, M, 49, not working due to illness, cannabis)*

## Consumption in relationships

Participants were asked to comment on how consuming alcohol or another drug affects their relationships and social lives. Many expressed the view that **consumption is an important part of their social lives** that can increase the enjoyment of social and leisure activities. Some added that consuming their preferred drug(s) with others creates a valuable sense of belonging and fellowship:

*My closest friends [and I...] have shared interests in all sorts of ways, one of them being, you know, that kind of communion [of*

*taking speed together]. You know, you can call it 'community' in some ways [...] With a lot of people I know that do it, I've known for years, decades. You know, they are still my friends, my closest friends, who I've probably known for 30 years, and we've done it on and off together and I'm still in touch with them. So I value that [social...] side of it [...] Taking speed] is a very social activity. (Brad, M, 50, unemployed, speed)*

A few of those who consume ice, GHB, MDMA or cannabis with partners said it fosters intimacy and sexual connections. While many participants described the value of consumption in their social lives, some noted that **consuming with others can lead to heavy use**, which was concerning for some, prompting them to change social circles in an effort to cut down, stop or otherwise vary their consumption.

In some cases, consumption was cited as a **means of coping with relationship difficulties, social isolation, or the death of a loved one**. A few of those who consume alcohol, cannabis, heroin, ice, speed, or over-the-counter or prescription drugs described the role of consumption in these terms. For example, George (M, 58, not working due to illness, alcohol), a widower who lives on his own, described drinking as a means of coping with social isolation:

*[The alcohol habit] is a daily ritual, mostly created by my isolation. And so [...] when six o'clock comes, I just get this feeling, like I've got to go to the bottle shop [...] I'll spend the whole day saying, 'I'm not going to drink tonight', but come six o'clock and the sun is going down, I think, 'What am I going to do tonight? I don't watch TV. There is only so much radio you can listen to, so many drawings you can do. What am I going to do?' And the next minute, I'm getting together seven bucks to buy a cheap bottle [of wine].*

## Parenting and children

Concern was expressed by some participants about the **possible effects of their consumption on their children**. This prompted several to seek treatment, cut down or stop altogether. As Melanie (F, 29, unemployed, ice) put it:

*[I'm seeking treatment because] I want to put that part of my life behind me [...] My kids deserve a better mum. They deserve a healthy mum and dad. They deserve a better life.*

In other cases, **experiences of parenting** were described as shaping patterns of consumption. For example, some reported that their consumption increased when they were coping with the pressures of parenting. As Dawn (F, 38, works in manufacturing, alcohol) explained:

*I guess I really did start to drink more after I became a mum. I had more stress then once I did become a mum and I did use [drinking] to relieve anxiety.*

Several people interviewed had lost custody of their children due to their contact with the criminal justice system for offences considered alcohol or other drug-related. They all said they found the experience traumatic and took steps to regain custody of their children, often by seeking drug treatment. Kate's (F, 36, works in the health sector, prescription drugs and ice) account is illustrative:

*[I was arrested for a driving offence] and then, yeah, a week after withdrawing [from heroin] and actually nearly receiving a sentence in jail I received the notification from [the court] or*

*something that my son had been removed. And [then later Community Services] came in and said, 'He doesn't speak.' Well, yeah, you've just taken him away from everything he knows and he's only just starting to use his words. Of course he's not speaking. He's shut down. You are traumatising him [...] So I sort of had a bit of a think about [it] and got in touch with the rehab [...] and went on a waiting list to go on a program that I could take my son into as well [as a step towards regaining custody].*

These accounts demonstrate the range of ways in which **consuming alcohol or another drug can affect relationships** with family, friends and partners. In some cases, it was seen as contributing to these relationships and in others as disrupting them, or as a source of concern. Common across these varied accounts was the recognition of the **role of addiction-related stigma in shaping decisions to disclose consumption to loved ones**. This points to the impact of stigma on the everyday lives and relationships of people who see themselves as affected by addiction, and suggests an **urgent need to educate health and other providers, and the public about the effects of addiction-related stigma and discrimination**. Education efforts should address the fact that people affected by addiction are not a homogeneous group. They are individuals with diverse experiences, who share recognisable concerns and challenges, and who do best when contact with family and friends is not lost. Given the concerns about disclosure that some participants identified, education should also cover the **importance of preserving confidentiality and recognising the individual right to decide when and to whom they disclose**.

## 2. Work, study and managing money

Most of the people interviewed for this study were in paid employment or had been in the past. Many had also undertaken post-secondary or tertiary study. They described how they **combine alcohol or other drug consumption with their work and study commitments**. They also discussed how they **manage their money** to afford their preferred drug(s) while supporting themselves and their families.

### Consumption and work

Most of our participants reported not consuming alcohol or other drugs at work, but some explained that **drug consumption helps them to perform in their jobs**. For example, Renee (F, 35, works in hospitality, ice) began taking ice every day as an 'enhancement' to help her complete her work tasks while on a seven-day roster.

*For the last three years, I was on ice every day, working up in [another city]. I was [working in hospitality and tourism] there, but it was too easy a life up there and I was getting too caught up in the game there. Like, even the bosses would be leaving [drugs] in my pocket, you know, like just [to] make sure I was able to do the job every day. So I came back to [this city] and I was working [in tourism] here [...] and it was a seven-day roster and, again, I got caught up [...] smoking it every day, using it every day, like, as an enhancement.*

Others described how taking their preferred drug(s) helped them to manage their work commitments when they were experiencing depression or other personal struggles:

*[I] only smoked [cannabis] casually all my life [...] just at night. I'd [...] work all day [...] I worked hard, I was in high pressure jobs and it was just a way, when I got home, to sort of unwind and switch off [...] That was most, sort of nights and then it sort of got worse [...] when I had trouble at work, yeah. I sort of fell into a bit of depression and I was using that to sort of numb the pain I think. [It] takes your*

*mind off it, changes your mood [...] I used to, like, smoke on my lunch break and smoke in between jobs. (Matthew, M, 49, not working due to illness, cannabis)*

The **consumption of alcohol and some illicit drugs was described by some as a tacitly accepted part of their industry or workplace culture**. This was seen as encouraging consumption as it created opportunities or incentives to drink or take other drugs at work. In some cases these expectations led to the development of consumption patterns participants considered problematic. Scott (M, 25, working in hospitality and studying, alcohol) offered an example in relation to his experience of working at a nightclub:

*I got a job working at a nightclub in the city and I'd just end up drinking, you know, every day of the week [...] You weren't told to drink but they didn't care at all [...] Then after work, you finish at like 5am and [...] I'm still wide awake, so you just keep drinking [...] There was so many opportunities [to drink].*

### Confidentiality, disclosure and the workplace

While some of our participants reported that consumption of illicit drugs is commonplace in their workplace, others described it as **stigmatised** so they prefer not to tell co-workers of their use for fear of losing their job or being discriminated against. For example, David (M, 25, unemployed, heroin) indicated that when he was on methadone maintenance treatment, he did not tell his employer because he was concerned about being judged or even fired for his history of illicit drug use:

*I never talked to my boss about going to the chemist... I just didn't want him looking at me as a druggie [...] I always had to [get my methadone dose] before work or after work. And with getting there on time and just a lot of hassle just to make it to the chemist, I thought to myself, it's not worth it [trying to get my*

dose during work hours... I thought if I told my boss he would] just look at me different and I know I'm better than that [...I was] scared to get sacked or discriminated against.

Consumption was described by some as something they do in their own time that does not interfere with their work so not their employer's business. As Kate (F, 36, works in the health sector, prescription drugs and ice) put it:

*I do kind of have a dependence [on benzodiazepines] now for sleeping and relaxation after work [...I don't want [my colleagues] to know [...I think it's also about keeping my personal and my work life separate, because I can see it as a personal thing and not necessarily something that everybody needs to know about.*

For reasons such as this, concern was expressed about the introduction of **mandatory drug testing** in some workplaces:

*I think all those jobs that mandatory drug test [...] it's all about bloody insurance [...] It's not about someone's capability or whether something is genuinely a risk or not [...] There are a few jobs that I wanted to go for and I couldn't because I found out they mandatory drug test. (Zadie, F, 33, works in the health sector, heroin)*

## Managing consumption and work commitments

**Prioritising work commitments** when planning consumption was cited as a key issue. For some, this means limiting it to after work. For others, it means avoiding consumption during the week and confining it to the weekends. Ted (M, 26, works in the arts, party drugs and cannabis), for example, limits 'partying' to Friday nights to allow time to 'recover' before work:

*In my mind, it's always better if I can party on a Friday night rather than a Saturday because [...] if I'm still partying on Sunday then I have*

*to recover on Monday [...I don't think I'll ever be the type of person who's taking drugs on a Tuesday night, unless it's a concert that I know I'm going to and I've taken the morning off or something but [...I don't think I'll ever be the type of person to be taking drugs all the time. My professional life and even just my personal well-being takes precedence over that.*

Connected to the issue of balancing work commitments and consumption, some participants reported that **access to flexible working arrangements** allowed them to manage their consumption without it impacting on their work. Sean (M, 48, works in education, over-the-counter painkillers), for example, commented:

*I think that [taking Nurofen Plus] enabled me to function in all sorts of ways that would have only benefitted my work [...It kind of contradicts that dominant story we have, particularly around, kind of, daily or dependent [drug] use, that [...] it] will inevitably, kind of, lead to some sort of shameful [...] exposure at work or calamity. That just was never the case for me [...] I was incredibly lucky to be in a workplace where I was part time, that was flexible, [...] where I was trusted, and for good reason, you know. I certainly never saw the drug use being in any way a violation of that trust but it just meant that I could just sort of choose my hours and as long as I produced the work, it didn't really matter.*

The **importance of formal treatment programs, especially opioid pharmacotherapy treatment, in managing consumption and work commitments** was also mentioned by some. They indicated that by reducing the desire for the drug and physical symptoms of 'withdrawal', opioid pharmacotherapy treatment allows them to continue working while cutting down or stopping altogether. As Zadie (F, 33, works in the health sector, heroin) put it:

*I just didn't have the luxury to stop work [to detox]. I had to keep working. So the only way to do that [while] taking the heroin away was with some pharmacotherapy.*

However, it was also noted that **pharmacotherapy dosing regimes are difficult to fit in with work schedules**. For example, Helen (F, 53, not working due to injury, heroin), commented:

*It has been an issue for me where employers haven't been very flexible to allow me to get to the clinic on time or, you know, allow me to come in half an hour late because I have to go to the clinic first.*

## Study

Of those interviewed who were studying, several said that **consuming their preferred drug(s) helps them with their studies**. Some, for example, reported that consuming cannabis makes them feel more creative, motivated or better able to concentrate:

*[Smoking cannabis] affects my creativity. It means my brain can process things in different ways. It has a good effect on my proprioception and musical interpretations and stuff, yeah. [...] So it means I can come at [my] projects from a different angle, [with] different sensitivities to music and movement particularly [...] So if I'm playing music, like playing an instrument and singing, I've got a much better sense of pitch when I'm high on weed than I do off it [...] I can just hear a lot more subtlety in notes and things. (Jenna, F, 31, studying, cannabis)*

However, it was also noted that **consumption can hinder studying** so some avoid it when they have classes or assignments due. As Scott (M, 25, studying and working in hospitality, alcohol) commented:

*I almost found that I couldn't drink if I really wanted to work hard at uni[versity] as well. It's like, I could go to the pub, or I could do that assignment.*

Studying was considered by some to offer opportunities to 'party' and to consume alcohol or other drugs often. For example, Dee Jay (M, 24, studying, party drugs and cannabis) said that he became 'curious' about drugs when he started university and began taking MDMA and cocaine.

*In high school, probably about year 11 or 12 [...] everyone was going to parties, drinking alcohol and whatnot [...] but then I had to kind of concentrate with school back then. But then once I got into uni I just let loose and then one thing led to another. Well, I started with weed first and then I just got very curious [...] It was just a whole new world [...] Probably about six months in, that's when I started popping the pills or MDMA and then cocaine came a bit later.*

As these accounts demonstrate, participants who were working or studying identified a need to strike a balance between their work or study commitments and regular consumption. Some cited the importance of access to flexible work arrangements in facilitating this balance. Others stressed the value of formal treatment programs, especially opioid pharmacotherapy treatment in helping them to fit their consumption around their other commitments but some also observed that daily, supervised dosing disrupts work commitments. **These issues concerning the delivery of opioid pharmacotherapy treatment and the need for more flexible dosing arrangements have been documented in Australia since at least 2007 (Fraser et al., 2007) and our research suggests a continuing need to address them.**

## Managing finances

**The financial cost of regular consumption** was identified as a downside by many of our participants. Some reported having spent a lot of money on their preferred drug(s) over the years, adding that this had led them to consider stopping or cutting down. Paying for rent, food, utility bills and family expenses was the first priority for most, with participants describing how they organise their consumption around these responsibilities. For example, when Rachel (F, 50, works in the health sector, heroin) found it hard to make ends meet, she took on more work to fund her consumption and cover family expenses.

*The [heroin] drought really fucked us up [...] All of a sudden, you just couldn't get [heroin ...but] I just kept trying to [...] You had to buy it in large amounts [...] but I'd use it in the same amount*

*of time that I would use a smaller amount, so everything escalated and I was using more and more, and [...that cost] a lot of money. I ended up in debt [...So] I just took on a lot of jobs, I was working four jobs. So I'd get up in the morning, you know, go find some gear, get to a job. It was like that. I'd get to my next job and then my next job [...] and I did that seven days a week [...] Things would be all right and I kept it together, I kept a roof over our heads [...] I've always kept my family housed and clothed and fed.*

In other cases, the need to keep up with work and financial responsibilities encouraged some to change their consumption patterns or seek treatment, but a few also pointed out that treatment is especially hard to afford when money is tight. For those on **opioid pharmacotherapy treatment**, a few reported finding it hard to afford (see also 'Accessing treatment' under 'Pharmacotherapy/medication-assisted treatment'). Others indicated that pharmacotherapy helped them to manage the cost of their consumption, or stop when it became too expensive:

*[My partner and I would take heroin...] as often as we could possibly afford it without being on our knees. You know, we always kept our rent paid up, bills paid up pretty good. Sometimes [we'd get] a little bit behind but we would use as much as we could afford to [...] It was usually*

*pretty often when we were [living in the city] and we'd sort of [...take breaks by going] on the methadone [...We'd] stop it for a while [...] Being perfectly honest, [we would take breaks because of] lack of money mostly [...] and that's when we'd go onto methadone or Suboxone]. (Grace, F, 58, works in manufacturing, heroin)*

Our participant accounts of managing regular consumption in relation to work, study and financial commitments **raise questions about the dominant understanding of addiction as a disorder of individual compulsion associated with impaired control and social harm**. They challenge its key premise that heavy regular consumption will inevitably undermine individual capacity to 'fulfil major role obligations at work, school or home' (American Psychiatric Association, 2013) and is thus inimical to a productive, satisfying life. Contrary to this view, our data show that **people who identify as experiencing addiction can and do manage their consumption in relation to work, study and other everyday commitments, suggesting a need to consider carefully the assumptions at work in dominant conceptions of addiction**, and the extent to which they resonate with individual experiences.

### 3. Stigma and discrimination

Stigma was a key issue for our participants. It came up repeatedly as a problem associated with almost every aspect of life. Many of those interviewed talked at length about the impact of stigma on their everyday lives, including how it shapes their experiences of healthcare, their relationships with family, friends and their work. The sections that follow break up kinds of stigma according to context for clarity and as a means of focusing on the variety of settings within which participants describe encountering and, in some cases, challenging stigma. Importantly, however, such experiences overlap for many, highlighting the ubiquity of stigma in everyday life.

#### In the health system

Perhaps unsurprisingly, given the extensive literature documenting the persistence of stigma in the health system (e.g. Anstice *et al.*, 2009; Henderson *et al.*, 2008), **one of the most commonly cited contexts participants describe as stigmatising is the healthcare system.** Some participants describe experiences in which healthcare professionals treated them differently from other patients, with several commenting that they feel like staff ‘look down on’ them. As David (M, 25, unemployed, heroin) explained in relation to filling his methadone prescription:

*Just at the chemist, I feel like they are looking down on us. They don't treat us [like] a normal patient. Like, we'd go in there for a prescription [and we] are always second best. Like [the staff will] push you to the side or push you back, and deal with their people first and then deal with the 'druggies'. That's what we look like [to them].*

Zadie's (F, 33, works in the health sector, heroin) experience of hospital care after an accidental overdose is especially striking:

*I was unconscious and I came to in the hospital [...] I became conscious but I couldn't move a muscle [...] I could feel pain but I couldn't move, and I could hear what the doctors and the paramedics were saying about me [which*

*was] just really derogatory, you know: 'Stupid fucking junkie, [we] get them all the time'. It upsets me even thinking about it [crying]. They were being very, very rough with my body. There was no care.*

Several say they found it hard to get medication for pain relief because of their medical history of alcohol and other drug dependence. For example, when George (M, 58, not working due to illness, alcohol) was injured, he stated that he could not access adequate pain medication due to his ‘history of drug use’:

*Once I was hospitalised. I'd actually been attacked and had fractured my back and they sent me out of the hospital with Panadeine (paracetamol and codeine). I couldn't even get [Panadeine] Forte (paracetamol and a higher dose of codeine) because they knew I had a past history of drug use. So they wouldn't give me anything stronger than Panadeine. I mean it's ridiculous. I had a fractured back.*

Past experiences of stigma and discrimination in the health system mean that some of our participants are hesitant to discuss their consumption with health professionals or access healthcare. In some cases, this acts as a **barrier to accessing healthcare in a timely manner:** it can mean that people seek medical help belatedly by which stage an initially minor health problem may have become much more serious and difficult to treat.

#### In the workplace

Another key area in which participants describe stigma is **employment and the workplace.** Some reported that they decided not to tell their employers about their drug consumption because they were concerned they would be judged and lose their jobs. As Jenna (F, 31, cannabis, studying) put it:

*I don't think people judge based on performance [...] If they think you're [a drug] user, then [...] the judgment is made that you are not employable.*

Some of those interviewed were recipients of **opioid pharmacotherapy treatment**, and, as noted above in Helen's case, described **particular challenges relating to managing employment** and participation in this form of treatment. A few said they avoided telling their employers that they were having treatment for fear of being judged or even losing their jobs, even though limited dispensing hours meant difficulties accessing dosing. As David (M, 25, unemployed, heroin) explained:

*[I never talked to my boss about going to the chemist...] I just didn't want him looking at me as a druggie [...] I always had to [get my methadone dose] before work or after work. And with getting there on time and just a lot of hassle just to make it to the chemist, I thought to myself, it's not worth it [trying to get my dose during work hours... if I told my boss he would] just look at me different and I know I'm better than that [...] I was] scared to get sacked or discriminated against.*

David's experience suggests that despite its supposedly non-judgmental approach based in medicine's aim to cure or alleviate disease, the healthcare framework within which treatment operates did not resolve the potential for stigmatisation (see also Fraser & valentine, 2008; Radcliffe & Stevens, 2008; Rance & Treloar, 2013; Smith, 2010).

## In the criminal justice system

Experiences of stigma in the criminal justice system were also described with some participants recounting instances in which police officers, lawyers or judges expressed negative attitudes towards them or targeted them unfairly (see also Radcliffe & Stevens, 2008).

**Criminalisation was seen as a key driver of the stigma surrounding them drug consumption.** As

Jim (M, 21, studying, cannabis) explained:

*I think if [cannabis] was legal, there wouldn't be this whole stigma around it. And, like, the anxiety and stuff that comes when people are high, I think, is based around the fact that you have done something wrong now and you can get in trouble.*

Jim's comment highlights the **need to address the relationship between stigma and institutional and legal arrangements**. Measures that treat stigma as an individual issue that can be tackled through education and interaction with stigmatised individuals ignore its institutional dimension and are thus unlikely to eradicate the pernicious forms of stigma inhering in institutional processes. This points to a **need to take seriously increasing calls for decriminalisation** (see for example, Douglas & McDonald, 2012; Hughes et al., 2016; Macintosh, 2006; Ritter, 2012; Wodak, 2012) as a means of reducing the harms associated with criminalising and policing drug use, and with the related stigmatisation of addiction.

Several participants described being **unfairly targeted by police officers** and recounted incidents in which they were publicly searched on suspicion of carrying illegal drugs:

*That's the embarrassment there [shows interviewer a mark on his forearm]. That's one of the marks there from using [...] And yeah, as soon as the police see that, just, they know and they do treat you different. They treat you with such little respect. I've had them drag me into an alley before and fully strip search me in an alley, just because they thought I had drugs on me, they thought I was dealing and I had nothing on me. And anyone could've walked down that alley. And just little things like that, and your lack of dignity really. They really do take away [that] from you (Peter, M, 41, unemployed, heroin)*

Peter characterised being publicly strip searched as a 'little thing', yet he also noted that encounters of this kind deprive him of his dignity.

Alongside accounts that identify policing as a key site of stigmatisation are accounts that focus on other aspects of the criminal justice system, including legal processes. When Dawn (F, 38, works in manufacturing, alcohol) was facing assault charges and hoped to access an alcohol treatment service, she felt that her lawyer condemned her as just a 'drunk':

*The guy that represented me [...] I really felt that he was judging me for what I'd done. He was also a lawyer for kids and so when he was*

*representing me, maybe I just felt that he [...] really felt that I didn't deserve to go to rehab [...] I really felt that he thought that I should just be thrown into jail and I was a drunk.*

## In the media

The **role of the media in creating and reinforcing stigma and discrimination** was also cited as a significant issue. Several pointed out that media coverage can be sensationalist, exaggerating the harms of drugs and contributing to misinformation and damaging stereotypes. According to Artemis (M, 28, works in education, party drugs) media coverage of crystal methamphetamine consumption exaggerates rates of 'problematic use', reinforcing the stigma surrounding it:

*Certainly in the media, addiction is the only discourse when it comes to drug use. I mean, we have to only look to the recent coverage of crystal meth use to like shake our heads and wonder, you know. Everyone is addicted to crystal meth, I take it. Not that crystal meth isn't very addictive and problematic for some people, there's no question about that, but [...] there are [many more] who use without issue [...] In terms of addiction, I mean it's stigmatising.*

Others talked directly about how stigmatising media reports impact on the everyday lives of people who consume drugs. For example, Nick (M, 50, not working due to illness, heroin) noted that news reports reinforce negative attitudes towards people who take drugs, and he believes this has affected his relationships:

*[Living with a drug habit] you lose contact with friends [...] Friends that can help [...] are no longer around [...] because I think [...] they read the paper and the news, and they see crimes committed by people to get drugs. They put me in that category, I suppose.*

As with the healthcare system and the criminal justice system, the media are understood by participants to be key agents in the stigmatisation of drug use and of people engaged in it. These findings suggest that **better training of the media is needed on how to report sensitively on drug use and addiction issues**. We recommend a set of guidelines governing media coverage of drug use and addiction be developed, similar to the Australian guidelines for [\*Reporting on suicide and mental illness\*](#) (Hunter Mental Health Institute, 2014).

## 4. Creating change: Treatment, self-help and other responses

Many of the people interviewed for this study talked about **changing their patterns of consumption** and described different types of change, including cutting down, taking a break, stopping altogether, replacing one drug with another, or otherwise varying routines of consumption. For many, varying consumption patterns is part of making wider changes to their lifestyle and routine by rearranging priorities and everyday activities. Some of these changes occur without any particular plan or effort. A variety of active **strategies for creating change** were also discussed. These include changing social circles, moving to a new place, completing a home detox and pursuing new hobbies and interests. In addition to the informal strategies discussed, many participants **sought treatment or took part in self-help programs** to create change. Below we present participants' experiences of informal and formal strategies for creating and maintaining change.

### Informal strategies

**Common strategies identified for cutting down or stopping altogether** include limiting the amount of alcohol or other drugs purchased, avoiding social settings associated with consumption, changing social circles, restricting access to cash, only consuming on special occasions or weekends and relying on willpower. Some participants described combining several of these strategies. For example, Jason, (M, 34, studying, ice) cut down by planning his consumption and limiting it to special occasions:

*So I haven't used [ice] for at least five or six weeks now [...] Because I have been using on my own quite a bit, I am trying to [...] use with someone else, have it as a special occasion [...] So I think about two months ago, I did have some visitors and so that was nice to have something different [and take ice with them]. And yeah, so as long as it's structured, planned, organised, then that could work for me. But if all those things aren't there, then I would more than likely not do it.*

Many people said they **monitor how much and how often they consume**, and make changes when

necessary to limit the risks they see as related to more frequent consumption:

*Moderation with everything is [important] because if you do it too much, the enjoyment is sucked out of it and you build a tolerance to it [...] With the Valium (diazepam)] I think I have enough self-regulation and knowledge to [...] not have it out of control [...] You know, one Valium a night isn't really that out of control. I've cut down from where I was. I was taking a lot more a few months ago so I'm regulating it already (Kate, F, 36, works in the health sector, prescription drugs and ice)*

**Support from family and friends** was frequently cited as important in creating and maintaining new patterns of consumption:

*I had a three-month stint, close to twelve months ago now, where I was able to get off [ice] with the help of my family. And [I] did that alone, cold turkey at home [...] As I said, I have got a support network with my family and friends so that if I am struggling on a particular day or around a particular subject, I'll just give them a call [...] My mum is there for me. (Zoe, F, 30, studying, ice)*

Although many expressed a desire for change, several were generally **satisfied with their consumption habits** and were **only looking to make small adjustments** to ensure they still experience the benefits of consumption:

*[My partner and I] are aware of the problem that we are abusing [cannabis] a little bit too much. But at the same time, it's like, well, we're still looking for work. We are still being productive and paying our taxes and doing great stuff [...] So we talk about it. We are both trying to mellow it down a little bit. But at the same time, we don't really want to stop because we enjoy it. And you know, it's something we do together and it's good [...] Like I said, it helps me relax and be nice, and same for her. So we are better together when we are not cranky, so there's less*

*tension in the house (Jacob, M, 33, works in hospitality, cannabis)*

These accounts demonstrate two important points: 1. when individual circumstances change so do patterns of consumption, and 2. people adopt varied, highly contextually specific, strategies to alter their consumption patterns. In order to ensure genuinely responsive care, it is essential that current and future **policy recognises and supports the range of contextually specific strategies people use to initiate and maintain change**. These may include, but far exceed the bounds of formal treatment measures.

## Treatment

### Pharmacotherapy/ medication-assisted treatment

One of the forms of treatment commonly discussed by our participants is **pharmacotherapy or medication-assisted treatment**. In Australia, pharmacotherapies are available for the treatment of dependence on opioids, alcohol and nicotine. At present no pharmacotherapies are approved to treat dependence on methamphetamine, cocaine or cannabis (Hart & Lynch, 2017; Marshall *et al.*, 2014; Quinn, 2016). The aims of pharmacotherapy treatment, and how it is delivered, differ depending on the drug of concern. In the case of **alcohol dependence**, it is generally **intended to prevent drinking and control or reduce ‘cravings’** (Swift & Aston, 2015). Pharmacotherapy for people diagnosed with **opioid dependence** involves replacing the opioid normally consumed, such as heroin, with a legally prescribed opioid.<sup>1</sup> Beyond reducing other opioid use and

preventing physical symptoms associated with opioid withdrawal, opioid pharmacotherapy treatment (OPT) is associated with people staying in treatment, reduced overdose risk (Degenhardt *et al.*, 2009), reduced risk of HIV and hepatitis C transmission (Cousins *et al.*, 2011), and general improvement in mental health and well-being (Ritter & Chalmers, 2009). Some of these health improvements relate both to the use of pharmacotherapy and that fact that when in treatment people may connect with health and welfare agencies better. In this sense, OPT is also thought to aid ‘social reintegration’, ease the economic burden of illicit consumption, allow better access to employment and reduce harms associated with injecting (Department of Health and Human Services, 2016).

Some of our participants had experience of OPT and one participant undertook pharmacotherapy for alcohol dependence. Of those who undertook OPT, most went on methadone maintenance treatment (MMT). Others had buprenorphine or combination buprenorphine and naloxone. Some tried more than one type of OPT. In this section, we begin by presenting experiences of accessing treatment. Experiences of treatment with specific opioid pharmacotherapies are discussed next and we conclude by presenting an experience of pharmacotherapy for alcohol dependence.

<sup>1</sup> The three main opioid pharmacotherapy medications currently used in Australia are methadone (or Biodone<sup>®</sup>) syrup, buprenorphine (Subutex<sup>®</sup>) sublingual tablets and combination buprenorphine and naloxone (Suboxone<sup>®</sup>) sublingual film.

**Methadone** is a synthetic opioid initially developed for the treatment of pain. It is an opioid agonist: it is designed to bind to the receptors in the brain which otherwise take up heroin or other opioids and give an opioid effect. **Buprenorphine** is also a synthetic opioid initially developed for the treatment of pain. Buprenorphine is a partial opioid agonist: it is also designed to bind to opioid receptors in the brain but it has a ‘ceiling effect’ which means that its psychoactive effect reaches

a maximum level that doesn’t increase even with increasing doses. **Combination buprenorphine and naloxone** (Suboxone<sup>®</sup>) treatment combines the partial opioid agonist buprenorphine with naloxone, an opioid antagonist intended to reverse the effects of opioids. Combination buprenorphine/naloxone is a sublingual film designed to be absorbed under the tongue. When taken under the tongue (or sublingually), only the buprenorphine is absorbed, and the medication has an opiate effect. If the medication is injected, the naloxone is absorbed and the medication can produce withdrawal effects. The addition of naloxone to buprenorphine was intended to discourage the injecting of treatment medication.

### Accessing treatment

Australia has a significant demand for OPT and many of our participants, keen to commence treatment and access its benefits, described **difficulty accessing treatment. They often persevere for some time and travel long distances to secure access to treatment.** In Australia, pharmacotherapy is delivered through dedicated, government-funded clinics, private clinics, community pharmacies and GP prescribers. Delivery arrangements vary by state. A few of our participants reported finding it especially hard to access OPT outside major cities, and some such as Grace (F, 58, works in manufacturing, heroin) travel to the nearest major city to access it:

*We tried to get a doctor [in our local town to prescribe treatment] but apparently there was only one and he's really hard to get in to see. So that's why we just keep [seeing our regular prescribing doctor in the nearest major city]. It was just easier to ring up, make an appointment and he can see you in the next couple of days.*

Having to queue for a long time to get their dose from a prescribing clinic or chemist was a concern for several people. It was suggested that clinics employ more clinical staff to cope with the demand and reduce waiting times. In most states, doctors must apply for approval to prescribe OPT, but some states (e.g. Victoria, South Australia, New South Wales) are granting exemptions to increase the number of buprenorphine-prescribing doctors and facilitate access to treatment.

**Affording OPT** on top of other regular expenses was also an issue in some cases. Fees can vary significantly, from \$15 to \$90 per week, and treatment is not subsidised by Medicare. Research has found that dispensing fees can be a significant financial burden for pharmacotherapy clients on fixed incomes or welfare support and contribute to people prematurely dropping out of treatment due to financial stress (Lord et al., 2014). Participants such as Rachel (F, 50, works in the health sector, heroin) reported finding it hard to afford OPT top of their other expenses. This **suggests a need to review dispensing fees, particularly for clients on fixed incomes or welfare support:**

*I pay the bills and I'm lucky to have \$100 left, you know. [With] that I've got to feed the*

*family, I've got to get transport [...] I have to pay for [my partner's] medication. He has a lot of medication and that's \$30 or \$40 a hit, and he's on about seven different medications. My [child] is on two different medications. Plus the methadone, so there's all that. So if the methadone was free, God that would help!*

Experiences of **stigma and discrimination** when accessing OPT at chemists or clinics were also described and, in some cases, this discouraged people from seeking or continuing treatment (see also section on 'Stigma and discrimination in the health system'). Despite these issues, many stressed the **value of OPT** and described the **difference it makes in their lives.** As Nick (M, 50, not working due to illness, heroin) put it:

*I'm on methadone as well, which is, you know, to get off heroin. But I am not on a very large dose. If you haven't got methadone to back you up, where it takes away the withdrawals, there is no other choice but to use the drug to feel normal, which is a shame [...] The best way to stop using heroin [...] is methadone and Suboxone and Subutex and all those things that they have got available now [...] They're very helpful in] managing withdrawal symptoms.*

The structured dosing arrangements of OPT were questioned by some who noted that supervised dosing and restrictions on takeaway doses mean they have to visit the chemist every day to get their medication. This **disrupts work and family commitments, and limits opportunities for travel.** As Harry (M, 52, works in arts, heroin) explained:

*I had to [go on methadone] because at the time I was working a full-time job in a place that required a lot of shift work and a lot of hours per week. And I couldn't even financially [...] maintain the heroin and the job. So I had to go on methadone [...] It just made sure you could continue to go to work and not necessarily use heroin every day. So there was 10 years of that until I finally got away from the methadone and now my opinion of*

*methadone is fairly low. I wouldn't ever go back on it again. It wasn't as though it wasn't convenient or useful. It was the rigmarole, the process that you had to go through. And also that it bound you to a particular location.*

Related to these concerns about restricted dosing arrangements, some participants mentioned the **importance of access to takeaway doses:**

*[The prescribing chemist that my partner and I go to is] really good because we can get takeaway doses. And we're allowed five, I think, a week [...] but we sort of just pace it out to average probably three takeaways [...] Sometimes we'll just get two. And they're not open on Saturday or Sunday so we've got to keep that in mind too, to always have the weekend sort of covered [...] But it suits. It's no hassle because you can get the takeaways (Grace, F, 58, works in manufacturing, heroin)*

Overall, takeaway doses were identified as centrally important in finding and retaining employment, facilitating travel for work and leisure, fulfilling parenting and other everyday responsibilities, and reduction or cessation of illicit drug use. As has been identified in past research (Fraser *et al.*, 2007; Treloar, Fraser & valentine, 2007), these findings suggest that **policy on takeaways needs to be sufficiently flexible to accommodate differences in clients' circumstances and allow prescribers to manage treatment on an individual basis.**

### **Methadone**

Most of those interviewed who had experience of OPT had undertaken **methadone maintenance treatment (MMT)**. Some of our participants described **positive experiences of MMT**, citing its effectiveness in treating withdrawal symptoms and managing 'cravings'. For example, Barry (M, 40, unemployed, heroin) stated that being on MMT helps him avoid getting sick from not taking heroin, which allows him to manage his work commitments:

*I've been on and off methadone most of this time [...] since I started [taking heroin] really. I'd start and I'd go berserk, and that would affect*

*my work. So [...] I said to [my GP...] 'You know, I need to go on methadone because I want to keep my job'. So that's where the methadone sort of started. And it helped. And then, you know, I got clean off [the methadone...] But the only reason I've gone back on methadone this time was because I was working [...] I could not afford to get sick [from heroin withdrawal] and miss work [...] I just couldn't [...] afford to do that. I had to keep going because work was the thing that kept me going.*

Others reported that it supports efforts to cut down or stop consumption altogether. A few, such as Kate (F, 36, works in health sector, prescription drugs) indicated it helps them manage their consumption and avoid spending too much on drugs:

*I've been on opiates for nearly 20 years now, 19 on and off, and whenever I haven't had them in my system except for a few [...] periods [of several months], I have returned to them. So if I've got something that's feeding that [opioid] receptor as well as blocking it, and is doing what it does for me, and it's not costing me any time or minimal time, minimal effort, minimal money [...] then I'll just stick with it, because it's working. And it's a lot cheaper than having that risk of going back to, you know, putting \$50 to \$100 [of heroin] up my arm every day.*

**Negative or mixed experiences of MMT** were also reported, and some **disadvantages** mentioned. These include unpleasant side-effects and the difficulty some experience when reducing their dose or stopping treatment:

*The first time [getting off methadone] was all right but I don't think [my partner and I] have ever properly completed it without using [heroin] you know, because once you get [to a] really low dose, just a couple of [milligrams], well then you start [...] feeling [ill...] I've always thought, 'Oh, I'll just be on it for a few weeks and then I'll be able to cut down'. I found it really hard to cut down quickly and I found myself stuck on it [...] for a year (Grace, F, 58, works in manufacturing, heroin)*

### **Buprenorphine (Subutex®)**

A few participants had tried treatment with **buprenorphine** and described it as having **similar benefits to other opioid pharmacotherapies**. These include preventing or easing 'withdrawal' symptoms, reducing the desire for the drug and relieving pain. Some indicated that it helped them cut down or stop altogether. As Zadie (F, 33, works in health sector, heroin) put it:

*I realised that I just needed to stop [taking heroin]. I know that's going to involve being sick for a week or two [but] I didn't have time to be sick for a week or two [...] I needed to go to work [...] So I went to a doctor and got on [buprenorphine] which got me over that period. In two weeks, I was fine. I wasn't using any more.*

Others, such as Sean (M, 48, works in education, over-the-counter painkillers), reported finding it difficult to reduce their dose of buprenorphine in order to eventually stop treatment:

*I think I ended up going and seeing this psychiatrist [...] and he suggested that I go on buprenorphine [...] It's such an odd drug [...] but it was amazing [...] I just didn't have any withdrawals [from stopping Nurofen Plus...] I guess I was on buprenorphine then for [a few years] so I just came off [it...] I had a shitty time [coming off it.] Even though I had kind of reduced and done it slowly, I was still staggered by how difficult it was coming off.*

### **Buprenorphine naloxone (Suboxone®)**

Some of our participants had undertaken treatment with **combination buprenorphine and naloxone**. As with methadone and buprenorphine, those who undertook combination buprenorphine and naloxone treatment reported that it helps to **prevent or ease withdrawal symptoms** experienced on stopping heroin. For some, being on combination buprenorphine and naloxone treatment means they do not experience the desired effect from consuming opioids, and this **helps them cut down or stop altogether**:

*At the moment I'm on Suboxone so there's not much point [in] using heroin until you haven't*

*had [Suboxone] for a couple of days [... Taking] Suboxone means that if you are going to use [heroin] you really have to plan it, which means you are inevitably either going to use less or jump off the [Suboxone treatment] program. And it has such a long-lasting effect that, you know, even the fourth day you don't feel that awful [...] I think I'll probably end up not using at all because once you've got Suboxone in your system, you're really talking a week before you'd get the same effect from a shot [of heroin] that you did before [...]*  
*So like I'm already finding that [...] it's starting to become pointless [taking heroin]. (Helen, F, 53, not working due to injury, heroin)*

### **Pharmacotherapy for alcohol dependence**

One of our participants, Phoenix (M, 48, works in media, alcohol and prescription painkillers) had tried **pharmacotherapy for alcohol dependence**. He was treated with a medication called acamprosate (Campral®) and says it **curbed the desire (or 'craving') for alcohol** and **helped him stop drinking altogether**:

*So [my counsellor] actually insisted I go and spend some time in [...] the detox unit at [...] the hospital [...] They put me on Campral, acamprosate, which took away the cravings for the alcohol. I came out of there and I've never experienced anything like that in my life. It still confuses me. Just that absence of the need to go to the pub [...] My wife and I got back together again at that point and we had ten years sober [...] I did Campral probably for maybe eighteen months, I think.*

### **Talking therapies**

Undertaking counselling or psychological therapy is one way some of our participants reported changing their patterns of consumption. Often referred to as **'talking therapies'** or 'talking treatments', these treatments involve talking to a psychotherapist, psychologist, psychiatrist or counsellor in either group or individual sessions. Many of our participants with experience of talking therapies undertook **alcohol and other drug counselling**, while others had experience of general psychotherapy with a psychologist or psychiatrist. A few took part in **cognitive behaviour therapy (CBT)**, which is

a short-term talking treatment aimed at changing unwanted patterns of thinking or behaving. Here we present their accounts of the benefits and drawbacks of these different types of talking therapies.

### Alcohol and other drug counselling

Our participants identified a number of **benefits of alcohol and other drug counselling** including professional advice on how to manage consumption or initiate and maintain change. Some stated that it helps more generally to deal with difficult experiences and gain insight into problems. Others described the features of counselling they find most beneficial. These include a non-judgmental counsellor, the use of complementary treatments and a trusting relationship between the counsellor and client. As Luke (M, 44, works in retail, alcohol) explained in relation to the counsellor he was seeing at his local alcohol and other drug service:

*Well [my local alcohol and other drug service] has been really, really good. The person I speak to is super nice, non-judgmental. It's not confrontational. It's kind of like counselling but more psychology in there. Asking you how you feel and that sort of stuff. But really super nice. Like I'll get texts through the week, like, 'How you feeling? Are you still coming next week?' [...] which is nice.*

Negative or mixed experiences of counselling were also described, with several commenting on the **limitations of some approaches**. These include not having time to reflect on questions raised in counselling, a lack of connection between the counsellor and client, and a narrow treatment approach not tailored to individual needs. Lala's (F, 35, works in health services, cannabis) reflections on her first appointment at a community alcohol and other drug service describe some of these concerns:

*I went once and I do want to make a follow-up appointment [...] It was good [...] but I would have liked to get some information before the appointment. I think [it] would have been useful because he asked me all these questions about my use that I just didn't really have time to consider. So now reflecting back [...] on the answers that I gave him then, I've realised*

*just how they weren't accurate. Like, I totally underestimated my use. So I felt like it could have been more useful for me to reflect and maybe keep a diary before I go for my first appointment. So I'm coming armed with the information.*

### Group therapy

Some of our participants had taken part in group therapy and described its **benefits** as being that it provides a peer support network, and opportunities to share coping strategies and overcome problems. For example, John (M, 34, works in the health sector, ice) described how attending group therapy sessions made him feel less alone:

*It's a group of people, probably about eight or nine of us, specifically gay men who are drug dependent and [...] either want to minimise their use or stop altogether [...] So we meet each week for about six weeks [with a professional counsellor] and talk about different issues regarding the drug itself [ice] and the drug addiction [...] It's been good to be able to talk about my own experiences each week, but not only that, to be able to listen to others and realise that [...] you're not alone. There are other people out there who are going through the same, similar, things.*

While some found group therapy beneficial, others had **negative or difficult experiences** that made them feel anxious and distressed:

*Through group therapy [at the residential rehab I attended] it was like, I call it 'emotional boot camp' [...] we had things like conflict resolution. So we'd have to sit in a circle with all the other residents and people would write conflicts about you, or you could write a conflict about someone and you'd have to sit opposite that person and then sort of say, 'When you didn't clean up the other day I felt really angry' [...] Conflict was my biggest fear. It was like, 'Oh my God', you know [...] All my anxieties and having to sit in that room covered in sweat just going, 'Oh my God!' It was like I was about to be shot (Emma, F, 42, works in retail, alcohol)*

## Psychotherapy

Those with **experiences of psychotherapy** observed that it offers a range of benefits, including the opportunity to gain deeper insight into thoughts and feelings, and a 'safe space' to talk about distressing or difficult experiences. Some described **what makes a good experience of psychotherapy**. Features mentioned as most important include an understanding, caring therapist and a good personal connection between client and therapist:

*I think, most importantly, I found [my psychiatrist] incredibly [...] engaged and engaging. Like, incredibly sort of present whenever I was with him [...] I think it was actually really liberating to [...] go along and see someone at a time when I was incredibly vulnerable [...] I've just always had the sense that he [...] cared and he did, you know. (Sean, M, 48, works in education, over-the-counter painkillers)*

While most with experience of psychotherapy found it helpful, some stopped going when their government-subsidised sessions ran out and they could not afford to pay for it themselves, suggesting **a need to increase the number of government-subsidised sessions per client**. Misja's (M, 40, not working due to illness, cannabis and heroin) case exemplifies this need:

*I was seeing a counsellor. I was seeing him for quite a while about two years ago [...] I had to sit down and talk about whatever, all kinds of stuff. That's probably the only counselling that I've done. It was helpful at the time because I could blurt everything out and [it was helpful to talk to] someone who actually listens to me, apart from my missus. But yeah, I found it quite okay. There was nothing bad about it [...] I just stopped going because you can only get like eighteen sessions a year on Medicare.*

## Cognitive behaviour therapy

A few of our participants described experiences of cognitive behaviour therapy (CBT), which is a short-term goal-oriented psychotherapy that aims to address unwanted thought patterns or behaviours.

Those who had taken part in CBT indicated that it helped them to **address emotional issues linked to consumption and change their patterns of consumption**:

*I found the experience [of CBT] very good and I think that's the way to go for me, the more CBT route [rather] than twelve-step<sup>2</sup> [...It's] not necessarily better for everyone but for me [...] there's a lot more emotional stuff behind why I started taking drugs. And when I went [to the rehab that offered CBT...] I had recently been diagnosed HIV-positive. And [...] I knew where I needed to be [...] So my psychologist [...] was one of the first people I contacted and I said, 'Look [...] get me back in [to that rehab]'. (Dean, M, 32, works in hospitality, ice)*

## Residential treatment

One form of treatment especially widely experienced by our participants is **residential or in-patient treatment** (often called 'residential rehabilitation' or 'rehab'). Residential treatment facilities vary but usually offer 24-hour a day care, including on-site housing and medical attention. In Australia there are different types of residential treatment including long-term residential treatment (three to twelve months), short-term residential treatment (one to three months) and therapeutic communities, which offer long-term treatment using self-help and peer support to promote change.

Some participants underwent longer-term residential treatment, while others completed short-term residential treatment, or treatment in a therapeutic community. Several had experiences of more than one type of residential treatment. Due to the **high demand** for treatment, a few reported having to **wait several weeks or even months** for an opening in a residential treatment facility. Others said they had to contact more than one facility to secure a place, suggesting **a need to increase the number of treatment facilities to meet demand**.

<sup>2</sup> Twelve-step treatment programs are **abstinence-based self-help groups such as Alcoholics Anonymous and Narcotics Anonymous** that meet regularly to help members give up alcohol and other drugs and remain abstinent. Although the format of meetings varies, they often include readings that illustrate the twelve steps of change on which the programs are based.

As Dawn (F, 38, unemployed, alcohol) explained:

*I had to ring different rehabs and just wait to see where there was a vacancy or opening. So yeah, I waited for say about three months and then I got into this [one].*

A number of **benefits of both long and short-term residential treatment** were identified by participants. These include medical care, life skills training, counselling and accommodation in an alcohol and drug-free setting. The features of residential treatment seen as helpful include the availability of a wide range of recreational activities, alternative health treatments and caring staff with personal experience of alcohol and other drug-related problems. The opportunity to 'get in touch with feelings' and process emotional issues was also mentioned as a benefit, as these comments indicate:

*I remember discovering [at rehab] that I had anxiety [...Like] the feeling that I had which I thought meant I needed more drugs was actually the feeling of anxiety [...] Rehab kind of opened me up to [...] this idea that I might have sensations in my body and that's what people refer to as a feeling [...] I learnt a lot through rehab. (Ethan, M, 39, works in hospitality, ice)*

*[Treatment involves] giving you strategies on how to cope without craving for whatever drug you have and [to cope with] your emotions. [At this residential treatment centre] we do have morning groups where you can voice [...] whatever you are having a problem with and [...] you just have to, as they say, sit with your feelings. (Dawn, F, 38, unemployed, alcohol)*

**Negative or mixed experiences** of residential treatment were also reported, with some commenting on the **limitations of some programs**. These include their structured nature, having limited contact with loved ones, the use of twelve-step abstinence-based approaches, regular drug testing and the regulations that some programs apply. For example, Grace (F, 58, works in manufacturing, heroin) questioned the need for the strict, highly structured program and daily drug testing in place at some residential treatment facilities:

*I just don't have much faith in [...] these rehab joints [...] Only because of my brief experience at one [...] You had to pee in a jar every day, and you had to be there by a certain time, you know [It was] really pathetic, just the way you were treated [...Especially the staff...] if they go into that sort of work or whatever, you think they'd have a little bit more [compassion] and not be so mean.*

A few, such as Eva (F, 20, works in the entertainment industry, ice) indicated they found it hard to stick to the rules and decided to leave before the end of their treatment program:

*The [rehab] I went to, they had some ridiculous rules. And it wasn't rehab, it was like a boot camp almost. You had to get up and clean and [...] if you talked to boys too much, they'd put you on like a boy ban, and shit like that [...] We couldn't say certain words. We couldn't listen to certain radio stations. Like things like that [...] Everyone's recovery is different, you know. But they didn't really seem to notice that so I left.*

Comments such as these suggest **a need for treatment practices to be managed on an individual basis** and in ways that are **sufficiently flexible to enable tailored care**.

A few of our participants had experiences of **therapeutic communities**. Those who had undertaken treatment in a therapeutic community said its benefits include a 'loving and caring environment', having the opportunity to make new friends and being able to draw on the support of other residents:

*I think it's pretty good here [at this therapeutic community], like, I enjoy it [...] It's good to be able to talk about stuff that you wouldn't normally talk [...] about without getting shunned for it [...] It's good to be able to relate to other people's stories when you thought that you were the only one that was going through it (Melanie, F, 26, primary carer for her children, ice)*

*This [therapeutic community] is, like, the most loving and caring environment where [...] we support each other [...] I found a sense of*

*belonging [...and] you know, a new whole set of friends. (Tiffany, F, 33, works in hospitality, ice)*

While most were generally positive about their experiences, one participant Melanie (F, 26, primary carer for her children, ice) identified a need for therapeutic communities to integrate professional counselling into their programs because as she explained:

*A lot of us do come in here with a lot of trauma [...] and because we are [a therapeutic community...] we don't really know how to deal with that sort of thing so that's why nobody speaks about it.*

## Detox

Completing a **detoxification ('detox')** is one of the ways our participants described changing their patterns of consumption. This is a short-term process of **reducing or stopping consumption to allow the body to eliminate the drug entirely**. It usually involves managing physical symptoms that can be experienced when stopping or cutting down (often called 'withdrawal'). Sometimes considered the first step in treatment, detox can be done through formal programs at an outpatient withdrawal service or a residential service. Detox can also be done at home as an informal strategy for changing consumption patterns. It differs from other informal strategies because it usually involves stopping abruptly and allowing the body to eliminate the drug. Often people do this by isolating themselves at home while they manage the physical symptoms that can be experienced when stopping. Some of our participants completed a detox through health services, while others undertook home detox. Several had experiences of both and here we review their accounts of formal and informal detox.

### Formal detox

Those who completed a detox through a health service identified its **benefits** as being access to medical care, professional advice on how to manage 'cravings', alternative health treatments, counselling and support. Others described the features of residential detox services they see as most helpful. Unrestricted visiting hours, a fairly unstructured daily program, a wide range of recreational activities and caring staff were all mentioned as important, as

this comment from Kate (F, 36, works in the health sector, prescription drugs and ice) indicates:

*The most recent [detox] that I did [...] they left you to your own devices. And the [...] youth detox was very good [...] We got to pick what meal we had, we did art classes, they had acupuncture, aromatherapy, four hourly medication. You could bring stuff in, like books and things [...] You could have visits whenever. So it was very, very good and supportive.*

Some described negative experiences and identified a number of **drawbacks of formal detox programs**. These include the structured nature of some programs and the lack of follow-up or continuous care. For example, Peter (M, 41, unemployed, heroin) had completed three residential detoxes and **identified a need for better aftercare and support**:

*I've done [...] three detoxes. I did agree with them, but what I should've done too was follow up with a rehab maybe afterwards. Because after seven or eight days at detox they basically say, 'Okay, everything's good now, see you later'. They ship you off onto the street. And they've pumped you up full of all sorts of things throughout the week to help you get off the stuff, then all of a sudden you have nothing. It's, 'Goodbye, good luck, see you later. Here's an NA pamphlet if you're curious', and that's it [...] At least a support worker [would be helpful], if [I] could drop in once a week or once a fortnight to see them or something similar.*

One participant, Emma (F, 42, works in retail, alcohol) commented that her stay at a residential detox centre did not prepare her to cope with her everyday responsibilities when she returned home:

*[Being in residential detox] was a way for me to escape the anxiety I had at home of being a mum, which I wasn't coping with at all. Being a wife and earning money [...] I wasn't coping with any of that. So being away from all of that [...] I didn't care about drinking. I didn't crave it once. So that was when I went, 'Ah, I think I know what I'm running away from' [...]*

*So when I came home I remember [...] sitting outside and just going, 'Oh my God, it didn't work'. [...] I'd realised straight away that, no I want to drink now.*

Comments such as these confirm the **pressing need identified in past research** (Berends et al., 2004; Griswold et al., 2008; NSW Health, 2007; Taylor, Thompson & Davis, 2010) **for better continuity of care, including aftercare and support for those undergoing treatment in residential settings.**

### Home detox

Participants with experiences of home detox stated that its **advantages** include not being separated from family and having the support of loved ones. For example Zoe (F, 30, studying, ice) reported that she was able to stop taking ice for a few months by detoxing at home with the support of her family:

*I had a three-month stint where I was able to get off ice with the help of my family. And I did that alone, cold turkey at home.*

A number of **disadvantages** were also mentioned such as the lack of medical care to manage withdrawal symptoms and the difficulty of coping with everyday tasks while detoxing at home. As Sean (M, 48, works in education, over-the-counter painkillers) explained in relation to his experience of detoxing from Nurofen Plus®:

*I was back on the Nurofen [Plus] (ibuprofen and codeine) then [...] and I was still seeing the GP, but I think she was at a bit of a loss as to what to do because I refused to go into an in-patient detox [...Then] towards the end of that year [...] it was just kind of hellish, you know, because I would just try to detox myself and that was [...] really impossible. If I had sort of a week or two with no responsibilities, no child care, whatever, [being] looked after, I could've managed it, but not on top of everything else.*

Having access to alcohol and other drugs when trying to cut down or stop was also seen as a drawback. As Kate (F, 36, works in the health sector, prescription sedatives and ice) explained:

*Home detox is challenging in that you know you can still go out and get drugs if you want to.*

### Self-help

Taking part in self-help programs is one of the ways participants described changing their patterns of consumption. Self-help programs **use support from people with similar experiences ('peer support') to promote change.** They include Narcotics Anonymous (NA), Alcoholics Anonymous (AA), Self-Management and Recovery Training (SMART), and programs focussed on the needs of minority groups or those with mental health issues. **NA and AA are twelve-step abstinence-based groups** that meet regularly to help members give up alcohol and other drugs and remain abstinent. Although the format of meetings varies, they often include testimonials in which people share their experiences. They may also include readings that illustrate the twelve steps of change on which the programs are based. These programs are generally perceived to be religious because references to a 'higher power' are interpreted as relating to God, although some participants and literature note that the 'higher power' can refer to a range of phenomena. By contrast, **SMART Recovery** is an explicitly secular support program that **uses strategies from cognitive behaviour therapy** (a type of psychotherapy aimed at changing unwanted patterns of behaviour) and **self-help tools to encourage self-directed change.** Groups meet face to face or online and are guided by trained peers and facilitators.

### Twelve-step programs

The **benefits** of twelve-step programs that our participants identified include support from others, fellowship and encouragement to remain abstinent. A few indicated that taking part in a twelve-step program helped them to realise they had an 'addiction' and needed to give up alcohol and other drugs altogether. As Bill (M, 43, works in retail, alcohol) put it:

*I only actually ever went to one [AA meeting] but as I said, I sort of got the information. I realised that I was an alcoholic at that point and yeah, that I did have a problem.*

Others reported that attending twelve-step groups helped them to change unwanted behaviours and learn to manage their desire to consume alcohol or other drugs. As Tiffany (F, 33, works in hospitality, ice) explained:

*[I'm grateful that [...] I'm attending [these meetings] and that keeps me clean and I know it helps me [...] Not only does it help you address your addiction [...] but also your behaviours [...] that you need to change.*

**Negative or mixed experiences of twelve-step programs** were also described with some participants commenting on their **drawbacks**. These include the focus on past experiences, the references to a 'higher power', the requirement to be abstinent to take part and the expectation that members share their personal stories in a group setting. For Emma (F, 42, works in retail, alcohol) talking about past experiences and what she 'used to be like' made her feel like she 'was going backwards', rather than focusing on the future. Some noted that the groups can be exclusive or 'cliquey', making it hard for a newcomer to establish relationships with other members, a view perhaps best articulated by Amy (F, 52, studying, heroin) who commented:

*The big thing about NA [and] AA is the newest person is meant to be the most important member and I didn't feel that. I felt like it was a cliquey group and the older ones just wanted to hear the sound of their own voice.*

### Other self-help programs

A few participants had experiences of **other self-help programs**, such as SMART Recovery and other peer support groups focussed on alcohol and other drug use. Those who have participated in **SMART Recovery groups** said their **advantages** include fairly unstructured meetings, non-judgmental facilitators and peers, an emphasis on self-reliance and tailoring to individual needs:

*SMART Recovery is amazing [...] The only rule is you're not allowed to turn up intoxicated. But everyone can ask questions and they feed off each other and say, 'Well, how do you deal*

*with this? How do you deal with that?' And no one tells each other what their addiction is or anything like that. It's just really, really chilled out and [...] everyone [gives advice saying] 'Well, I've done this and you might be able to do that' [...] In SMART Recovery, you can sit there and say nothing [...] You don't have to do anything [...] It's totally how you are, whether you want to not drink, whether you want to cut down. (Luke, M, 44, works in retail, alcohol)*

The fact that SMART Recovery supports harm reduction as well as abstinence was also seen as part of its appeal. As Jason (M, 34, studying, ice) put it:

*SMART is about choosing a level of risk or harm minimisation for you at the time. Having a list of pros and cons of using, pros and cons of not using.*

Those who have taken part in **other self-help groups** said their **benefits** include providing support to initiate and maintain change, and an opportunity to discuss difficult experiences and develop strategies to manage consumption. For example, Renee (F, 35, works in hospitality, ice) reported that going to a self-help group for Aboriginal women gave her a support network and an opportunity to learn about issues that were relevant to her:

*These women's groups that I used to go on used to make me feel so normal because it's the same girls going through the same stuff. It didn't matter what your poison was, you know. They were all just very supportive of each other and things like that, you know [...] One week we would be talking about foetal alcohol syndrome. Another week we would be talking about hep C, you know [...] just all health issues that Aboriginal-identified women were having trouble with. Anything to do with alcohol and drugs that we'd be sort of open to hear.*

## 5. What is recovery and how important is it?

A topic that sometimes emerges in discussions of addiction is 'recovery'. Alcohol and other drug professionals have different views on the idea of recovery, and there is little agreement about what it means or how to assess it, or indeed whether the concept is relevant to experiences of addiction or dependence. Recognising that definitions of recovery are no less complex and varied than those of treatment or addiction itself, participants were asked what they understand by the term 'recovery' and whether it is relevant to their experience.

Perhaps unsurprisingly given the lack of consensus on the meaning of recovery, participants expressed a range of views about the idea. While many opted not to use the term 'recovery' to describe their own experiences, **most shared the view that it usually refers to giving up alcohol and other drugs altogether**, with some noting that this prospect can be frightening. For example, Dawn (F, 38, works in manufacturing, alcohol) expressed concern about remaining abstinent when she leaves residential treatment but said she was looking forward to returning to being her 'real' self:

*I'm afraid of [the idea of recovery] in the sense where, I've got to be honest, I really am going to miss alcohol. It's been part of me for so long. Even though I felt like it was my friend, it really wasn't, but on the other side of recovery, it's great, I mean, just to be able to be sober and live my life without alcohol in my system and to be able to [...] be real and be that person, be me without alcohol. Because that helped a lot too in social situations, the alcohol. I could come out and have the fake confidence. But yeah, that'll be great, health wise, mentally, physically, but I really am scared to be without it [...] I'm all for [recovery] I just don't know if it's going to work for me.*

While some associated recovery with stopping, others took a different view, saying it **involves reducing or moderating consumption and minimising the risks** they see as related to it:

*Well, there's short-term recovery so you party*

*for a weekend and then you [...] recover [...] Your recovery is the period of [getting] through the comedown, and starting to feel better, and eating, and going back to the gym [... But, like] I suppose [you could say] I've been in periods of recovery, like, where [...] I didn't use [crystal] for the first five months when I [moved] here. Now that, I suppose, is recovery, but I did it on my own and I've had lots of periods like that. (Zac M, 53, works in health services, party drugs)*

For some, recovery does not just refer to patterns of consumption but is also about **dealing with mental health and emotional issues**, along with **developing self-awareness**. For example, Lala (F, 35, works in health services, cannabis) offered a broad view of recovery as regaining 'wholeness and wellness':

*I think [...the idea of recovery] does resonate, but I don't think it's from drug use [...] I think it's recovery from the stuff underneath, and I think that's what is really scary [...] knowing that it's a lot more than just about stopping drug use. It's about dealing with everything that's underneath and finding a way to live without it and to live with all the pain [...] and still function [...] It's recovering wholeness and wellness in a deep way.*

Others noted the social dimensions of recovery, suggesting it should involve **reconnecting with people**:

*Rather than focusing on taking something away from people, I think recovery ought to be focused on reconnecting people. I know that in a situation where I feel loved and supported, heard, respected, whatever, I'm not as thirsty. But if I feel I have to fight for recognition, [I'm] not happy about that, and I tend to drink more. (Phoenix, M, 48, works in the media, alcohol and prescription painkillers)*

The term 'recovery' is widely used in healthcare settings but some of our participants **questioned its relevance when applied to alcohol and other drug**

**consumption.** They observed that the idea of recovery implies that a person is sick or otherwise has a problem that needs to be addressed, adding that they do not see their consumption in these terms. As Rachel (F, 50, works in the health sector, heroin) explained:

*If you're recovering, it implies there's something wrong with you to start with, right, you are recovering from something. But I don't think there's anything wrong with drug use, I really don't [...] I believe that I use [drugs...because] sometimes it's just fun. Sometimes you just want to relax. Sometimes it feels really nice [...] I really like it.*

While recovery usually involves renouncing drug use, Rachel and others expressed no desire to do so and instead presented their consumption as an important part of their lives with benefits as well as disadvantages. For such consumers the idea of recovery is at best irrelevant, and at worst, alienating and stigmatising as it effectively pathologises continued consumption. **It is therefore essential that an awareness of diverse consumption trajectories be integrated into policy and service delivery via, for example, an increased emphasis on harm reduction measures and other strategies that accommodate continued consumption and a recognition of the positives people can experience from it.**

## 6. Messages to health professionals and policymakers

Recognising that people who have accessed services or been through treatment often have suggestions for improving policy and service delivery, participants were asked to comment on any **gaps in alcohol and other drug services** and **barriers to accessing services** that they may have encountered. Drawing on their experiences, they made **suggestions for improving treatment and harm reduction services** such as ensuring wider access to services, providing continuity of care and addressing the stigma surrounding drug use. The need for culturally accessible services was also highlighted. Several questioned the effectiveness of prohibitionist drug laws and called for **drug law reform**, with some expressing support for the legalisation of cannabis.

### Drug law reform

Several participants questioned the effectiveness of current alcohol and other drug policy approaches and called for drug law reform. For example, Jacob (M, 33, works in hospitality, cannabis) questioned the differing

legal status of tobacco and cannabis and advocated for the legalisation of cannabis:

*People that think [cannabis] is like the devil and all that stuff, it's not [like that]; it's okay. Cigarettes are heaps worse than marijuana, and they are fully legal and taxed [...] so it's really important to me [that cannabis be legalised], especially as a smoker, especially because what I'm doing on a day-to-day basis is illegal and I don't want to break the law. I'm not out there, you know, to cause trouble and stuff. Like, I just want to smoke my joint and be left alone so it is very important for me the whole legalisation thing [...] I've been] trying to sign whatever petition I can and go to meetings, and go to gatherings.*

### Improving services

Participants suggested a range of ways alcohol and other drug services and allied health services could be improved and these are detailed in the table below.

#### Suggestions

**Address other aspects of life that shape consumption**

#### Indicative quotations

*I find it's often very much focused on the drug use itself, and [...] my impression of services is that there's not much support for the emotional and spiritual stuff that underlies problematic drug use. And I feel like that's what I need help with [...] I don't see any information around coping mechanisms, emotional care of self, how to deal with uncomfortable emotions, strategies when relationships are dysfunctional.*

(Lala, F, 35, works in health services, cannabis)

**Provide better continuity of care, e.g. aftercare and re-integration programs**

*[Rehabs] are incredibly structured environments and I don't think they really set people up for the real world afterwards [...] Just taking someone out [of their normal life] and putting them in a rehab, where everything's lovely and the meals come three times a day, the washing gets done for you. It's a very unreal environment [...] It's like people who come out of jail who have become institutionalised, they have nowhere else to go but the environment that put them in jail in the first place, with the abusive [...] partner, and the screaming kids.*

(Helen, F, 53, not working due to injury, heroin)

**Offer stigma and discrimination training as a core part of workforce training in the health sector**

There's clearly such a high level of stigma and discrimination, and misunderstanding of drug users and drug use. And they're professionals, they need to work that out. I mean, you know, that's just unprofessional. I think there needs to be much more training for healthcare professionals.

(Zadie, F, 33, works in the health sector, heroin)

## Suggestions

## Indicative quotations

Improve the availability and delivery of services by:

### Increasing funding

*I really think there needs to be more pharmacotherapy places [...] And yeah, there's private clinics around that you can get into, but like on the dole, if you're just starting out on a treatment journey, then you don't have like \$80 [...] a week to have to fricking pay for that [...] so the cost of treatment is] a big deterrent.*

(Kate, F, 36, works in the health sector, prescription drugs and ice)

### Improving access to information

*Nobody really wants to give you a lot of information to begin with when you're on the drug [...] For me personally, I wish there was a lot more of that [information] in the community, because to start with I had absolutely no idea where to go, where to start.*

(Zoe, F, 30, studying, ice)

### Speeding up intake and assessment times

*[They also need to reduce] the long waiting lists [...] Like, even just to have your first initial assessment, I think that was about three or four weeks that I was on a waiting list for that, and then it was, I think, another six weeks on the waiting list to get into the detox [...] I mean, it's a lengthy process.*

(Zoe, F, 30, studying, ice)

### Provide workforce development to ensure delivery of culturally sensitive services

*I'm Aboriginal-identified, yeah, so my culture is a big part of me. So I would really love [it] if all rehabs were Aboriginal-identified culturally friendly, if that makes sense [...] [For example, rehabs could] have an Aboriginal worker, get their culture in their programs where they can just be Aboriginal and do their thing. Here [at this rehab] I just pray a lot to my ancestors here because that's all I can do at the moment, because there's no programs within these programs about my culture.*

(Renee, F, 35, works in hospitality, ice)

## 7. Narrating lived experiences and challenging addiction stereotypes

A key aim of the study was to present participant experiences in the context of whole lives. To do this, we composed participant biographies drawing on the de-identified interview data and fieldnotes written after each interview outlining the key points in each person's narrative. **Participants were invited to review their biographies and those who did generally confirmed their accuracy** (any errors of fact or emphasis were corrected).<sup>3</sup> Contrary to common stigmatising assumptions, the biographies show that many people who see themselves as affected by addiction cope, and lead rich, full lives, regulating their consumption, actively managing the risks of heavy use and looking after their health. In the interests of brevity, we quote select extracts from the biographies below. Full biographies can be found in the 'Personal Stories' section of the [Lives of Substance website](#).

The biographies open with a general summary of participant interests and lifestyles:

*Bill works part-time in retail and enjoys spending time doing outdoor activities with his wife and two children. He goes camping and bush walking, and also enjoys cycling, skateboarding and swimming at the beach. A creative person, he also paints, draws and takes photographs.*

*Helen has completed a PhD, which involved research overseas, and has written several books. In the past she worked in the health sector. She has a teenage child and describes becoming a mother as 'the best thing [she] ever did'. She's fond of walking, travelling and spending time with her child.*

<sup>3</sup> Participants were invited to correct any errors and indicate any information they did not want included. Only five of those who opted to review their biography requested any changes, including correcting minor inaccuracies and removing potentially sensitive information.

These accounts show that those living under the sign of 'addiction' are **whole people with multifaceted lives**. In many respects their experiences do not fit with the usual reductive narratives. These findings point to **a pressing need to see those affected holistically, rather than as a series of problems**.

The accounts show how participants cope with consumption patterns that would attract a diagnosis of addiction or dependence:

*In her early twenties, Helen moved interstate to go to university. She says she 'drifted into' a 'population of people' who took heroin and began taking it herself. Heroin, she says, made her 'feel much better about doing' her day-to-day tasks and 'a bit more inspired' to 'sit and write'. She continued to take it [daily] for several years, while completing her university studies and working overseas. She found that 'money wasn't really a problem' while she was working full time and doing occasional sex work. However, at various times over the years, her income was limited and she found it hard to afford heroin. At these times she reduced her consumption by completing residential detox programs, or by moving to places where heroin was less easily available.*

Like Helen, 50-year Rachel manages her consumption to maximise the benefits she says it offers her:

*Rachel met her current partner when she was in her mid-thirties and they began taking heroin together [...] After some time Rachel says she felt 'physically dependent' on heroin and would get 'really crook' if she didn't take it. In her late thirties, she became pregnant and started opioid pharmacotherapy treatment (methadone maintenance treatment [MMT]). After she had her child, Rachel returned to work, resumed taking heroin, and remained on MMT.*

*In the years before the interview, Rachel has been working full time to support her*

partner and child. She now limits her heroin consumption to a few days a weeks after work for 'fun' and 'to relax', as she says this contributes to her 'mental health'. In the future, she plans to stay on MMT as it helps her manage her heroin consumption.

Accounts such as these show that many see **regular consumption as able to enhance health and well-being, as well as diminish it**. These findings support the need identified in past research (Duff, 2015; Race, 2008) for **more nuanced, effective responses that do not treat regular or heavy consumption as necessarily harmful to health**.

Acknowledging this more explicitly would allow for the provision of additional resources that support people who regularly consume alcohol and other drugs to maintain their health and well-being.

The patterns and dynamics tracked in the biographies also showed that for some, **consuming certain drug(s) can ease, or aid coping over time with, chronic physical and emotional pain or distress**:

*George [(58)] lives in a boarding house and describes feeling quite socially isolated. Every day he meets some of the 'old folks' at a nearby café for a cup of coffee and a chat. Then he visits his local primary healthcare service because it offers him 'good company, people [...] chat with and have a cup of tea, read the newspaper, stay out of the bar'. When the service closes, he goes home, puts the radio on, has 'a few cones' of cannabis and does some painting or drawing. In the evening when the night stretches ahead of him, George says the 'alcohol habit hits' and he thinks: 'What am I going to do tonight? I don't watch TV, there is only so much radio you can listen to, so many drawings you can do [...] And the next minute, I'm getting together seven bucks to buy a cheap bottle'. He describes the alcohol habit as a 'daily ritual created by [his] isolation'.*

*Phoenix [(48)] says he grew up in a 'violent home' and that his parents were 'alcoholics'. He began drinking regularly after leaving home*

*in his mid-teens when his parents separated. He says he supported himself financially during high school by 'thieving', for which he was later arrested and given a custodial sentence of several months. After his release he moved to another city and began working in the construction industry. At the time he says he 'drank fairly well all day, every day' [...] A year or so later Phoenix had a motorcycle accident and broke his back. To treat the pain associated with the injury, he was prescribed Panadeine Forte (a combination of paracetamol and codeine) but says he began drinking alcohol because he found it more effective for relieving the pain than the prescribed medication.*

Many of the issues George and Phoenix describe arise out of social circumstances and the suffering they generate cannot be ascribed solely, or even largely, to consumption itself. Situating consumption in the context of whole lives highlights that **alcohol and other drug-related issues may be as much an outcome of other problems as a source of them**. This finding concurs with previous research (Fraser et al., 2007; Galea, Nandi & Vlahov, 2004; Rhodes et al., 2003) and points to an **ongoing need for greater coordination between alcohol and other drug services and other agencies so that collaborative approaches to the care of clients can be enhanced**.

Individually and together the biographies show that people who see themselves as affected by addiction have extremely varied experiences of regular consumption. These warrant understanding in ways other than the usual reductive narratives. Many cope and lead rich lives, regulating their consumption, juggling work or study, managing the risks of heavy use and looking after their health. Taking the insights generated through the biographies into account suggests strengths-based health and policy approaches focusing on whole people with skills and assets may be appropriate for many.

# Conclusion

This report details findings and recommendations from a national qualitative research project on alcohol and other drug addiction, dependence or habit in Australia, undertaken between 2014 and 2016. The findings and recommendations are based on interviews with 60 people affected by addiction issues from a variety of different backgrounds living in Victoria and New South Wales. Interview questions addressed participants' experiences of living with addiction, including how consumption fits into daily life, coping with stigma and discrimination, seeking help or initiating change, experiences of treatment, and views on the idea of recovery.

A key concern for many of those interviewed is coping with the **stigma associated with addiction and drug use**, with participants describing the impact of stigma on their everyday lives, including how it shapes experiences of healthcare, relationships, decisions to disclose and experiences of work and study. In light of these accounts of addiction-related stigmatisation, **the report makes a number of recommendations for combating stigma in the contexts most commonly described by participants, namely the health system, the workforce and the media.**

Language and terminology emerged as an important issue for some participants concerned about stigma (for example the terms 'dependence', 'addiction' and 'recovery,' were considered stigmatising for some). In relation to this, several commented that even though their drug use is regular and holds a key place in their lives, they do not see it as an illness that they need to 'recover' from, or a problem that needs to be addressed. Instead they presented it as an important part of their lives with benefits as well as disadvantages. These findings point to the limitations of dominant discourses and the **need for alternative ways of framing regular, heavy alcohol and other drug use without pathologising it as 'addiction'**. Similarly, a need exists to **take on board increasing calls for decriminalisation** as a means of reducing the harms associated with policing and criminalising drug use, and with the related stigmatisation of addiction.

Most of our participants were working or studying

and described the various ways in which they **strike a balance between their work or study commitments and regular consumption**. They also described how consumption fits in with their other everyday responsibilities and how they manage it to maximise benefits and minimise harms. Related to this, participants discussed how they initiate and maintain change using a variety of formal and informal strategies. Some of these changes occur without any particular plan or effort, and others are part of broader changes to lifestyle and individual circumstances. Moving to a new location can prompt change by shaping access to treatment services and informal support structures that play a role in maintaining new patterns of consumption. Transitions into and out of residential treatment and custody are particularly important in this regard, underscoring the need identified in past research (Binswanger *et al.*, 2012; Griswold *et al.*, 2008; NSW Health, 2007; Taylor, Thompson & Davis, 2010) to ensure effective post-treatment and post-release care. More generally, it is essential that **policy recognises and supports the range of ways in which people change their patterns of consumption** in order to ensure genuinely responsive care for those in need of it. Service providers should ensure that **access to resources and care is maintained when individuals relocate and/or their living arrangements change.**

In relation to experiences of formal treatment, many participants reported difficulty accessing treatment and long waiting times. The high demand for treatment points to a **need for increased funding for treatment in Victoria and New South Wales**. Some of those interviewed were recipients of opioid pharmacotherapy treatment, and described particular challenges in managing employment and other responsibilities due to the structured dosing arrangements of pharmacotherapy treatment. Takeaway doses were described as centrally important in finding and retaining employment, facilitating travel, fulfilling everyday commitments, and the reduction or cessation of illicit drug use. These issues have been documented in Australia since at least 2007 and our research suggests a continuing

need to address them. In particular, the findings point to the need to ensure that **policy on takeaways is sufficiently flexible to accommodate differences in clients' circumstances and allow prescribers to manage treatment on an individual basis.**

Some of those with experience of residential treatment reported a lack of follow-up or continuous care, while others noted that the institutional environments of residential centres made it difficult to return home and resume everyday responsibilities. Their experiences point to **a need for better continuity of care, including aftercare and support for those undergoing treatment in residential settings.**

In addition to exploring key themes relating to everyday life with addiction, the interview material was used as the basis for composing participant biographies, which situated individual experiences in the context of whole lives. Together with the thematic analysis of the interview data, the biographies raised many important questions about addiction stereotypes:

- ▶ Contrary to the commonly held view that addiction is a disastrous state, associated with suffering and misery, many people who see themselves as affected by addiction cope and lead rich, full lives. Moreover, their experiences can be understood in ways other than the usual reductive narratives. These findings point to **a pressing need to see those affected as whole people with complex lives, rather than as a series of problems. Strengths-based approaches focusing on whole people with skills and talents may be appropriate for many.**

- ▶ People who identify as experiencing addiction often report carefully regulating their consumption, actively managing the risks of heavy use and looking after their health. For many, regular consumption is experienced as capable of aiding health as well as impeding it. These findings suggest a **need for more nuanced, effective responses that do not treat consumption as necessarily inimical to health. Policy and practice should provide more resources that support people who regularly consume alcohol and other drugs to maintain their health and well-being.**

- ▶ By situating consumption in the context of whole lives, the biographies make clear that alcohol and other drug-related issues may be as much an outcome of other problems as a source of them. This finding concurs with previous research (Fraser *et al.*, 2007; Galea, Nandi & Vlahov, 2004; Rhodes *et al.*, 2003) and points to an **ongoing need for greater coordination between alcohol and other drug services and other agencies so that collaborative approaches to client care can be enhanced.**

Overall, these findings indicate that people who see themselves as affected by addiction issues are extremely diverse, and their experiences of consumption are equally varied. If services are to be responsive to individual needs, a fuller awareness of this diversity, and of the limitations of narrow understandings of addiction, needs to be integrated into policy development and service design and delivery.

# Website evaluation survey findings

As noted, this project's main outcome is a new online resource [livesofsubstance.org](http://livesofsubstance.org), Australia's first dedicated website presenting carefully researched personal stories of alcohol or other drug addiction, dependence or habit. These stories are presented in people's own words using video re-enactments, original audio recordings and written extracts from the interviews. Also presented are the key themes discussed above (called 'Topics' on the site), such as consumption in everyday life, coping with stigma, and looking after health and well-being. [Livesofsubstance.org](http://Livesofsubstance.org) was launched publicly in October 2016 and evaluated via a short online survey of website visitors. Below we outline the findings of the evaluation which indicate that the site is reaching its target audiences of the general public, those affected by addiction, and alcohol and other drug professionals; the personal stories are considered helpful and informative; and visitors overwhelmingly indicate they will recommend the site to others. Further evidence of the impact and reach of the website is presented in Appendix 4.

## Evaluation method

An open invitation to complete the anonymous online survey was included on the website for one month after the launch. It was also promoted on social media and via announcements in professional newsletters. Survey respondents were asked to indicate why they were interested in the website, which parts were most helpful or informative, whether they would recommend the site to others, and what could be improved (see Appendix 3 for survey tool). Sixty responses were received and the findings are presented below.

## Results

### Who visited and what were visitors seeking?

The majority of survey respondents were aged over 30 years (93%) and equal proportions identified as male and female (47%), with 7% indicating 'other'. When asked why they were interested in the website

(multiple answers could be chosen):

- ▶ 33% wanted to learn more about addiction or dependence
- ▶ 33% were interested because they worked in the alcohol and other drug sector, health services or government
- ▶ 20% were interested because they were a student or researcher
- ▶ 13% indicated that their interest in the website was related to their own or others' drug use

These figures reflect the diverse audiences the website targets and their reasons for visiting. The relatively high proportion of professionals who responded may be a product of promotional activities targeting alcohol and other drug service providers and health services. It also indicates the website's utility as a training and information resource for health professionals, practitioners and policymakers.

### Which aspects of the website were most useful?

When indicating which parts of the website were most helpful or informative, the most frequent response given was the Personal Stories (75%), followed by the Topics (or key themes, many of which are presented above) (58.3%), the Welcome/Introduction on the home page (50%), and the Resources and Information page (35%). The vast majority of respondents (93%) indicated that they would recommend the website to others. More specifically, respondents indicated that they found the website helpful because it allowed them to:

- ▶ Learn about people's experiences of self-help, treatment or changing consumption practices (58.3%);
- ▶ Learn more about alcohol and other drug addiction or dependence (45%); and
- ▶ Hear/read about experiences that were new or unfamiliar to them (38.3%).

In addition to this general feedback, respondents' qualitative comments indicate the features of the website that they found most valuable:

## Website feature

### Presents content informatively and accessibly

## Indicative quotations

*Great and very comprehensive website. Someone close to me has a drug issue and I found the site very helpful. (Respondent 26)*

*It's a really great website. Easy to navigate and very informative. (Respondent 29)*

### Challenges stereotypes of alcohol and other drug use and addiction

*Using stories from real people helps us look beyond the stereotypes and challenges prejudices surrounding drug consumers. (Respondent 48)*

*I like the way that drug use is not positioned as the central defining feature of the people on the site. It's good to highlight how drug use is part of a person's whole life which is a complex and worthwhile as the lives of those who do not use drugs. (Respondent 25)*

### Offers non-judgmental, balanced content

*This website presents a really balanced view [of] people who describe themselves as addicted or dependent on substances. (Respondent 11)*

*I liked that the stories I read did not all end with '...and then I stopped using and my life got better.' I believe that the more society acknowledges that positive change can occur regardless of use, the more people will feel prepared to enact some of those changes in their lives. (Respondent 59)*

### Presents content appealingly and relatably through use of audio and re-enacted video recordings

*Having all the videos makes this website incredibly appealing. The videos make you feel as if you can relate, more than just hearing the story. The original voice recordings are also incredibly effective. (Respondent 49)*

### Allows a range of applications

*Think this is a wonderful, thoughtful and much needed resource and intervention. Can see lots of potential applications including in terms of education, self-help, research and advocacy. (Respondent 51)*

*This is a brilliant resource — thanks. I provide AOD-related training in a workforce development capacity and the audio and video clips will be a wonderful way to illustrate information/concepts in presentations. (Respondent 4)*

## What could be improved?

When asked what could be improved or added to the website, many respondents indicated they would like to see more stories, presenting an even greater diversity of experiences:

*More stories! These are great, they put a real face on drug use. (Respondent 27)*

Other suggestions included adding a gender-neutral category of personal stories (stories are organised by age and gender), and more stories about particular drugs (e.g. prescription and over-the-counter drugs) or issues (e.g. the intersection between marginalisation and consumption; drug law reform;

more material for family members). Because addiction is stigmatised in Australia, and people associated with it face discrimination, the website's interview material was altered to protect the identities of participants. Notably the video clips were produced using actors who re-enacted the original interview material and a few respondents expressed a desire to see real people in the videos rather than actors:

*if [it's] about decreasing stigma, how about doing it so we (as users) don't have to hide [e.g.] behind actors (Respondent 44)*

These comments highlight an ongoing need to combat addiction-related stigma and reform

prohibitionist drug laws so that people can share their experiences publicly without fear of discrimination and/or the threat of legal action. A few respondents also offered content and design suggestions, which we incorporated where possible in making updates to the website.

The survey results indicate the value of online alcohol and other drug resources such as [livesofsubstance.org](https://www.livesofsubstance.org) that present balanced accounts of drug use experiences in an engaging, accessible format using people's own words. Importantly, they highlight the **pressing need to reduce drug-related stigma by challenging stereotypes and presenting a diverse range of experiences** including those not commonly heard in public discourse.

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# Appendix 1: Table of participants

Gender <sup>^</sup>	Number
Men	35
Women	25
Main preferred drug*	
Alcohol	11
Cannabis	14
Opiates	14
Stimulants	12
'Party drugs' (e.g. MDMA, GHB)	4
Prescription and over-the-counter drugs	5
Employment status	
Working or studying	41
Not working or studying	19
Age	
18-29	14
30-39	20
40-49	14
50+	12
Education level	
Secondary	26
Post-secondary	12
Tertiary	22

Cultural & ethnic background~	Number
Australian	31
Australian Aboriginal	2
New Zealander	1
Polynesian	2
North-West European	12
Southern and Eastern European	4
North African and Middle Eastern	1
South-East Asian	1
North-East Asian	2
North American	2
Southern and Eastern African	2
Sexuality	
Heterosexual	41
LGBTIQ+	18
Unspecified	1
Residential location	
Urban	40
Regional	20

<sup>^</sup> All participants identified as either male or female.

\* Some participants described consuming only one drug, while others talked about two or more. The table lists the drug that participants identified as their primary preferred drug.

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

# Appendix 2: Publications and presentations

## Refereed journal articles

### **New narratives, new selves:**

#### **Complicating addiction in online alcohol and other drug resources**

Kiran Pienaar, Suzanne Fraser, Renata Kokanovic, David Moore, Carla Treloar, Adrian Dunlop  
*Addiction Research & Theory*, 2015: 23(6), 499–509.

Within the expansive qualitative literature on alcohol and other drug use, knowledge of lived experiences of addiction is limited with much of the existing scholarship reifying addiction as a disastrous state, and imputing negative attributes to those experiencing it. Such research discounts the many ways people live with regular alcohol and other drug use and is unable to tell us much about how addiction emerges through, rather than precedes, people's experiences and understandings of it. This article draws on the theoretical literature on the production of social problems and the concept of 'ontological politics' to introduce an innovative approach to understanding lived experiences of addiction. Applying this literature to a critical analysis of personal narratives from two Australian alcohol and other drug websites, we demonstrate how addiction is conceived narrowly in these narratives as a disorder of compulsion, amenable to treatment. Not only does this conception reproduce unhelpful assumptions about addiction, it also reifies it as a stable, unified entity, the boundaries of which are fixed. Against this familiar account, we conceive addiction as an emergent, fiercely contested phenomenon, constituted in part through the very measures designed to treat it. This shift in focus allows an innovation in engaging with addiction, which is being pursued in a new Australian research project: the development of a public website presenting lived experiences of addiction that will be 1) a means of challenging existing public discourses, and 2) an intervention in the social production of addiction. The article concludes by considering the politics of this approach and how it might reshape addiction.

### **Diffractioning addicting binaries:**

#### **An analysis of personal accounts of alcohol and other drug 'addiction'**

Kiran Pienaar, David Moore, Suzanne Fraser, Renata Kokanovic, Carla Treloar, Ella Dilkes-Frayne  
*Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*.  
Early online, November 10, 2016.

Associated with social and individual harm, loss of control and destructive behaviour, addiction is widely considered to be a major social problem. Most models of addiction, including the influential disease model, rely on the volition/compulsion binary, conceptualising addiction as a disorder of compulsion. In order to interrogate this prevailing view, this article draws on qualitative data from interviews with people who describe themselves as having an alcohol or other drug 'habit', 'dependence' or 'addiction'. Applying the concept of 'diffraction' elaborated by science studies scholar Karen Barad, we examine the process of 'addicting', or the various ways in which addiction is constituted, in accounts of daily life with regular alcohol and other drug use. Our analysis suggests not only that personal accounts of addiction exceed the absolute opposition of volition/compulsion, but also that the polarising assumptions of existing addicting discourses produce many of the negative effects typically attributed to the 'disease of addiction'.

### **Addiction stigma and the biopolitics of liberal modernity: A qualitative analysis**

Suzanne Fraser, Kiran Pienaar, Ella Dilkes-Frayne, David Moore, Renata Kokanovic, Carla Treloar, Adrian Dunlop  
*International Journal of Drug Policy*.  
Early online, March 30, 2017.

Definitions of addiction have never been more hotly contested. The advance of neuroscientific accounts has not only placed into public awareness a highly controversial explanatory approach, it has also shed new light on the absence of agreement among the many experts who contest it. Proponents argue that calling addiction a 'brain disease' is important because it is destigmatising. Many critics of the neuroscientific approach also agree on this point. Considered from the point of view of the sociology of health and illness, the idea that labelling something a disease will alleviate stigma is a surprising one. Disease, as demonstrated in that field of research, is routinely stigmatised. In this article we take up the issue of stigma as it plays out in relation to addiction, seeking to clarify and challenge the claims made about the progress associated with disease models. To do so, we draw on Erving Goffman's classic work on stigma, reconsidering it in light of more recent, process oriented, theoretical resources, and posing stigmatisation as a performative biopolitical process. Analysing recently collected interviews conducted with 60 people in Australia who consider themselves to have an alcohol or other drug addiction, dependence or habit, we explore their accounts of stigma, finding experiences of stigma to be common, multiple and strikingly diverse. We argue that by treating stigma as politically productive – as a contingent biopolitically performative process rather than as a stable marker of some kind of anterior difference – we can better understand what it achieves. In turn this allows us to consider not simply how the 'disease' of addiction can be destigmatised, or even whether the 'diseasing' of addiction is itself stigmatising (although this would seem a key question), but whether the very problematisation of 'addiction' in the first place constitutes a stigma process.

### **Challenging the addiction/health binary with assemblage thinking: A qualitative analysis**

David Moore, Kiran Pienaar, Ella Dilkes-Frayne, Suzanne Fraser  
*International Journal of Drug Policy*.  
Early online, April 18, 2017.

Critical analyses of drug use and 'addiction' have identified a series of binary oppositions between addiction and free will, independence, self-control, responsibility, productivity and autonomy. This critical work has also examined how science, policy and popular discourses frequently characterise alcohol and other drug (AOD) addiction as antithetical to health and well-being. Furthermore, those diagnosed with AOD addiction are often understood as indifferent to health and well-being, or as lacking the knowledge or desire required to maintain them. In this article, we draw on data from 60 qualitative interviews with people who self-identify as living with an AOD 'addiction', 'dependence' or 'habit', to argue that the binary opposition between addiction and health struggles to attend to their rich and varied health perspectives and experiences. We explore three themes in the interview data: reinscribing the binary opposition between addiction and health/well-being; strategies for maintaining health and well-being alongside addiction; and AOD consumption as aiding health and well-being. Perhaps because addiction and health have been so thoroughly understood as antithetical, such perspectives and experiences have received surprisingly little research and policy attention. Yet they offer fertile ground for rethinking the strengths and capacities of those who self-identify as living with an AOD addiction, dependence or habit, as well as untapped resources for responding to the harm sometimes associated with AOD use.

**Iterating ‘addiction’: Residential relocation and the spatio-temporal production of alcohol and other drug consumption patterns**

Ella Dilkes-Frayne, Suzanne Fraser, Kiran Pienaar, Renata Kokanovic

*International Journal of Drug Policy.*

Accepted for publication, May 6, 2017.

Addiction is generally understood to be characterised by a persistent pattern of regular, heavy alcohol and other drug consumption. Current models of addiction tend to locate the causes of these patterns within the body or brain of the individual, sidelining relational and contextual factors. In this article we query this approach, inspired by accounts of residential relocation found in interviews undertaken for a large research project on experiences of addiction in Australia. In conducting our analysis we conceptualise alcohol and other drug consumption patterns using Karen Barad’s notions of intra-action and spatio-temporality, arguing for greater attention to the spatial and temporal dimensions of the material and social processes involved in generating consumption patterns. Drawing on 60 in-depth interviews conducted with people who self-identified as experiencing an alcohol and other drug addiction, dependence or habit, our analysis focuses on the ways in which patterns of consumption were generated, disrupted and maintained across time and place. In doing so it illuminates how these patterns are produced within highly localised relations, demonstrating the need for understandings of consumption patterns that acknowledge the indivisibility of space and time in their production – that address the spatio-temporality of consumption and daily life. In concluding, we argue for a move away from static conceptions of place, and sceptical assessments of relocation as ‘geographic cure’, to consider avenues for integrating place and time better into strategies for generating preferred consumption patterns and initiating and sustaining change where desired.

**Telling life stories, making selves: A critical analysis of ‘addiction’ biographies**

Kiran Pienaar, Ella Dilkes-Frayne

*International Journal of Drug Policy.*

Accepted for publication, May 5, 2017.

Personal narratives of alcohol and other drug addiction circulate widely in popular culture and they also have currency in professional therapeutic settings. Despite this, relatively little research has explored the conventions operating in these narratives and how they shape people’s experiences and identities. While addiction biographies are often presumed to be straightforwardly ‘true’ accounts, in this paper we draw on the insights of critical alcohol and other drug scholarship, and science and technology studies theory to argue that they produce normative ideas about addiction and those said to be experiencing it. Our analysis compares traditional addiction narratives with the biographies we reconstructed from qualitative interviews with 60 people in Australia who describe themselves as having an ‘addiction’, ‘dependence’ or drug ‘habit’. We track how addiction is variously enacted in these accounts and comment on the effects of particular enactments. By attending to the ways in which people cope, even thrive, with the kind of consumption that would attract the label addiction, the biographies we produced disrupt the classic narrative of increasing drug use, decline and eventual collapse. Doing so allows for consideration of the benefits of consumption, as well as the ways that people carefully regulate it to minimise harms. It also constitutes individuals as active in managing consumption – an important move that challenges dominant understandings of addiction as a disorder of compulsivity. We conclude by considering the implications of providing an alternative range of narratives, which resonate with people’s diverse experiences.

## Presentations

**Fraser, S. (Forthcoming 2017).** Doing ontopolitically-oriented research: Investigating and enacting lives of substance. *Contemporary Drug Problems Conference*, Helsinki, Finland, 23-25 August.

**Fraser, S. (Forthcoming 2017).** Rethinking addiction: Promoting understanding and reducing stigma. Invited plenary presentation and discussion panel. *Counties Manukau Alcohol and other Drug Research Symposium*, Auckland, New Zealand, June 14.

**Farrugia, A. and Fraser S. (2017).** Experiences of alcohol and other drug addiction, dependence or habit in Australia: Findings from a national qualitative study. *Addiction Conference*, Gold Coast, 15-17 May.

**Dilkes-Frayne, E. (2016).** Producing continuity and change in drug consumption in the dynamic spaces of daily life. *Social Studies of Addiction Concepts (SSAC) and Monash University Law Faculty research symposium: Social and legal concepts of addiction*, Melbourne, 7 October.

**Dilkes-Frayne, E. (2016).** How does place generate or disrupt alcohol and other drug consumption? Residential relocation in accounts of 'addiction'. Lives of Substance (LoS) Symposium: Experiences of Addiction, Dependence or Drug Habit in Australia. *Australasian Professional Society on Alcohol and other Drugs (APSAD) Conference*, Sydney, 31 October.

**Fraser, S. (2016).** Beyond disease: Responding to accounts of 'addiction'-related stigma and discrimination. LoS Symposium. *APSAD Conference*, Sydney, 31 October.

**Moore, D. (2016).** Consumer accounts of 'addiction', health and well-being: Implications for policy and practice. LoS Symposium. *APSAD Conference*, Sydney, 31 October.

**Moore, D. (2015).** Challenging addiction. Invited keynote address at the *Australian Youth Alcohol and other Drugs Conference*, Melbourne, 25 August.

**Pienaar, K. (2015).** A new online resource on lived experiences of alcohol and other drug addiction in Australia. *Turning Point seminar*, Melbourne, 24 June.

**Pienaar, K. (2015).** Beyond the volition/compulsion binary: A diffractive reading of personal accounts of alcohol and other drug (AOD) addiction. *Contemporary Drug Problems Conference*, Lisbon, Portugal, 16 September.

**Pienaar, K. (2015).** New narratives, new selves: Complicating addiction in online alcohol and other drug resources. *Victorian Substance Use Research Forum*, Melbourne, 28 April.

**Pienaar, K. (2016).** Telling stories, making selves: A critical analysis of addiction biographies. *SSAC and Monash University Law Faculty research symposium: Social and legal concepts of addiction*, Melbourne, 7 October.

**Pienaar, K. (2016).** Telling stories, making selves: A critical analysis of 'addiction' biographies. LoS Symposium. *APSAD Conference*, Sydney, 31 October.

# Appendix 3: Interview guide and website evaluation survey tool

## Interview guide

This project explores people's experiences of alcohol and other drug addiction, **whatever that means to them**, how they cope and how they make decisions about drug use, treatment and everyday life. This research will help us develop a website with information for people experiencing issues with alcohol and other drugs, and those working to support them.

- ▶ All participants are invited to tell their story about living with [addiction/dependence/a drug problem/a drug habit/insert term participant uses throughout] after which all are asked additional questions to clarify key points. All participants are also asked about their general health, mental health, priorities in life and outlook for the future.
- ▶ You don't have to talk about anything you feel uncomfortable with and you don't have to answer any questions you don't want to.
- ▶ Everything is kept confidential and a range of strategies will be used to protect your identity if you are quoted (as outlined in the consent form you have signed).
- ▶ To protect your identity, try to avoid using names. If you do mention any names, we will change or remove them.

## Opening question inviting uninterrupted narrative of living with addiction/dependence/a drug habit

- ▶ Can you tell me why you were interested in participating in this study?
- ▶ Extra prompts: Do you consider yourself to have an [addiction/dependence/drug habit]? What, if anything, prompted you to think so? Can you tell me about your experience of living with this [addiction/dependence/drug habit] from when you first thought you might be experiencing it?

## Experiences of drug use and [addiction/dependence/a drug habit]

- ▶ **Day-to-day experience of drugs:** when did you start taking your preferred drug(s)? What do these drugs 'do'?
- ▶ **How does drug use contribute to daily life?** Can you tell me about a typical day/week and how drug use fits in?
- ▶ **Living with [addiction/dependence/a drug habit]:** experience of diagnosis (if relevant), telling people/keeping it confidential, talking about it with healthcare professionals, any experiences of overdose, looking after health and well-being, **coping with this way of life (practical strategies).**
- ▶ **Experience of criminal justice system and policing** including searches, sniffer dogs, arrests, custodial sentences.
- ▶ Role of **drug laws** in shaping everyday life and risks. Views on drug laws.

## Experiences of alcohol and other drug-related healthcare, treatment and recovery

- ▶ Experiences with **alcohol and other drug services** (e.g. harm reduction services). Did contact with services change your experience? Ease/difficulty in accessing service. Opinion of service.
- ▶ Have you tried any **drug treatment?** **Seeking treatment:** What prompted it? Where did you go/who did you consult? Treatment options and how were decisions made? Types of treatment tried?
- ▶ **Experiences of treatment:** what kind of treatment, unwanted effects, coping with them, impact on daily activities, impact on relationships and social life. Multiple treatment experiences: how many of each type and best/worst treatment? If no experience of treatment, would you consider it? Under what circumstances? Incentives/disincentives to seeking treatment?

- ▶ **Recovery:** views on recovery, what it involves, assessing recovery. Family, friends', partner's and healthcare practitioners' views of recovery.
- ▶ How is your **general health?** Any health conditions and impact on experience of [addiction/dependence/drug habit]. Experiences of primary healthcare.
- ▶ Any **mental health conditions** and impact on experience of [addiction/dependence/drug habit]? Experience of diagnosis and treatment (if relevant).

#### **Improvements in AOD treatment and healthcare**

- ▶ What is important for someone starting treatment to know? Anything you wish you'd known before starting treatment?
- ▶ Any services that you think could be added/changed/replaced? What would help you cope now?
- ▶ What does good healthcare involve for someone experiencing [addiction/dependence/a drug habit]?

#### **Views on addiction**

- ▶ How would you describe addiction: What is it? Why does it happen? Three words to best describe it? What do you think about the term 'addiction'?
- ▶ How do you think addiction is treated in: the workforce, the legal system, the health system, the media?
- ▶ Feelings about the future and priorities in life
- ▶ How do you feel about the future? How, if at all, do drugs and alcohol feature in your vision of the future?
- ▶ What is important for you in life?
- ▶ What are your hobbies/what do you do for fun?

#### **Final points**

- ▶ The aim of this project is to create a resource for people wanting to learn about experiences of addiction/dependence/drug habits. Is there anything you think is important for that aim that hasn't been covered in the interview?

## Website evaluation survey tool

### Lives of Substance website feedback survey

Thank you for visiting the *Lives of Substance* website. We'd like to hear your views on this website and invite you to answer a few questions about your experience of visiting the site. This will take about **five minutes**. Your response will be anonymous.

**\* 1. I was interested in *Lives of Substance* because... (please choose all that apply to you):**

- I want to learn more about addiction or dependence
- I want to learn more about safer drug consumption
- I'm concerned about my alcohol and other drug consumption
- I'm concerned about someone else's consumption
- I work in the alcohol and other drugs sector, health services or government
- I am a student/researcher
- Other (please specify)

**\* 2. Which parts of the website were most helpful or informative to you? (please choose all that apply)**

- Welcome/introduction (home page)
- Topics (summaries of key themes with clips from interviews)
- Stories (biographies of participants and clips from their interviews)
- Resources and information (including links to support, advocacy and campaigning organisations)

**\* 3. The website helped me to... (please choose all that apply):**

- Learn more about alcohol and other drug addiction or dependence
- Learn about people's experiences of self-help, treatment or changing consumption practices
- Hear/read about experiences that were new or unfamiliar to me
- Feel supported by other people's stories
- Have more confidence to talk to someone I am concerned about
- Have more confidence to talk to professionals about alcohol or other drug consumption or addiction
- Other (please specify)

**\* 4. Would you recommend this website to others?**

- Yes
- No

**5. What would you like to see improved or added to the website?**

**6. Please leave any other feedback you would like to share with us.**

\* 7. What is your age?

- 17 years or under
- 18-29 years
- 30-39 years
- 40-49 years
- 50-59 years
- 60 years or over

\* 8. What is your gender?

- Female
- Male
- Other (please specify)

Done



# Appendix 4:

## Initial impact of livesofsubstance.org (7 October 2016 – 10 January 2017)

### Media coverage

**Radio National 'RN afternoons' interview** with project lead Suzanne Fraser and website advocate Kate Holden, 5 October 2016. Listen to the [podcast](#).

**Radio Adelaide 'Small Change' interview** with Suzanne Fraser and Kiran Pienaar, 22 Nov 2016. Listen to the [podcast](#).

### Coverage in sector newsletters

News items about the launch of Lives of Substance appeared in a range of professional network newsletters including the Australian Research Council *ARChway* newsletter, Curtin University Health Sciences News, *Drug and Alcohol Research Connections*, Network of Alcohol and other Drugs Agencies *Advocate*, Queensland Mental Health Commission Newsletter, Youth Drug and Alcohol Advice e-news, Western Australian Network of Alcohol & other Drugs Agencies, and the Victorian Alcohol and other Drug Association e-newsletter.

### Links and posts from other websites

At the time of writing, 32 organisations had provided a link to the LoS website from their own. These comprised six harm reduction organisations (three Australian and three international), seven alcohol and other drug policy and advocacy organisations (six Australian and one international), four alcohol and other drug services in Australia, five local or state-based health services, two national community organisations, two media agencies, five research and/or higher education organisations and one drug law reform blog.

### Selected social media coverage

In the 14 weeks from when it went live to the time of writing (10 January 2017), the site has attracted considerable attention on social media, generating 1046 social media referrals, the majority of which were from Facebook (66.92%) and Twitter (29.06%). The following local and international organisations have promoted the website on Twitter and Facebook\*:

Alcohol and Drug Foundation; Alcohol & Drug Information Service; Association for Participating Service Users; Centre for Social Research in Health; Counselling Online; DIPEX International; Disability and Occupational Therapy; EDP Drug & Alcohol Services UK; Enpsychedelia community radio show; Eurasian Harm Reduction Network; Health Consumers Alliance of South Australia; Hepatitis Victoria; Hume Area Pharmacotherapy Network; International Centre for Science in Drug Policy; International Drug Policy Consortium; International Network for Hepatitis in Substance Users; Kalgoorlie Local Drug Action Group; Neuroethics Australia; Queensland Mental Health Commission; Queensland Network of Alcohol and other Drugs; Uniting Care ReGen; Positive Life NSW; Small Change Radio Adelaide; Western Australia Network of Alcohol & Other Drugs; Society for the Study of Addiction; Support Don't Punish; Tamarind Trust; The Australian Sociology Association; Victorian Alcohol and Drug Association; Youth Support and Advocacy Service

*\* Reporting of specific social media mentions is limited to those trackable via the site's dedicated Twitter feed and publicly accessible posts on Facebook. Due to privacy settings applied on Facebook accounts, we cannot identify the individual sources of much of the Facebook coverage.*

## Teaching applications

**LaTrobe University** – [2016 Drugs and Addiction PHE3DUB unit](#) (2nd and 3rd year elective). Personal stories on website used to facilitate discussion on narratives and counter-narratives of drug use.

**Monash University** – [2017 Masters of Addictive Behaviours unit](#). Video re-enactments and audio recordings featured on the website will be used to generate discussion on the role of stigma in the lives of people who use drugs and how to combat stigma.

## Testimonials and feedback

*This site will be a great resource for the sector and for the general public, as it provides referral information and real life stories of people who use and/or who have a problem with their alcohol and other drug use.*

*We [the Queensland Network of Alcohol and other Drug Agencies] are in the midst of a Media Kit project to engage with Queensland media around language, values and framing on this issue and will be referring to this site for case examples. We are also encouraging our member services to view and use the site. This could be used in a variety of ways including as an opportunity for clients to hear others stories and de-stigmatise their own experiences or to encourage media who may approach them seeking someone to share their story.*

*Projects such as this give a voice to the people who use and/or have a problem with their substance use and it's a very important message for the general public, workers in the field, policy makers and media to hear, as many would otherwise, not get the opportunity.*

*Gillian Marshall-Pearce,  
Policy and Communications Officer,  
Queensland Network of Alcohol  
and other Drug Agencies*

*We are very excited about lives of substance ad [will] happily promote it [...] congratulations on this significant research and beautifully relatable website.*

*Cara Munro, Manager,  
Youth Drug and Alcohol Advice Service*

*The social history of people who use drugs remains poorly understood and our stories and experiences of drug use remain largely untold [...] And what is known about people who use drugs is heavily weighted towards the most disadvantaged and perpetuates a negative and simplistic stereotype that all people who use drugs are mad, bad and dangerous to know. I'm enormously hopeful that this website will [help...] to end this silence and misrepresentation. [Lives of Substance](#) not only humanises people who use drugs, it allows them to tell their stories in all their complexity.*

*Jenny Kelsall, Executive Officer,  
Harm Reduction Victoria*

