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AIVL National Anti-Discrimination Project

Qualitative Research Report

Prepared for:

Australian Injecting and Illicit Drug Users' League (AIVL)

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1 BACKGROUND TO THE RESEARCH

The impact of stigma and discrimination on the health and lives of people who inject or have injected drugs is significant. Although research in this area is limited, on the occasions they have been asked, people who inject drugs and those on pharmacotherapy treatments routinely identify stigma, discrimination and fear of poor treatment as the main reasons they do not access primary health and other services including Blood Borne Viruses services. Research into the general population views on drug users has also been limited, unless it has been tied to a specific project such as a safe injecting room.

AIVL has received funding to undertake a research project to identify the feasibility of developing a national campaign to address the stigma and discrimination that people who inject drugs face. As a result AIVL commissioned research to better understand the feelings of the general public in relation to injecting/illicit drug users. The research was focused on identifying the basis for the public worries and fear in regards to injecting drugs users.

The overall project aims were identified as:

- to work with AIVL to undertake a national consultation process to identify key issues within the general population that would need to be addressed in a National Anti-Discrimination Campaign;
- to conduct market research and make recommendations to inform a future campaign; and
- to develop a report based on the findings of the national consultation.

2 RESEARCH OBJECTIVES

The overall aim of the research task was to gain a better understanding of why there is a stigma attached to injecting drugs among the broader community and how these prejudices might be addressed in a future campaign.

Specifically the research sought to:

- understand the community's perceptions of people who inject;
- explore in detail the existing stereotypes;
- understand why the stigma / prejudice exists; and
- in this context how the community might respond to messages aimed at addressing misconceptions and prejudices.

3 RESEARCH METHODOLOGY

3.1 Overview

The research was conducted over two stages. The first stage of research involved consultation with key stakeholder groups of AIVL national representatives, and people who inject drugs. The second stage consisted of a five group discussions among a sample of the general community and medical professionals.

Stage One Methodology

The consultation with key stakeholders in Stage One of the study was designed to:

- provide background information for the moderator and to answer any questions that AIVL may have had about the process:
- ensure interested stakeholders are provided with a forum to voice opinions and ask questions of the research process;
- ensure all hypotheses as to why prejudice exists are tabled and then aired in subsequent groups; and
- provide the basis on which exploratory communication concepts can be developed.

The National meeting of the AIVL membership provided an opportunity to undertake Stage One of the research. Two moderated information sessions were conducted. The first comprised a round table discussion with the AIVL Hepatitis C and project steering committee. This focused on defining the parameters of the research and involved a detailed discussion about proposed sampling (see below). The second information session involved a 'workshop' style discussion with the national representatives present at the meeting, identifying their perceptions of the general public's attitudes and opinions towards injecting drug users. These are reported on in Section 4.

Stage Two Methodology

The main aims of Stage Two of the research were to understand source and depth of the stigma / prejudice to injecting and to obtain reactions to some broad communication concept ideas. These concept ideas were developed by GfK Blue Moon for the purposes of the research only. The concepts were used to determine which broad approaches in terms of messaging, tone and style of communication may have potential to be developed further into communications.

As discussed above, part of the discussion during the round table with the AIVL team and reference GP was focused on sampling. It was determined that there were likely to be some sections of the community that held attitudes that may be more responsive to any communication on injecting drugs users, and some sections of the community that had attitudes which no amount of

communications could influence. To ensure maximum value was gained from the research, it was determined that the research should focus on the former section of the community. Including the latter section of the community within the group discussions would have resulted in gaining little insight for future direction of communications.

Background literature and Stage One discussions with stakeholders identified that one of the key areas where people who inject drugs felt they faced a large amount of discrimination was from the medical profession. It was therefore thought to be beneficial to include at least one group discussion with medical professionals. General Practitioners (GPs), Pharmacists and emergency department nursing staff were included within the group discussion.

3.2 The Sample

The final sample of the group discussion with the general public and medical professionals was as follows:

Group	Target group	Demographic	Attitudinal criteria	Location
1	General Public	Parents of 15-28 year olds	Parents must be aware that their children use recreational drugs and relatively comfortable with this	Sydney
2		Regular / occasional drug users (non – injectors) age 18-24	Use illicit drugs one or more times a month (non- injecting)	Sydney
3		18-30 year olds	Respond positively to attitudinal statements that indicate that enjoy use of alcohol and / or illicit drugs themselves	Adelaide
4		Over 30 years of age		Adelaide
5	Medical Professionals	N/A	Inclusion of GPs, pharmacists, nurses in emergency units	Sydney

The sample was designed to reflect a cross section of the community in terms of age, socio-economic group, lifestage and gender. However, the attitudinal criteria variable in the sample table above was included to ensure that the sections of the community who may be able to be influenced by communications were included within the group discussions. This was determined by using a attitudinal screening question at the time of recruitment of respondents (Appendix A).

Each group discussion in Stage Two of the research involved 8 respondents and was approximately 1 ½ hours in length.

3.3 Recruitment of Respondents

Respondents were recruited using specialised market research recruitment agencies. These agencies use commercial databases to source sample. Screening questionnaires designed around the attitudinal and behavioural specifications of the sample are administered to potential respondents. All recruitment agencies used for the project hold Interviewer Quality Control Australian (IQCA) accreditation which is a quality assurance standard for market and social research within Australia.

3.4 Discussion Guide

A semi-structured discussion guide was approved with AIVL prior to the conduct of Stage Two of the research. A copy of the guide is appended (Appendix B).

3.5 Analysis

Qualitative research deals with relatively small numbers of respondents and explores their in-depth motivations, attitudes, feelings and behaviour. The exchange of views and experiences among participants is relatively free flowing and open, and as a result often provides very rich data that can be broadly representative of the population at large.

Findings were analysed using a thematic analysis model, whereby participant views and opinions are analysed to find common themes and patterns. In qualitative research, the findings are not based on statistics. The research findings are interpretive in nature and are based on the experience and expertise of the researchers in analysing the discussions using a thematic model.

The analysis included a full review of each of the target audiences, in terms of identifying any commonalities or patterns of factors that influence attitudes and behaviours relating to stigma and discrimination, and how these may be successfully overcome among some groups within the population.

3.6 Research Timing

Stage One of the research involving stakeholders was conducted on 13 November 2009. Stage Two of the research involving the group discussions with the community and medical professionals was conducted on 20-21 January 2010 and 1 February 2010.

4 STAGE ONE: STAKEHOLDERS

4.1 Defining the Issue

Perceptions of how other people see people who inject

The stakeholder groups of the AIVL Education team and the national representatives that attended the conference were asked how they believed the general public thought of people who inject drugs and why this caused stigma and discrimination. These stakeholders perceived that the general community believe people who inject drugs having the stereotypical characteristics of:

- being criminals and thieves who are willing to do anything to get what they need without considering others;
- having poor hygiene habits;
- being bad parents who neglect their children / are unreliable.
- using dirty needles in desperation of needing to use drugs;
- being irresponsible in the disposal of needles;
- likely to have disease of some kind caused by use of dirty needles or poor hygiene habits; and
- ultimately selfish with no consideration for others.

People who inject drugs identified that underpinning all of these is the perception held by the community of the person being out of control and unable to act rationally. It is believed that that the general public feel that people who inject drugs are only focused on the need to gain access to drugs due to their addiction, and are then impaired by their use of the drugs so unable to act rationally.

The stakeholder groups also felt it likely that the general public are somewhat fearful of people who inject drugs because of the method of administration of the drugs. They either:

- fear needles;
- are unable to understand how a person could practice injecting on themselves; and/ or
- identify the practice of tapping directly into one's own bloodstream as very risky.

Lastly, people who inject drugs claimed that because drugs are illegal, the general public tend to equate this illegality with immoral and deviant behaviour. The example used to illustrate this is homosexuality. When homosexuality was illegal, the general public saw homosexual behaviour as immoral and deviant. The same is now seen to apply to people who inject drugs.

This was very different than how people who inject drugs see themselves. As expected, resistance to the stereotype is very strong with people who inject drugs identifying that they do not fit the

physical and behavioural characteristics of the stereotype. Just like all sections of the community, there are positive and negative behaviours exhibited by individuals who inject drugs. However, people who inject drugs feel that the positive are never seen by the general public, only the negative.

People who inject drugs identify themselves has being survivalists, resilient and resourceful, with their drug use only a small part of what they are as opposed to the 'out of control' junkie for whom drug use is perceived to over ride all other characteristics or qualities.

Reasons for stigma and discrimination

Stakeholders identified that both government policy and media exposure contributed to creation of the stereotype that the public have about people who inject drugs, and the stigma and discrimination that people who inject drugs experience. By certain drugs being illegal the government establishes the sense that use of these drugs is immoral and / or indicative of deviant behaviour. This, in turn, is seen to characterises the person using the drugs as immoral.

Governments were also seen to deliberately create a sense of fear around the use of drugs through prevention campaigns such as the National Illicit Drug Campaign and by likening police activities against drugs to that of terror. For example, by use of phrases such as 'the War on Drugs' being similar to 'the War on Terror'.

Media activities are usually aimed at reinforcing the fear that people have towards drugs. Stakeholders identified that media exposure of drug users, especially people who inject drugs, is generally focused on those who are obviously undergoing a difficult time. In addition, images of people asking for food and money, or stories of people undertaking criminal activities such as theft or prostitution, are often related back to being caused by a need to fund a drug addiction.

In turn, injecting drugs is seen as signifying addiction to illegal drugs. This is because self administration of drugs is perceived to be a risky practice, so the public are thought to believe that only those addicted to a substance would take the risk.

As the general public tends to have a lack of knowledge and experience with people who take drugs, their only point of reference is the media portrayal and government policy. These are seen to encourage the general public to think that 'Drugs are bad, therefore drug users are bad'. The public are encouraged to identify all people who inject drugs as being people who are struggling and / or participating in criminal activities to fund their drug use. Overall, the result for the general public is fear of all people who inject drugs.

Groups from which stigma and discrimination comes from

People who inject drugs were asked about specific groups among the community where they experienced stigma and discrimination. The most common group mentioned were medical professionals, particularly pharmacists. People who inject drugs identified instances where they had been:

- made to wait for their specific opiate replacement therapy while pharmacists served other people who had come into the pharmacy after them;
- asked to enter and leave that pharmacy via a different entrance to other customers; and
- only able to access opiate replacement therapy at specific times which may not always be convenient to them.

Instances of discrimination by hospital emergency staff and GPs were also mentioned. One stakeholder recalled not being given appropriate treatment for a broken arm as hospital staff and doctors surgeries refused to undertake the necessary tests to identify the break. He claimed that medical staff dismissed his claims of pain as drug seeking behaviour.

A number of other 'professional groups' were perceived to regularly practice discriminatory behaviour towards people who inject drugs. These included:

- shop owners;
- staff at clubs and hotels;
- staff at drug and alcohol services
- staff at correctional facilities; and
- government agencies.

Each of these are discussed below.

People who inject drugs claimed that shop owners who will ask someone they think inject drugs to leave the premises or not allow them in the shop in the first place. The refusal to let them enter is perceived to be based on fear that the people who inject drugs will steal products from the shop. It is thought that shop owners often feel they need to watch people who inject drugs all the time they are in the shop to prevent this, resulting in a lack of service for other customers. Therefore, they stop the problem from occurring in the first place by just not allowing people who inject drugs in the shop. This was identified as a common situation experienced by pharmacists that participated in the medical professionals group discussion in Stage Two of the research.

Pub owners, bouncers and security were identified as being discriminatory in not allowing people who inject drugs into premises. It was believed that this occurred as the owners / bouncer /security

felt that other patrons would not like to have 'such people' in the pub or club and would leave themselves or complain. Ultimately, it was seen as bad for business.

People who inject drugs also identified that they were discriminated against by workers in drug and alcohol services and correctional facilities when compared to others within these services. While no specific examples were given, perceptions were that they were just treated badly compared to others simply because they were a known as an injector, rather than due to a specific action or behaviour that may warrant negative treatment by staff in these services.

Government agencies, such as those responsible for family and community services, were also perceived to make assumptions about parents who inject drugs simply based on this characteristic alone, rather than due to a specific action or incident. Generally, people who inject drugs believed that government agencies such as this tended to assume they were incapable of looking after their children and that children were often neglected even when there was no evidence to suggest this.

Groups within the general community that were identified as being particularly discriminatory against people who inject drugs included:

- elderly / older people who had no knowledge of the people who use drugs in general, aside from that learnt from media stories and 'TV specials', which were perceived to invariably demonstrate the most negative characteristics of drug users;
- parents of teenage children who are perceived to feel that all people who inject drugs were out to get their children addicted to drugs ; and
- 'Club' drug users who were perceived to treat people who inject drugs badly despite their own drug use.

People who inject drugs identified that the discrimination experienced from this last group was likely caused by recreational drug users trying to justify their own use of drugs by it not being seen to be 'as bad' as people who inject drugs. People who inject drugs feel that this group of people typify the view that 'drug use is cool until you lose it' in that this cohort of people tend to see the people who inject drugs as signifying having 'lost it', whereas they themselves had their drug use under control as they did not inject.

4.2 Impact of Stigma and Discrimination

Not a great deal of time was spent discussing the impact of the stigma and discrimination on people who inject drugs during the information sessions with stakeholders. That said, two key impacts were identified:

- a reluctance to access services; and
- reinforcement of negative self –worth.

When people who inject drugs feel they are stigmatised or discriminated against when accessing medical services, such as opiate replacement therapy in pharmacies, they report developing a reluctance to go to the service when they need to for other reasons. Often an alternative medical service is not available, meaning they are faced with experiencing the negative treatment or go without the medical treatment they require.

Experiencing stigma and discrimination tends to reinforce any negative feelings of oneself that people who inject drugs may be experiencing. Over time, discriminatory treatment from others can results in feeling that they are not worth being treated any better.

4.3 Moving forward

Idea for what communications could involve

During the information sessions, the stakeholder groups were asked how they would like to change the general public's perception of them. The key perceptual changes that people who inject drugs felt were desirable among the general public included:

- seeing people who inject drugs as having a sense of responsibility and not causing harm to others;
- understanding that people who inject drugs function the same as other people, they are 'normal', in that they hold jobs and care for their children; and
- understanding that people who inject drugs do not fit the stereotypical physical and behavioural characteristics that the public believe people who inject drugs have.

People who inject drugs were then asked what they felt that communications directed at the general public needed to achieve. Ideally, it was felt that communication could:

- 'Humanise' people who inject drugs through:
  - appealing to people sense of compassion, in terms of seeing people who inject drugs as people more likely to harm themselves rather than 'harm' others;
  - demonstrating a functional drug user that is typical of the majority of people who inject drugs;
  - identifying people who inject drugs who have achieved something in their field (celebrity or fame);
  - highlight that people who inject drugs as people who have the same rights as others, and have their own issues to deal with the same as others;
- Highlight that people who inject drugs actually do not cause harm to others, by:
  - providing comparative health and social costs with 'other' supposedly more acceptable drugs such as alcohol and 'club' drugs

  - provide factual information about the harm done to society by injecting drug users compared to users of other social drugs.

- Ask people to identify and face up to their own discriminatory attitudes:
  - by asking if they would discriminate against someone who drinks alcohol; or
  - if they can actually 'tell' who may be injecting drugs out of a range of supposedly 'normal' people.

A number of these ideas were incorporated into the broad concepts used among the community groups. They allowed elements such as message direction, tone and style of possible communication to be determined. These are discussed in Section 8.

5 COMMUNITY PERCEPTION OF PEOPLE WHO INJECT DRUGS

5.1 About the Sample

General Public

A range of ages, lifestages, socio-economic status and occupations were represented within the group discussions. The occupations of respondents demonstrate the broad mix of people represented in the group discussions. These included accountancy, media, IT, law, teaching, hospitality, construction and retail.

Due to the specifications targeting certain attitudinal groups, most of the sample had a relatively liberal attitude towards illicit drugs. Younger members of the sample had clearly used 'soft' drugs, such as marijuana and 'club' drugs such as ecstasy and speed. A small minority claimed experience with meth / ice.

Older respondents were more conservative, with most claiming to enjoy an alcoholic drink but having had little exposure or experience with drugs. Even the parents group which was recruited based on the fact that their child had used recreational drugs and were *relatively* comfortable with this, were ignorant of drugs. The parents group were all aware of their roles as parents and, as is often the case with this demographic, prided themselves in their ability to communicate and influence their child. This demographic feel they are aware of their children's attitudes and behaviour towards illicit drugs, but their perception is often not completely accurate. Parents tended to claim that their child had tried marijuana, but none were aware of their children trying ecstasy.

Medical Professionals

The group discussion with medical professionals involved three pharmacists, three nurses working in emergency departments of hospitals, and two general practitioners (GPs). All had specific experience with drug users, including injecting drug users.

Two of the pharmacists were relatively young, but had for a short period of time worked in a pharmacy on which had a specialist 'sharps' section. This pharmacy had a high proportion of people who inject drugs as customers. They now both worked in different pharmacies with a small number of customers on pharmacotherapy treatments. The other pharmacist worked part time in retail pharmacy and part time in a clinic providing pharmacotherapy treatment and support (methadone/buprenorphine) on the north shore of Sydney. She was also funded as a liaison between the clinic and local medical practices / pharmacies.

One of the three nurses had a great deal of experience with drug related incidents from working for a number of years in a major hospital which receives a high incidence of drug related cases in their emergency room. The other two nurses were younger, but had both worked in emergency

departments for five years or more. All nurses reported seeing a range of drug related problems in emergency, with overdoses of ecstasy, cocaine, heroin and sleeplessness from excessive meth/ amphetamine use common. Nurses reported increasing issues related to methamphetamine use, with incidents of psychotic breaks and associated violence becoming more common.

Both GPs involved in the group discussion claimed to have a particular interest in working with patients dealing with drug or alcohol issues. One of these GPs was affiliated with a nearby clinic providing pharmacotherapy treatment and support.

5.2 Attitudes to Drug Taking

All respondents felt there was a clear line of what is and what is not acceptable in terms of drug taking. The parents and older general public groups were the most conservative in terms of attitudes, reflecting their lack of experience and exposure to illicit drugs. While most may have experienced drugs in their younger years, they all felt that drugs had changed since they used drugs in their late teens and twenties. Illicit drugs today were perceived to be much stronger, with many quite ignorant about different drugs. For example, some thought that ecstasy was more, or as dangerous, as ice.

However, as a whole, the older respondents participating in the research were relatively liberal about other individual's drug use. For them it was a private decisions and as long as it did not impact on them or their children, they were not overly concerned with drug use.

Younger respondents all demonstrated very accepting attitudes towards drugs. Most younger respondents accept drug taking at a social level. It is something they participate in on weekends and on special occasions with friends to have fun. They are seen as a way to enhance the quality of life.

That said, most younger respondents identify a line in regards to drug taking. For those that identify drug use as a social experience, drug taking becomes unacceptable when people start to use drugs when they are by themselves.

"Doing anything by yourself is bad, you remove the social scene from it."

"Takes drugs for no reason, like just at home on their own"

Others clearly perceive that drug use alone could still be an enjoyable experience. For these respondents, the line of unacceptable drug taking occurred when:

- drug use impacted on other areas of a person's life such as their employment or study;
- others around that person may be at risk either physically or mentally; and / or
- they demonstrated personality changes.

"I accept a person who is drug taking in their own space."

"I think drugs are fine in a party atmosphere to have fun every once in a while, but sometimes it can get out of hand and I've seen good friends lose their careers over it."

Essentially, these respondents identified that drug use was acceptable provided it did not impact on others around them.

Addiction to any type of drug was perceived as undesirable by all respondents. For most respondents addiction is signified by the drug becoming the main focus of a person's life, with all other elements considered secondary. For most of the general public, addiction is the point when a person is unable to be rational in their decision making and they do not seem to care about the impact of their actions on others as their focus is on using and scoring drugs.

Addiction to drugs was seen as likely to ruin a person's quality of life rather than enhancing it as occurs with more social or recreational use. A person addicted to drugs was thought likely to get into financial difficulties as they use their money to feed their habit, while at the same time possibly having employment difficulties associated with drug use. From there it was seen as easy to fall into criminal activities such as theft, prostitution or dealing drugs in order to continue to fund their addiction. Beyond the financial, people addicted to drugs are seen as unreliable as they prioritise drug use over the needs of others in their lives such as family and friends and untrustworthy as they could potentially steal from family and friends to sell items so they could obtain drugs.

"I wouldn't accept a person who has stole or tried to push to anybody especially my children ... a person whose drug taking affected dramatically their moods and dependability and all aspects of their life and anyone that's involved with them."

"I wouldn't accept if it was impacting on other people and particularly people who have children because the kids will find out."

"You'd be a little bit more unsure depending on what sort of drugs so if you had somebody who was taking heroin or ice or crack those sorts of things, then yeah you might be a bit iffy about maintaining a relationship with them."

5.3 Attitudes to Injecting

General Public

All of the sample were very negative about injecting drugs. While more sympathetic, young drug users also have a very negative, stereotype of people who inject drugs. Even among these respondents, injecting drugs was seen as going too far with drug taking. This is due to most people perceiving that injecting is synonymous with addiction, and then not understanding the nature of addiction. The behaviours they perceive characterise an addicted person, described in the section above, are therefore associated with people who inject drugs.

"No, I think these days it's now proving to be much more of a genetic disorder is what my understanding an addictive personality."

"Even when I was in my early twenties I always thought injecting was the worse thing, other things were kind of acceptable."

People perceive that people who inject drugs prioritise drugs over all other elements of their lives – their employment, their family and friends, their general health and others within the community. Based on this, people fear the possible consequences of associating with people who inject drugs as they feel they may be placing themselves at risk.

"I think by associating with someone on hard drugs you become very vulnerable ... just the stealing."

Many respondents had no empathy for people who inject drugs. These respondents tended to feel that people who inject drugs had made a choice to 'cross the line' into addiction and / or to become an injector, with the full knowledge of possible consequences of financial difficulties and loss of trust of family and friends. Therefore, they should deal with these consequences and any negativity that others may hold towards them.

"The hardened drugs that we are now talking about there's no ifs, ands, or buts, you are not a fringe dweller, you are all the way in."

"They made the decision and too often then you're supposed to feel sorry for them, that's the thing that always irks me."

Some less extreme attitudes, more sympathetic attitudes toward injecting drugs were also expressed, however even those with empathy still expressed a fear of people who inject drugs.

"Who would choose to be a drug addict. I actually feel sorry for drug addicts, I don't feel sorry for the dealers and drug runners and all that ... I feel they're all victims...but the situation they are in can be frightening."

Medical Professionals

Attitudes of medical professionals towards people who inject drugs tended to vary according to the experience of the individual. The more experienced pharmacist, GP and nurse were more likely to be understanding about the difficulties that people who inject drugs may face in certain situations than the less experienced medical professionals in the group discussion. Additionally, the experienced medical professionals in the group discussion had generally chosen to work in areas where they came into contact with intravenous drug users. Therefore, they spoke from the perspective of having an interest in the area. In contrast, the views and opinions expressed by the younger, less experienced medical professionals in the group discussion were reflective of medical professionals who had not chosen to pursue an interest in the area of intravenous drug use. Much

like most medical professionals, the only reference point from which these medical professionals have on which to form an opinion is on the interactions they experience in their working capacity.

Overall, younger medical professionals tended to be more negative toward people who inject drugs than other drug users. This negative attitude was driven by the perception that more time is necessary to monitor and look after people who inject drugs under their care than others, and their lack of experience with injectors. The reasons for this perception and how these influence attitudes of medical professionals is provided in Section 7.

6 STIGMA AND DISCRIMINATION TOWARD PEOPLE WHO INJECT DRUGS

6.1 Existence of the Stereotype

The General Public

There was a great deal of consistency in the image that respondents have of a person who injects drugs, with all respondents readily labelling a person who injects drugs as a 'junkie' or at a minimum, an 'addict'. As was anticipated by stakeholders, respondents typically described the stereotypical of a 'junkie' or 'addict' when asked to describe a person who inject drugs.

> *"It's the drug associated with injecting drugs, it's not that you inject marijuana or ecstasy, it's that you inject heroin and there's such a high addiction rate."*

Physically, a person who injects drugs is expected to be:

- thin, gaunt, frail;
- look unhealthy with pale skin and dark circles under their eyes;
- unclean, dirty; and
- unkept, ungroomed.

> *"Skinny, unclean, pimples, no job, vacant eyes"*
>
> *"Thin not healthy looking"*
>
> *"Furtive, skinny, smoking, malnourished, dirty, selfish"*
>
> *"Gaunt, frail, pale, very skinny, black circles under eyes, dilated pupils"*

The dominant personality traits of a person who injects drugs are seen to be selfishness, unreliability, dishonesty and untrustworthiness. The expectation is that as drugs are the focus of the person's life, they are selfish in all the actions they undertake and do not consider the impact of their actions on others. It is expected they would do anything to get drugs, due to being addicted, so are unable to be trusted as they are not able to control themselves from acting on impulses.

> *"Dirty low life, unsuccessful, untrustworthy"*
>
> *"Dishonest, can't trust them, will do / say anything to get drugs"*

Aside from this, there is an expectation that the impact of taking drugs and in consistently trying to find ways to finance and find more drugs, leaves the person with very unpredictable, extreme mood swings. Some associate this with a potential for violence, while others identify a tendency for the person to withdraw from social circles. A small few, felt that injecting drug use probably meant that person has relatively low self-esteem.

> *"Mood swings, nasty can be violent"*

"Void of personality, edgy, talkative or silent – extremes, dull, angry"

The stereotype of the injecting drug user is perceived to be unlikely to be in full time employment. As it is perceived that they are addicted to drugs, it is expected that the injecting drug user would find it difficult to maintain full time employment as they would be unlikely to be focused on their job enough to be productive (it is expected they would only be able to focus on drug use). Due to this, injecting drug users are perceived as likely to have money problems and reliant on government benefits and/ or a criminal activity such as prostitution and theft.

"Can't find work, but doesn't really want to"

"Maybe in low paid work, or casual jobs which they often change"

"Dole bludgers"

"Prostitutes, artists, unemployed or casual work at Woolworths etc."

"You generally find a pattern with injecting they don't take care of themselves or their responsibilities."

While there was some recognition by a minority of that not all injecting drug users are addicts, this was minimal. Most members of the community attribute the perception they have of an 'addict' to injecting drug users. As an 'addict', injecting drug users are thought to disregard all other people and responsibilities in their lives. There is no or little understanding among the community that addiction can be managed, with people able to maintain normal employment, family and social relations.

"They constantly let me down, I want nothing to do with them unless they quit."

"If someone is taking heroin … if they told me, they hadn't started and they said I'm going to take heroin next week, I'd just wipe them even before they started just because it's so highly addictive, they're just totally responsible for themselves."

"That's addicts by the way; I've met occasional users with regular jobs and regular lives."

Even among people who held some empathy for injecting drug users, the stereotype is too well established to be open to another perspective. The limited experience and exposure they have with people who inject drugs also seems to reinforce the negativity. For example, some reported issues regarding the behaviour of people who were openly injecting drug users near where they live – arguments and general verbal abuse. These respondents feared walking past the areas where the injecting drug users were as they were unsure as to what the drug users may do. The fear is based on the possibility of the injecting drug users approaching them physically, with the perception that possible harm could result. Even though, rationally, respondents knew this is unlikely, they still held a fear that this could occur.

"I feel like they're going to stab me with a needle, I know it's not going to happen."

"I don't want to sit next to a meth addict because they look scary too. It's not what they're doing it's how they look."

"I think it's because usually they go hand in hand with not being able to hold down a job. My Aunt was really addicted to heroin for 20 years, she said she was a cab driver in New York and she could barely hold down her job, took over her whole life."

"From my experience of seeing people on heroin they can't function in society which is why they get isolated, they usually don't have a job, financially unstable, not giving anything back … I don't want anything to do with them, they're an annoyance."

Inherent within the fear that people report is the fear of needles, particularly discarded needles. Respondents could all recall media reports of discarded needles in parks and on beaches, with a small few having seen this themselves. This fear is based on the possibility of being infected with HIV or another blood born virus through an accident with a discarded needle, for example, treading on one in a park. This fear reinforces the perception that people who inject drugs are inherently selfish and are unable / unwilling to think of the impact they may have on others, as only someone with these characteristics would leave items like needles around and not dispose of them appropriately.

"The stigma that needles are the wrong thing to do, with pills there was never talk that it was a bad thing to do … remember healthy Harold, cigarettes and needles were always the wrong thing to do. Growing up it was always about needles."

"It makes me squeamish as well … if your kid was rummaging through a bin or on the beach and picked up a needle."

"A few years ago I went to Q Bar, there was a needle on the floor in the bathroom. I felt disgusted, I left."

Medical Professionals

Some medical professionals tended to have the same views in regards to a physical stereotype about people who inject drugs. Medical professionals felt that injecting drug users were physically characterised by a:

- thin, pale appearance;
- often a bit dishevelled and untidy in their appearance;
- often had slurred speech; and
- often had unhealthy teeth.

The younger, less experienced medical staff were more vocal in their views that a physical stereotype existed.

"The junkie look with the rotten teeth".

When challenged these medical professionals identified that they did have pre conceived expectations as to what their likely interaction with the person would be based on this appearance. As described by one of the pharmacists:

> *"I see them at the door and I've already got my drawer open and am looking around to see that other customers are there and what staff might be able to look after them, cause I know its going to take time…you don't want them waiting in the store because you've got to watch what they are up to (perceptions of shoplifting), but you can't just drop everything else".*

While making them aware of their preconceived views on injecting drug users was useful, the younger medical professionals all identified that such an awareness needed to backed up by experience. One of the younger nurses identified how she had recently had her preconceptions challenged:

A relatively well known writer living in wealthier suburb of Sydney was brought into emergency due to an overdose. His medical history identified that he was a long term heroin user. Following his overdose, the person had decided to start on a methadone program at the urging of his wife and children.

The nurse admitted that she had been surprised by this specific case. Firstly, his appearance was not typical of the 'junkie' look that she identified as being typical of an injecting drug user.

"He looked like any other North shore Dad, a bit scruffy, but pretty much just the same"

Secondly, the man had a wife and children that clearly loved him. This was surprising as it challenged the perception that an injecting drug user alienates all family and friends through negative behaviour caused by their addiction. Lastly, he had managed to be successful at a career that required focus, creativity and discipline – that of writing. This challenged the nurses perception that all injecting drug users could focus on is ensuring the extreme needs of their addiction are met.

The nurse admits that the man was treated differently to other people who inject drugs who are brought into the emergency room, most likely due to his fame. The nurse admitted that understanding how differently the man was treated compared to other injectors, who were commonly met with immediate scrutiny and suspicion regardless of exhibiting either positive or negative behaviour, was somewhat confronting when she thought it through.

6.2 Awareness and Attitudes towards Stigma and Discrimination

Stigma

As discussed above, all respondents among the general community and medical professionals were aware of a labelling and stereotyping of people who inject drugs. Very few, if any, of the general community did not describe the stereotype of a person who inject drugs as:

> A 'junkie' who looks thin, gaunt, pale with bad teeth and track marks. Likely to be unemployed and possibly homeless, living off their family, or in a run down place with others. There is a strong likelihood that the person is a criminal who will steal (or other illegal/ immoral activities) to get money for drugs. They are not to be trusted and are irresponsible and selfish in their behaviour to others, as they are addicted to their drug and are only concerned with fulfilling their addiction.

Almost all respondents among the general public expressed a reluctance to be around a person they suspect may inject drugs. Primarily, they feared the actions of people who inject drugs toward them. However, there was also a secondary fear of 'guilt by association' meaning that by being around someone who injects drugs, the individual might be subject to the same type of stigma and / or discrimination. The general public also had little empathy overall for people who inject drugs, believing that they choose to start and then to continue to inject drugs, so therefore, should deal with the negative consequences.

Importantly, these attitudes were indicative of most respondents. Use of labelling and stereotyping was done by all respondents, not just those at the extreme end of the scale of attitudes. **The general public strongly differentiate people who inject drugs from the rest of society by the use of the labels and stereotype, and make no apologies for doing so. The general public openly judge people who inject drugs, and readily admit to there being a stigma against these people. Use of the label of a 'junkie' and the described stereotypes are instead seen as a means of clearly and deliberately indicating that the person described should be seen as separate or living outside of the mainstream community. This stigma was believed to have an important role in minimising the potential acceptance of and spread of injecting drugs.**

Discrimination

When prompted, most respondents readily identified that they would likely be discriminatory in their actions toward injecting drug users should they be aware of interacting with them. That said, most of the general public claimed to have little, if any, direct experience and exposure to people who inject drugs. Most claimed that their only experience with people who inject drugs was on walking past them on the street. Therefore, while they were cognisant that they would likely discriminate

against someone in a situation if they found out they injected drugs, they could not actually report instances of doing so. This situation is very different than may be found in other situations of discrimination whereby people do not readily admit to their discriminatory actions against others and would reject their actions as being discriminatory. For this situation, most people admitted to and endorsed discrimination towards injecting drug users.

The strong association of injecting drug users with the stereotype described above, coupled with the fear that people have of this stereotype, means that discrimination against injecting drug users is readily condoned. The general view is that they made a choice to undertake an action that sets them apart from most of society and therefore must accept the situation that eventuates.

Younger respondents in the medical professionals group tended to believe that a stigma should exist for people who inject drugs (for the same reasons as the general public). However, they did not identify their different treatment of people who inject drugs as discriminatory for the most part. They believed that their action were consistent with a duty of care to minimise risk to the patient themselves and to others.

Older medical professionals felt that their colleagues often put processes in place that were unnecessary in regards to minimising risk. They were also very aware that their colleague used the concept of patient risk as an excuse when their concern was more about the reactions of other patients to be treated in the same vicinity, and / or by the same doctor as a person who injects drugs. These medical professionals did not necessarily agree with discriminatory action undertaken by their colleagues, but could understand them given common perception of the injecting drug users held by the general public

6.3 Instances of Stigma and Discrimination

General Public

The general public groups all readily identified that there is a stigma that exists with injecting drug users. The stereotype described above is readily applied once it is established that a person is an injecting drug user, even if no negative experience had occurred. Similarly, the general public readily admitted that it was likely that injecting drug users were discriminated against regularly. While some had specific experience of discriminating against injecting drug users, others just identified it as something they were likely to do should the situation arise. **Importantly, the general public do not identify stigma and discrimination towards injecting drug users as inappropriate**. At a general level, people identify the injecting drug user as having made a choice to undertake an act outside of what society as a whole accepts, therefore they should accept the consequences that society imposes. Part of those consequences is seen as being discriminated against.

Those among the general public, with little experience or knowledge of drug use, assumed that injecting drug users faced discrimination across a range of areas. These tended to be very broad and generalised, such as employment and in interacting socially.

In regards to employment, most of the general public felt that it was highly unlikely that employers would be able to trust:

- that the injecting drug users would not steal cash or product to help fund their drug habit;
- that the injecting drug user would be responsible enough to attend work everyday and do their job, as the perception is they would be always looking for the next shot of their drug, or would be suffering from the after effects; and /or
- for similar reasons, even if they did attend work when they should do, their productivity in the workplace would be less than others.

Very few in the general public groups felt they would be comfortable interacting with a person who they were aware injects drugs, and would therefore avoid doing so. Fear of physical harm from the irrational behaviour by the injecting drug user and / or of harm caused by a discarded needle was the driving force behind this assumed discriminatory behaviour. Another factor perceived to legitimise the discriminatory behaviour towards injecting drug users was the possibility of being thought to be an injector also ('guilt by association'), therefore then being subject to the same stigma and discrimination.

Some among the general public groups had closer experience and exposure to people they knew to be injecting drug users, and could provide some specific examples of discrimination. These were often discussed and condoned as a group.

Example 1: A male who worked close to a methadone clinic talked about people crossing the street to avoid them, and café owners excluding them. All in the group discussion felt this was quite acceptable behaviour.

> *"Where I work there's a methadone clinic just up the road and so there's people walking the street, you can see people walking across to be away from them. The people in the shops the coffee shops too will choose not to serve them, things like that."*
>
> *"I don't think the café not serving them is bad."*

Example 2: A woman in the group kept quiet about a room she had available to rent unless her friend's drug taking daughter moved in. Again, this was seen as understandable and acceptable, with the view that this sort of discriminatory behaviour would actually help the injecting drug user.

> *"I'm just thinking about the studio out the back and when I was renting that out I had a couple of people come over and one person I didn't tell about it because I thought she'd*

suggest her daughter who was terribly involved in the drugs so I thought I just won't mention it. I didn't want to be put in the situation where I wasn't getting my rent where as I was having to worry about who was visiting."

"If you want to help and I don't think giving someone a place to live where they're going to take drugs is going to help them at all."

Another issue of discrimination consistently raised across groups was towards pharmacotherapy treatment, which the general public specifically identified as methadone clinics. There was considerable prejudice and some misunderstanding about methadone clinics and treatments. Older respondents, in particular, did not see use of these treatments as a genuine attempt to overcome drug problems. Similarly, many perceived that injecting drug users used methadone as a cheaper alternative to heroin.

"Methadone they get it for nothing and they get the hit that they wanted from heroin."

The key challenge in overcoming stigma and discrimination towards people who inject drugs is that many among the general public believe that marginalizing people who inject drugs was positive for society as a whole. Having a strong stigma associated with injecting drugs, and acting to discriminate against them was thought to be a powerful means of minimising the chance of people starting to inject drugs in the first place. Essentially, stigma and discrimination toward people who inject drugs is perceived to be a useful prevention strategy among a large portion of the general public. It was seen as a means of containing the problem.

Although it was recognised that this type and level of stigma and discrimination was likely to make situations difficult for people who inject drugs, the general consensus was that this should then act as an incentive for them to overcome their addiction (the 'tough love concept'). In addition, it was felt that 'addicts', as they are perceived by the general public, would not be concerned about what society as a whole thought of them as their only concern would be in finding and using their drug.

"I think that most of them wouldn't give a stuff what the general population thought about them."

Scenarios of Discrimination

The general public groups were prompted with specific situations in which people who inject drugs face discrimination. The scenarios are provided below.

A	Injecting drug users have been refused treatment at dental surgeries or told to come back at the end of the day when they cover everything in plastic
B	People on Methadone programs paying up to $80 per week are made to wait until 'normal clients' are served, even if this means they are late for work
C	Injecting drug users are often refused appointments at doctors surgeries or told the service

	is full
D	Because there is a limited choice of Doctors who script Methadone, clients are often charged

Overall, respondents were highly critical of the situation where discrimination occurred from GPs and pharmacists. Most believed the situations to be inappropriate discrimination as it was health professionals holding the prejudice. It was generally believed that health professionals should have greater knowledge of people who inject drugs, and would be taking the appropriate precautions to be able to treat them properly, to be able to then provide the medical treatment that people are seeking. Notably, the assumption that specific precautions are required was not seen as demonstrating discriminatory attitudes. **The situation where clients are charged an extra $80 for the prescription of methadone was perceived to be the most inappropriate. This was seen as taking advantage of people in vulnerable situations, which bordered on the unethical when being done by a medical professional.**

> *"I think it's really inappropriate a medical professional is going to stoop to that."*

Older respondents were less critical of the medical professional described in the situations than younger respondents, although many did identify the situations described as inappropriate. Parents and older general public respondents tended to take a particularly unsympathetic view of the situation with the injecting drug user being treated at the dentist. Acceptance of the discriminatory position of the dentist was based on a possible risk of infection with dental instruments. Importantly, people also envisage the physical stereotype of an injecting drug user when imagining the scenarios.

> *"I wouldn't want to be sitting (or your kids) in the same dentist surgery as some guy who is swaying backwards and forwards with stab marks up his arm."*

> *"You're sitting in the dentist surgery and the person going in before you has got scabs and this and that and then you're going in afterwards and they're going to use tools on your mouth."*

Even those that rationally knew this view to be highly illogical and/ or were more less judgemental in their attitudes, such as younger respondents, held some trepidation when the scenario was made more personal, such as when being asked to put themselves in a situation where they were next in line at the dentist. The discomfort felt by the younger respondents when asked to place themselves in this situation was clearly based on fear of infection, rather than any moral position regarding the use of drugs. The line is not so clear cut with older respondents where reasons given for the attitudes displayed were a mix of both irrational fear and moral views.

Medical Professionals

All medical professionals within the group discussion identified that injecting drug users are treated differently than others when seeking care. However, there was marked differences based on the experience of medical professionals, as to whether they saw this different treatment as indicative of discrimination.

Emergency nurses

Emergency nurses are trained to assess and identify potential risks for patients when they are brought into the emergency room. Nurses claim that people who inject drugs are without a doubt treated differently due to the associated risks. Nurses tend to encounter people who inject drugs in a crisis situation, where their drug use has resulted in physical harm. In an emergency room environment, nurses often have the responsibility of having to find identification and evidence of what may have caused the physical harm, and are required to look through patient possessions. This can be a confronting experience for nurses:

- care needs to be taken due to 'sharps' hidden within possessions due to the possibility of people who inject drugs having HIV / Hep C;
- occasionally nurses find items such as unused drugs, stolen items such as other people wallets which then place the nurse in a difficult situation;
- unsurprisingly, patients can find nursing staff going through their possessions an invasion of privacy and confront the nursing staff.

Emergency nurses expressed the most frustration among all the medical professionals in regards to dealing with people who inject drugs. Having been brought to hospital emergency, the patient is highly likely to be in crisis of some kind with nurses having a duty of care to ensure that the patient does not inflict more harm upon themselves or others within the ward. Nurses identified that a particular risk associated with people who inject drugs in an emergency ward is the possibility of the patient trying to access 'sharps' and other drugs, given that they are likely to be a crisis situation. Nurses have to closely monitor the patient due to this, which takes further time. As time is a very valuable resource in an emergency room, nurses can become frustrated. If this is the primary experience with people who inject drugs, this causes some nurses to have quite negative attitudes.

Nurses were divided in their attitudes towards whether suspicions of 'drug seeking' leading to a reluctance to treat 'claimed' pain, was discriminatory or not. The younger nurses identified that suspicion of drug seeking was inherent within their assessment of risk when treating injecting drug users. These nurses were more likely to be suspicious of claims of pain due to injury, or instances where injecting drugs users present to emergency stating they had missed the opening hours or the clinic or pharmacy providing their pharmacotherapy treatments. The older nurse who had specialist

training in the area of drug and alcohol treatment was critical of the assumption made by younger nurses in regards to pain treatment. Based on greater experience and exposure to injecting drug users, this nurse strongly believed that injecting drug users were often not given the treatment they needed for injury due to emergency staff making misguided assumptions about drug seeking.

Pharmacists

Currently, the younger pharmacists' experience with people who inject drugs was mostly limited to providing pharmacotherapy treatments to a small number of clients in the retail pharmacies they worked in. Neither had had negative experiences with these patients, so did not have particularly negative attitudes towards people who inject drugs. At the same time, these pharmacists did admit to having preconceived ideas about the people they provided pharmacotherapy treatments for. These ideas tended to be of the stereotype described earlier. They also claimed that when working in the pharmacy that specialised in 'sharps', they felt that a lot of their customers tended towards this stereotype. At the same time, they did not claim to have any particular negative experiences with customers at this pharmacy.

The pharmacists working in retail pharmacies had established processes for dispensing pharmacotherapy treatments, such as set times to distribute methadone and other medications. The rationale for this was that they were essentially family businesses, other customers could be a bit frightened / unsettled by people who inject drugs if they demonstrated negative behaviour while waiting in the queue.

Pharmacists all admitted that some pharmacies do make methadone clients wait, however, this was rationalised by the attitude that methadone patients want privacy when receiving treatment. Therefore, it is better for them to wait until other customers have been served and gone. That said, pharmacists also identified that they do have some clients that they prefer to try and serve after other customers have gone due to the time they may end up having to spend with them. Although pharmacists claimed that they have many methadone clients who are 'easy' and never cause a problem, they had been warned by others about methadone clients who argue with pharmacists on regular basis because:

- they believe they are getting a smaller dose than they should be; and
- they feel they are entitled to more 'takeaways'.

General Practitioners

Both GPs in the group discussion were relatively experienced in treating people who inject drugs, and had chosen to work within this area. They identified that they tend to have the other end of the

spectrum in regards to experience with people who inject drugs compared to that of nurses. While emergency room nurses see the patient in a crisis situation, where something has gone wrong with the drug use, GPs tend to see these patients when they want to do something to manage their drug use better. Overall, it is a more positive interaction and experience which both identified as adding to their more positive attitudes towards people who inject drugs than that expressed by the nurses in the group discussion.

The GPs in the group discussion recognised that they were likely to be a minority among their colleagues and peers, as most GPs (often through choice) had relatively little experience in dealing with people who inject drugs. They realised that many GPs actively discourage people who inject drugs being a regular patient. The reasons for this were identified as:

- possible negative reaction from other patients in the waiting room and subsequent loss of business;
- expectation that they will become 'known' as a doctor that injecting drug users can visit with the perception being that some will be not legitimate visits from people drug seeking (it will attract a criminal element to the surgery);
- this was also seen to exacerbate any negative responses from 'other normal' patients;
- negative attitudes from practice staff;
- negative attitudes towards drug users themselves from the GP; and
- lack of experience resulting in a lack of knowledge and uncertainty about what their next steps should be when confronted with treating a person who injects drugs.

The GPs in the group discussion understood that these factors combined to provide a relatively uncomfortable environment for people who inject drugs, meaning that many do not feel they can go to any GP as they are unsure of the reception they will receive.

The GP and pharmacist in the group discussion that worked in a local pharmacotherapy treatment clinic claimed that their clients tended to encounter discrimination 'everywhere'. However, they felt that discrimination was most apparent from others within the medical profession, in workplaces and from retailers. They also provided specific examples of discrimination encountered by their clients in the open plaza retail shopping area across the road from their clinic. Despite having the name 'The Forum' and open spaces designed for people to sit, eat, drink and talk with others, retailers have asked the clinic to tell their clients to not stay within the area after visiting the clinic. They are told not even stop for a coffee. This is because the retailers feel that other customers/ shoppers are put off by the presence of people who *"appear as if they are drug users"*. Retailers rationalised this request by stating that customers fear being the victim of crime or believe that they will be hassled by people begging for cigarettes and / or money. Others were more open about the reasons behind the request, stating that it was a bad image for the retail plaza to have - people who 'look' like they

inject drugs sitting in groups together in the Forum. Sometimes, because they are drinking alcohol, this 'look' is made worse.

The pharmacist from the clinic also provided a good example of how one of the people who inject drugs that she knew was refused treatment for a number of weeks when he had pain in his hip and was having difficulty walking. Emergency rooms and doctors had said he was 'drug seeking', and none had done any tests or X-rays. He had had a fall. It was found later found that the man had a broken hip.

6.4 Reaction to being Stigmatised/ Discriminated

Perceived reaction of people who inject drugs

The general public groups were very ambivalent about how people who inject drugs may feel when discriminated against or stigmatised. While there is a degree of empathy from some younger respondents, this was minimal. Most tended to have a very black and white perspective, in that, negative treatment might prompt them to stop using. Therefore, they believe that negative treatment should be encouraged.

The more knowledgeable medical professionals felt that people who inject drugs are often fairly ashamed of themselves and when discriminated against just take it, feeling that they deserve it. They do not tend to react and will not complain about the discrimination.

"they feel the people don't see them like a human being and will often not blame people for it."

That said, medical professionals also recognised that the alternative reaction, where people can get very defensive and accusatory, also occurs. Overall, however, the more experienced medical professionals identified that people who inject drugs often do not complain about discrimination when they experience it, even if they do feel that they do not deserve it. The main reasons preventing people who inject drugs complaining were identified as:

- others are unlikely trust that they are telling the truth, and are more likely to believe the other party's version of event and / or be suspicious as to what agenda that the person who injects drugs has; and
- fear of not being able to access any services as there are no alternative services to go to should the one they are complaining about refuse to serve them in future.

With few or no alternative services, that are practical in terms of transport and location, people who inject drugs will often just put up with discriminatory practices. Even where an alternative GP, alternative pharmacist, alternative clinic, housing, or employment opportunity, may be able to be found, some tend to adopt a 'better the devil you know' attitude. That is, they assume that they will face the same type of treatment, whether they identify it as discriminatory or not, at other services.

They then choose to not complain and stay with the one they know rather than face an unfamiliar place where treatment could be worse.

Support organisations

The general public had no knowledge of places that people who inject drugs may go to for support should they be discriminated against. Knowledge among medical professionals was relatively limited. Those who worked in the local pharmacotherapy clinic identified that organisations such as NUAA and AIVL offered support if people who inject drugs contacted them about discrimination, as did the clinic. However, they felt that very few people who inject drugs took the risk of complaining about stigma and discrimination to organisations, due to fear that the service would be withdrawn.

Medical professionals did also raise the issue that support organisations can find it difficult to maintain ongoing contact with those that may complain when following up on issues. This is due to factors such as change of address and lost mobile phones.