

# Women who inject drugs in central Java and HIV risk



Catherine Spooner

Heather Worth

International HIV Research Group  
School of Public Health & Community Medicine  
University of New South Wales

Antonia Morita Saktiawati

Elan Lazuardi

Yanri Wijayanti Subronto

Retna Siwi Padmawati

Faculty of Medicine  
Universitas Gadjah Mada



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## **The Study Team**

*Chief Investigators:* Heather Worth and Catherine Spooner

*Co- Investigators:* Antonia Morita Iswari Saktiawati, Elan Lazuardi, Yanri Wijayanti Subronto, Retna Siwi Padmawati

*Interviewers:* Antonia Morita Iswari Saktiawati, Elan Lazuardi

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*Correspondence to h.worth@unsw.edu.au*

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## EXECUTIVE SUMMARY

HIV is a significant public health issue for Indonesia which, outside the Papuan provinces, has been largely driven by injecting drug use. The majority of people who inject drugs in Indonesia are men, so most of the research relating to HIV and injecting drug use has been with men. However, international experience identifies that the experience of women who inject is different to that of men and that gender-specific HIV prevention strategies are needed. Therefore, information about women who inject drugs in Indonesia is necessary for HIV policy and programs.

A qualitative study was conducted between February and May 2010 in three small cities of central Java: Yogyakarta, Solo and Salatiga. In-depth interviews were conducted with 19 women who inject drugs to investigate their vulnerability to HIV. Data were collected by trainee Indonesian researchers from Universitas Gadjah Mada (UGM), under the supervision of senior researchers from the University of New South Wales (UNSW) and UGM.

**Gender and culture:** The women in the study described how Javanese women are expected to be 'good', while being 'naughty' was tolerated for men; that women who were suspected of acting inappropriately (in particular, they engaged in extramarital sex and drug use of any kind) were subjected to social repercussions such as being talked about and being labelled. Within their own social group, however, the women reported general equality, kindness and consideration.

**Stigma and discrimination:** A double stigma was experienced as a result of both drug use and being women who use drugs. Negative discrimination was experienced from health services, the general community, friends and family. This discrimination left the women feeling hurt and ashamed. Their main response was to hide their drug use and to restrict their social circle to their partner and friends (mostly male) who also inject drugs. This social group was very important to the women, and friends and partners were described as considerate and able to be trusted.

**Drug initiation and use:** The women were generally initiated to drug use by a male partner or male friends. Drugs were generally obtained via a partner or male friends, and drugs were typically used with the friends or partner. Sharing drugs was partly for economic reasons (individuals rarely having enough money to

purchase them) and partly for social reasons.

**Sharing injecting equipment:** Most of the women interviewed had shared needles in the previous six months. This was usually with a partner or a small closed group of friends, who were mostly male. When needles were cleaned, it was generally just with water. The small injecting circle is likely to be protective of HIV. The strongest theme to arise around reasons for sharing was trust and bonding. The women felt very close to their partners and friends and trusted them, even though their trust was not complete.

**Condom use:** Most of the women were sexually active and this was mostly in the context of a regular relationship, whether living together or not. Only one woman disclosed having casual sex in the past year, and only three women reported sex work in the past year. Condoms were not routinely used, largely because condoms reduced sexual pleasure, for themselves and their partners.

The women did not tend to report being pressured to share needles or to not use condoms. Sexual partners and friends were typically described as considerate, rather than dominating. These ways of relating are consistent with Javanese cultural values which emphasise social harmony. Some women presented as quite assertive, particularly older women and women with economic independence.

**Harm-reduction services and HIV testing:** Most of the women had some contact with harm-reduction services, at least needle and syringe programs (NSP). There was little experience of methadone. Contact with NSP was not frequent and was often indirect (via male friends or partners) as the women did not want to be identified as a drug user. Less than half of the women

had ever been tested for HIV, most of those who had done so had not been tested for more than a year. The main reason for not being tested was fear and this was largely related to the likely social repercussions of a positive result because of the stigma attached to HIV and to drug use by women.

Implications: Recommendations for policy from this report include:

- Address the social stigma experienced by women who inject drugs, particularly within health services. The development of leaders and community organisations that represent and advocate for women who inject drugs might assist this issue.
- Increase the women's access to harm-reduction services. Women-only group discussions and social activities might be one way to do this.
- Increase the role of pharmacists in harm reduction. This could assist women to access injecting equipment and condoms more easily.
- Address the social isolation and exclusion of women who inject. Strategies could include the development of a network of women who inject drugs and social activities for women who inject drugs.



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Up until 1999, the prevalence of HIV in Indonesia was low, even among those groups who are the most vulnerable. During the mid-1990s, Indonesia experienced an increase in injecting drug use which fuelled an increase in HIV through the sharing of needles and, indirectly, via sex work.<sup>1-3</sup> By 2001, the number of people estimated to be living with HIV in Indonesia had increased to 93,000, and by 2007 it had reached 270,000.<sup>4</sup> Injecting drug users comprise the majority of HIV cases, and biological surveillance surveys of injecting drug users have identified that around half of injecting drug users have HIV.<sup>3</sup>

Behavioural surveillance of (mostly male) injecting drug users in Indonesia has identified that the rate of sharing of injecting equipment varies substantially across the country: surveys conducted in 2007 found that the rate of sharing in the previous week ranged from nine per cent in Semarang to 63 per cent in Jakarta.<sup>5</sup>

Indonesia's National Strategic Plan (2007-2010) identified the increase in the number of injecting drug users, particularly in cities in Java and some provinces outside Java, as a significant issue for efforts to address HIV.

Harm reduction is part of the policy response to HIV, particularly in cities in Java and the capital cities of the country's other provinces.<sup>6</sup> Harm reduction refers to programs that reduce the harms relating to drug use and includes (but is not restricted to) needle exchange programs, condom programs for injecting drug users and their sexual partners, outreach services for education and risk reduction, and opioid substitution treatment.<sup>7</sup> There is good research evidence to support these harm-reduction interventions,<sup>8</sup> particularly needle exchange programs, opioid maintenance treatment and outreach.<sup>9-10</sup>

The Indonesian National AIDS Commission identified that there was a need for more local data to inform national and local policies and programs. Much of what is known about HIV transmission and prevention among injecting drug users comes from research in western countries. However, the Indonesian context differs to western contexts. For example, while premarital sex is an accepted norm in western countries, this is not the case in Indonesia.<sup>11</sup>

In particular, little is known about vulnerability to HIV among women who inject drugs in Indonesia. International research on HIV risk has identified that

the experience of women who inject drugs is different to that of men who inject drugs, so gender-specific research is important for informing policy and program responses.

For example, research has identified that women who inject drugs can experience a double stigma: firstly because they are violating social norms against injecting drugs; and secondly because their drug use is considered a violation of the expectation that they fulfil traditional roles as mothers, wives and daughters.<sup>12</sup> Women who inject drugs are more likely than men who inject drugs to provide sex in exchange for drugs, money or other forms of sustenance; to suffer violence from their sexual partners; to experience rape; and to be caring for children.<sup>12-14</sup> Women have less capacity than men to negotiate safe sex or injection practices.<sup>12</sup> These gender differences are generally attributed to the lower social status and lack of power of women relative to men.<sup>12, 15-16</sup>

To what degree is this international research with women who inject drugs applicable to Indonesia? Little research has been conducted with women who inject drugs in Indonesia, largely because they form such a minority of injecting drug users there: research studies have typically found that less than ten per cent of injecting drug users in Indonesia are women.<sup>5, 17-18</sup> Yet rates of HIV among women who inject drugs (56 per cent) have been higher than rates for men who inject drugs (52 per cent).<sup>19</sup>



To address this gap, an in-depth study was conducted with women who inject drugs in central Java. The study aimed to describe the factors that contribute to HIV risk for women who inject drugs in this area. We were particularly interested in the social influences on HIV risk, especially sharing injecting equipment and sex without a condom. We were also interested in factors that hampered women accessing support services and health services.

The geographic region of the study was limited to three small cities (populations 200,000 to 600,000) in central Java: Yogyakarta, Surakarta (colloquially Solo) and Salatiga. While Indonesia is a predominantly Muslim country, it is ethnically diverse, with over 300 distinct cultural groups. Java is the dominant island of Indonesia, containing 45 per cent of the Indonesian population and the nation's capital city (Jakarta).

Of the four major cultural areas of Java, the *kejawen* of central Java is regarded as the dominant culture.<sup>20</sup>

Many social researchers have discussed how community, commonality, tolerance and social harmony are important Javanese values.<sup>21-22</sup> Hawkins describes *rukun* as a primary value that organises Javanese life. This places great emphasis on the appearance of harmony and helpfulness and correct social relations between people. To achieve harmony, people may sacrifice their individual goals for the common good. Ford et al have described how self-control is regarded as a key to self-actualisation for Javanese people, and individuals are raised to avoid exuberant emotional expressions.<sup>11</sup> Children are raised to be respectful, generous, avoid conflict and to practise empathy. Children learn to feel shame or uneasiness about behaviour that is counter to these values.

Javanese culture dictates particular behaviour for women.<sup>23</sup> There is a common notion held by Javanese that women are *konco winking*, which means the women's sole function is to deal with kitchen matters. Another popular proverb for Javanese women is *macak, masak, manak* (dress up, cook, and give birth). Women are also perceived as *swarga nunut, neraka katut* which means that they have to be totally devoted to their husbands (literally, it means either heaven or hell, women must follow). Although the importance of these three notions has diminished in the current era, people still hold the belief that women should behave

in a 'proper' way. Women are expected to be the main educator and role model for their children (nurturing role). Proper women cannot do 'bad' things like inject drugs or have sex outside wedlock.

This study aimed to provide information that will assist the Indonesian AIDS Commission (Komisi Penanggulangan AIDS) and other agencies who are concerned with addressing HIV among women who inject drugs. Specific questions to be addressed in this report are:

1. What factors contribute to HIV risk for women who inject drugs in central Java?
2. How consistent is the experience of women who inject drugs in central Java with international literature on HIV risk for women who inject drugs?
3. What lessons might be learned from the information provided by the women in this study for policy and programs in Indonesia?



The research method was developed after an extensive period of consultation from August 2009 to January 2010. Consultations were conducted with people working in non-government organisations (NGOs), government health services (including methadone programs and needle and syringe programs (NSP)), community organisations, prisons and police. The heads of community organisations that represent injecting drug users in Yogyakarta (Dimas) and women living with HIV in Yogyakarta (Diajeng) were consultants throughout the project.

## Design

This was a descriptive study with women who inject drugs in central Java. In-depth interviews were conducted with women who inject drugs to obtain qualitative data on their experiences relating to HIV risk behaviours. Some quantitative data on demographic background and HIV risk were collected via a survey questionnaire for sample description purposes only.

## Sample

The study population was women who inject drugs in three small cities in central Java: Yogyakarta, Salatiga and Solo. The data was not intended to be statistically representative of the total population of women who inject drugs in the region, but to capture and map a range of experiences and the contexts in which injecting drug use and HIV risk behaviours occurred.

An ethnographic mapping of women who inject drugs was not possible because so little was known about the study population.

Consultations identified that injecting drug use by women in the region was a particularly hidden behaviour due to fear of police and social stigma. Many key informants told us that we would not be able to access women who inject drugs for our study: that there were too few and those who existed would not want to talk with us. Their concerns were valid. Recruitment to the study was slow. Convenience sampling (via prisons, health services, NGOs and community organisations), snowball sampling (via injecting drug users sourced from NGOs and community organisations) and advertising (flyers placed at key services such as NSP, methadone clinics and NGOs) were planned. However, the only strategy that effectively recruited injecting drug users to the study was via outreach workers in the three cities.

Over the three-month data collection period (February to April 2010) 19 women who injected drugs were identified and were able to be interviewed.

Participants were reimbursed for expenses incurred in their participation (e.g. mobile phone credit, travel) and for their time assisting with recruitment and/or participating in an interview. The total reimbursement was approximately \$AUD5.

Inclusion criteria:

- Female
- Aged 18 years or older
- injecting drug use within the previous month
- Living or staying in a study site (Yogyakarta, Salatiga or Solo) during the data collection period.

The sample comprised women from Yogyakarta (n=2), Solo (n=10) and Salatiga (n=7). All of the study participants had injected an impure form of heroin called *putaw* or *etep* in the previous month. Injection of other drugs was rare.

Less than half of the sample had drunk alcohol in the previous month and even fewer had used other drugs such as tranquillisers, cannabis and amphetamines.

The age ranged from 19 to 36, mean=25 years, SD=5 years. Three-quarters of the sample were educated up to senior high school level and one woman had tertiary education. A fifth of the sample had only completed junior high school. The women had lived in the city of interview for an average of 16 years (SD=12 years).

Most of the women were Muslim, two were Christian; most were Javanese, two had mixed ethnic background. Half of the women lived in a boarding house; three did so with their boyfriend and one with her husband. The others lived in their parents' home, with parents-in-law, or with their husband in a home.

## Interviewers

The interviewers were trainee HIV social researchers who were Indonesian nationals and part of an AusAID-funded research capacity building program (The HIV Consortium for Partnerships in Asia and the Pacific [www.hivconsortium.org.au](http://www.hivconsortium.org.au).) The first ten in-depth interviews were conducted by two interviewers at a time to enable peer critiques of data collection technique, to enable detailed notes to be taken if the participant did not want the interview to be audio-recorded, and for the safety and support of the interviewers.

The interviewers were trained and supervised by senior academics from the University of New South Wales (UNSW) and Universitas Gadjah Mada (UGM). Training was accompanied by a written protocol for data collection. Adherence to the protocol was reviewed on several occasions.

## Ethical approval

The study was approved by the ethics committees of the UNSW and UGM.

## Collecting data

Interviews were conducted in locations that were private, quiet, comfortable and safe. These included public places (cafes), and private spaces (e.g. the home of an outreach worker). Interviews were conducted in Indonesian language. Generally the outreach worker who had recruited the study participant was present to introduce the woman to the data collector/s, then either left or waited in a nearby location that did not allow the outreach worker to hear the interview.

Interviewer safety protocols included: carrying mobile phones, ensuring mobile phones had credit, advising a UGM staff member of where an interview was being conducted and calling the UGM staff member when the interview had been completed.

Permission was sought to record the interview on a digital recorder and was granted for all interviews.

All participants were assigned a unique number and chose a pseudonym. Written notes and audio recordings only included these identifiers.

Having introduced themselves and the study, the

interviewers explained the purpose of the study and sought written consent from participants to take part in the study. The women were given a participant information form (in Indonesian language) which included information on the reason the woman was invited to participate, what participation would involve, how the information would be used, confidentiality of the data, and the complaint mechanism.

All the women who had come for an interview agreed to participate in the study.

Information was collected via in-depth interview, following a semi-structured interview schedule; and a survey questionnaire. The survey was face-to-face and recorded on a paper questionnaire. The order of these two forms of data collection was alternated in the first few interviews. The data collectors considered that it was best to conduct the in-depth interview first and the questionnaire second as this facilitated the development of rapport with the study participant. At the conclusion of the interviews, the interviewers asked the participants if they had any questions. Before thanking them, the interviewers asked the participants how they would like to receive the results of the study (most requested that the results be provided via the outreach workers). After conducting the interview, the interviewers wrote notes on the interview process, e.g. how open and honest the participant appeared, whether there were any topics they did not want to discuss.

It was anticipated that there might be some reluctance to discuss certain behaviours and this was in fact the case.

## Themes and questions

The in-depth interview was conducted to explore the lives of the women and the context of HIV risk. The interview investigated:

- Background (e.g. family background, initiation of drug use)
- Sharing of injecting equipment – reasons for sharing
- Sexual behaviour – reasons for not using condoms
- HIV testing
- Stigma and discrimination.

The questionnaire included standard multiple-choice

questions similar to the HIV/STI Integrated Biologic and Behavioral Surveillance (IBBS) survey in Indonesia and recommended by Family Health International for surveys with injecting drug users.<sup>24</sup> Domains investigated by the questionnaire were:

- Background demographics
- HIV knowledge
- HIV testing and prevention programs
- Sexual history, STIs and condom use
- Injecting practices.

### **Analysis and reporting**

Data comprised audio recordings of in-depth interviews and quantitative data from the multiple-choice questionnaire.

Quantitative data was entered into SPSS and checked for accuracy. Simple descriptive statistical analyses (frequencies and means) were conducted to describe the demographic background and provide an overview of the HIV behaviours of the women in the study.

Interview data was transcribed and translated into English by the research team and by paid transcribers and translators.

Data from in-depth interviews was read multiple times by researchers to generate codes. In consultation with a senior researcher from UNSW, the research trainees identified a list of 22 topics that had arisen from the data; for example, getting drugs, sharing needles, and so on. The transcripts were coded, and coded data were copied into separate documents: one for each topic. Eight documents for the most important codes (e.g. using condoms, sharing needles) were summarised separately by the junior researchers and a senior researcher and crosschecked. Any discrepancies or queries were discussed within the team. The summaries were merged into a single summary by a senior researcher. The remaining 12 summaries were drafted by the junior researchers then critiqued and rewritten by a senior researcher. These processes allowed for continual checking that the summaries were comprehensive of major themes and accurate.

The qualitative and quantitative data are presented together in this report according to themes.

Names attached to quotations are pseudonyms – real

names of interviewees are not presented in this report. Names of cities are not included in the results section to protect the anonymity of the interviewees.

The results are presented in terms of:

- Gender and cultural issues, including stigma and self-perception
- HIV knowledge
- Drug use issues: initiation, getting and using drugs, getting injecting equipment and sharing injecting equipment
- Sexual issues: condom use and sex work
- Harm-reduction service issues, including HIV testing and methadone.

## Gender and culture

The women who participated in this study described the gendered social expectations of women in Indonesia, particularly in central Java. Women are expected to be 'good', while being 'naughty' was tolerated for men. There is strong social disapproval of women having sex outside marriage, using drugs of any kind (even tobacco), or otherwise not fulfilling traditional roles for Javanese women.

*Well, women should be devout. They don't inject; they don't smoke. But, nowadays, where I live, there are women who smoke, drink – but maybe no one injects. See, a woman who smokes will receive comments ... people comment on smoking done by women, moreover, if a woman drinks, worse if injecting ... But people will think it is common for men. People will understand, it is common for men to be mischievous.*

(Putri)

*Yes, society. Moreover in [city x], maybe in [city y], too. A girl is regarded as a good person. Smoking, for example ... We rarely see a girl smoke in public. People will say, "shame on you" if they see one... So, it's in public opinion that a girl must be better in manner than a boy.*

(Dwi)

*A naughty man is common, but if a woman is naughty, it is not common. People will say something bad about her. It is always wrong for a woman. Too many risks... [It's] the custom I guess... generation to generation like this... Like a proverb "ancik-ancik pucukan eri" [stepping on the peak of a bamboo thorn] old people like to say that. For old people a woman makes them worried.*

(Susi)

The social repercussions for women who are seen or suspected of engaging in these behaviours include being talked about, receiving looks of disapproval, and being labelled. The women in the study feared being identified and labelled as a 'bad' woman as it could have negative social repercussions for them, such as impeding their ability to get a husband and to have children:

*Because men tend to be careless, and never think of the future. No matter how naughty a girl is, she still thinks of her future. If she is infected by HIV, what could she say? Your life is already stagnant in this point, you never get a man, never get a husband, and never be able to get pregnant or have a little chance to be pregnant. Men are different; they can do anything they want, as long as they can find hookers in the street. What about girls? They still think, but men do not think as the girls do. As long as they are happy, everything is fine. That is my opinion.*

(Dwi)

Despite the gendered nature of Javanese culture, most of the women asserted that there was generally equality within their relationships with male friends and with partners. In fact, friends and partners were commonly described as considerate and kind.

**I** *Have you ever, as woman, felt that the man dominates or controls the woman?*

**D** *Never.*

**I** *Never? They are very understanding?*

**D** *Yeah my friends understand. They are better than normal people, I mean street people are better in understanding more than other people. (Desi)*

*There are no differences between women and men, the feeling is the same ... yeah, you're asking whether as a woman, do I feel different or sit in different position with man – isn't that what you're saying? Like I said, there is no such thing, I feel the same. The position is the same.*

(Indah)

Three women did say that their male partners dominated them and that they had to do what their partners wanted. However, there was little complaint about this:

*Yeah, sometimes, women's position is weak. Sometimes we feel "why, I feel so powerless without him" ... well, I think sometimes those kind of feelings appear, but well it doesn't matter too much, so I don't think too much about it.... because when you do, you will be stressed out....Because sometimes he's also patient to me, so I don't think much about that.*

(Melati)

There are a number of possible reasons for this acceptance of male dominance. First, male dominance is so normal in Javanese society that some women just accept it. In fact, some women might not have even perceived that male dominance existed when it did. Second, it is important in Javanese culture for people to avoid conflict, and this could have contributed to women not complaining about male dominance. Third, some acceptance of male dominance appeared to be because many of the women were dependent on men for money, drugs and social position (within the small group of injecting drug users). As Melati said above, she feels powerless without her partner. Finally, power

was not typically abused. Male partners were more often described as considerate rather than malevolent. One woman reported a recent experience of violence from her partner, and two women related experiences of partner violence in the past. While these instances of domestic violence are a concern, there was no indication that domestic violence, or even excessive domination, was common among the women in the study. In sum, the women talked of relationships with partners and male friends as being relatively (but not completely) equal and of men being generally kind.

## Stigma and discrimination

Consistent with international literature,<sup>25</sup> stigma and discrimination were evident. The women described stigma associated with injecting drug use for men and women, noting that it was typical of Javanese culture to talk about people who are engaging in 'wrong' behaviour. Injecting drug users protected themselves by being introverted, reclusive and limiting social interactions to a small group of friends who also inject.

*Well, we're hated by people in general. You are junkie, so you are the trash of community. I don't want to be too vulgar, I am not proud at all. Other junkies feel so proud, "this is me". How can we be proud? We are bad. For me, after I get the putaw, I just go inside my room then I inject. Others do it in the kampong, in the public toilet, or any other place. I don't want to do that.*

(Sulis)

*(Discrimination) never happens I guess. I never hang out with people outside of my gang. So, if I hang out together with my friends, they are my soul mate, they also inject. So, there is no discrimination.*

(Desi)

Stigma was reportedly much greater for a woman engaging in any drug use and extramarital sex than for men. Consequently, women who inject drugs in central Java are a particularly hidden community. The difficulty experienced by the research staff in accessing women who inject drugs for this study testifies to how hidden this group is.

*...male injecting drug users are given a negative label by the community "see, he's a drug user, he uses drugs" although they don't know what kind of drugs he uses. They don't even know what drugs are anyway. People only perceive the fact that they are drug users. It is worse for the woman who injects drugs. People pay more attention to women, more than men. If a man cheats on his partner or has sex with a sex worker, people can accept that. It is different with women. People will talk more. It is the same with injecting drug use. If a man is a little naughty, that is fine, it is common for men. It is different with women. These are Indonesian people. I don't know about other places – like in Europe. Here it is like that. The eastern tradition is stronger here.*

(Bunga)

In hiding from broader society, male partners and the small circle of injecting friends (most of whom were male) were extremely important to the women. They talked of friends being 'soul mates' (see quote from Desi above), of not trusting people who did not use drugs and having complete trust in the friends in their small group.

Stigma and discrimination were experienced from all circles: healthcare professionals, family, friends, neighbours, and so on. For example, the women reported being looked at like they are 'scum' by nurses and doctors, parents trying to keep their children away from them, friends who don't use drugs avoiding them and not wanting to sit near them, and their own family members avoiding them. Some women attributed this stigmatisation to ignorance, saying the general public knew very little about HIV and drugs. Even so, the discriminatory behaviour of others resulted in the women feeling hurt and ashamed and experiencing social exclusion:

*From the community, from the hospital, nurses, doctors . . . how they act is so annoying. They look at me as if I were a scum. I am not a scum. I don't smell bad. Don't look at me like you're disgusted at me. Not only laymen, but also doctors act like that. They don't know the whole case... people who only understand half about HIV or narcotics they're the dangerous ones. If they know everything, they can accept more easily. They can take it. Or it's better if they don't know anything at all. But, those who know only half about that, they are more dangerous. They hurt me more.*

(Bunga)

*The doctor was really kind. But the nurses were rather arrogant. She gave me this kind of look, and then asked so many questions. She got away, and her eyes kept watching me. Actually it hurt me, but I couldn't do anything.*

(Desi)

One person noted that stigma and discrimination were more likely to be experienced where people are more connected, where people know their neighbours and there is a sense of community:

*Actually it depends on the neighbourhood. If she lives in the big city, in the middle of the city, she can buy needle in Circle K [a 24-hour shop]. And the people living in the city are more ignorant. But if she lives in the suburban area, like in Bantul or Godean, besides the community [is different], she has to buy in the drugstore. The drugstore is so far. And not every drugstore provides needles. Perhaps, the drugstore keeper is her neighbour or someone who knows her because people in the village usually know each other, right? Not like in the city, maybe someone doesn't even know her next-door neighbour. Well then it can be an influence. But after all, it depends on the neighbourhood she lives in.*

(Bunga)



## Self-perception

How did the women see themselves within the Javanese cultural context in which drug use by women is strongly stigmatised? From the discussions it was evident that the women felt shame about their drug use and sexual behaviour. They referred to themselves as 'junkies'. One used the term 'sampah masyarakat' (community trash). While they thought they could hide their drug use, they worried more about sexual behaviour which could become public if they become pregnant or they were discovered to be not a virgin when they marry. The concern was not just for themselves, but for the shame it could bring to their family.

*Well, we're hated by people in general. You are a junkie, so you are the trash of community. I don't want to be too vulgar, I am not proud at all. Other junkies feel so proud, "this is me". How can we be proud? We are bad.*

(Sulis)

*A junkie girl, like me, can't be confident with those who are not junkies. There is a sense of being inferior, fear of not being accepted.*

(Dwi)

Despite the shame, the women expressed some self-worth in a number of ways. One was to establish a social hierarchy in which injecting drug users were not at the bottom, but women who repeatedly had sex outside a relationship were. This might help to explain why most of the women were having sex in the context of relationships (as discussed in the section below on condom use).

*But they're slut girls...they're considered low class, junkie are also considered low but they're lower...sluts are considered lower class because they're easy, they can be taken here and taken there ... Used here, used there. That's why junkies are more respectable, what I mean is when we use drugs, we only use drugs...we don't, we don't get that low -let people use us.*

(Sulis)

Another way to assert one's worth was to attain financial independence. Women who had their own income felt pride in their self-sufficiency. In fact, as discussed later in this report, financial independence contributed to women being assertive within their social groups and relationships.

*So, although I am an injecting drug user, I want to show that I can produce something, can be productive. So, people won't say anything to stigmatise me because "Oh, Nana can earn money herself. She doesn't make trouble for anybody else." And even though I am HIV positive, I can still afford the money [for HIV treatment], I don't trouble people.*

(Nana)

Religion provided a mechanism for some women to feel good about themselves. While their behaviour was inconsistent with their religious tenets, many remained engaged with religion and obtained emotional support from this. Dwi hoped for protection from God, while for Bunga, religion provided a motivation to balance her 'bad' behaviour with 'good deeds':

*I was a Catholic. I prayed by having deep thought in my bedroom with the lights out, when my little sister was sleeping. I used to pray a lot. Every night, I prayed. If not praying, I just wanted to find who I really was, I lit a candle and everything else was dark. I reflected. I used to think of the things I've done, and what I was supposed to do, and I said to God, "I couldn't stop completely. It was really hard to stop and only You know how to quit from there. They could say 'stop, stop'... But they could not help in stopping it. It's only me who felt it". So then, I only said "God, keep me away from things that are not supposed to be in my body, and I try my best to be careful".*

(Dwi)



*Well, being like this, I get to be closer with God. Even though I often relapse, I still inject. But I am closer to God now, I pray more often. I realise that I will not be here forever to live. I am only here for a moment. So if I have only a moment here, when do I get the chance to search for rewards from God to save me in the afterlife? It is only a starting point. But I try to act well and leave the bad. Well, I still inject drugs, which is a bad thing. But we never hurt people; we never make people uncomfortable around us. We still use putaw, but we try to balance it with good deeds. The more, the better. So if I do 50 wrong things, I have to do at least 50 good things, or more like 100. Do you get that? ... Whether I give poor people in the street, or I go to the mosque, or I join a Koran meeting. The important thing is I get reward from moral conduct.*

(Bunga)

Thus, shame was a significant issue for the women. Primarily they dealt with this by isolating themselves from broader society.

## HIV knowledge

From the in-depth interviews, participants reported that they had got their information about HIV from various sources: mass media, high school, NGOs and outreach workers, friends and partners. However, the quantity and quality of this information is not known. When the women were asked about the reasons that their friends might share needles or not use condoms the women said that they did not discuss such things with their (mostly male) friends, suggesting that friends do not constitute a significant source of information.

Most of the women had good knowledge about HIV. In particular, all were aware that a person can get HIV by sharing injecting equipment, and most understood that always using a condom for sex was protective. Some misconceptions were evident. One-third of the women believed HIV could be transmitted by mosquitoes, saliva or fungi. These misconceptions are not likely to contribute to HIV risk, but some other misconceptions did. Three women thought that if a person looked clean or healthy then that person would not have HIV. Because of this belief, two of these women had sex

with 'clean' people (including commercial sex partners) without a condom and the other shared needles with people who looked 'clean'. One woman who was HIV positive thought that the incubation period for HIV was five years and for this reason was having unprotected sex with her current partner who was HIV negative. Thus misconceptions were contributing to HIV risk behaviours for a small number of women.

## Initiation to injecting

All but one woman was initiated into injecting by being injected by another person, generally a male partner or male friend. Some continued to be injected by others (generally male partners or friends) up until the time of the interview, whereas others became confident in self-injection.

Some women, such as Desi (below) attributed the initiation of injecting to pressure from a boyfriend or peers.

*Well actually, I didn't want to before, but he pushed me. He said "well, you must try this stuff, it is really nice", then I said "no, I don't want it, I'm afraid". I was really scared of needle actually. Since I was a little child, I never got injected, even when I was sick. Then he said "it was nice, it makes you feel light". He also said, "all right, if you don't want to try this one, we don't have relationship anymore". But, the things that made me crazy were that I've been living with him for a long time. He really touched my heart. So, I couldn't leave him. He was also the one who took my virginity. But I didn't really know how it was going to work, how to use drugs. "I don't understand" I said. That was what I did before. "Okay, you just follow me, obey me," he said. Then I said, "I don't have money". He said like, "leave it to me on how to get money.*

(Desi)

However, not all of the women felt pressured to start injecting. Others attributed it to their own choice, saying that watching their friends or partner inject made them curious to try it for themselves. It was evident that those in a relationship with a male injecting drug user were exposed to a social world that centred around injecting drugs. A desire to fit in with

the group or be closer to a boyfriend seemed to underlie a decision for some of these women to start injecting. Some boyfriends in fact tried to dissuade their girlfriends from starting to inject, but they eventually gave in to their demands.

Some women also mentioned that they started injecting because they wanted to seek relief from problems, particularly problems within families.

The women reported that they continued injecting because it helped them forget their problems and because it was now embedded within their social life: they were spending all their time with people who inject.

### Obtaining and using drugs

Among the 15 participants who reported that they had regular sexual partners in the previous 12 months, nearly all (n=13) reported that their regular partner had ever injected drugs.

In some ways, accessing drugs was easy for women, particularly for those with partners who could supply drugs. Nana described how she purposely dated a drug dealer to have access to drugs without having to do sex work:

*I never exchange my body to get drugs. I had a boyfriend who was a drug dealer before, accidentally. Well, I looked for a dealer. So I never have to sell my body to get putaw. I always dated the dealer, whether it was only a campus dealer or anything else. I dated the dealer. That's my target. So you don't have to exchange sex for drugs, no need for that.*

(Nana)

For those who did not have a male partner or friend to obtain drugs, it could be difficult to access drugs. One woman reported that a drug dealer refused to sell to her because she was a woman. Generally, one way or another, drugs were obtained via other people, mostly men. The women tended to not regard theft as an option, feeling that the repercussions of being a woman caught stealing (being beaten and shamed) were too severe. Sometimes sex was exchanged for drugs, but this was not generally regarded as 'sex work'.

*As women, even though we don't have money we still can get the drugs. We can get drugs in any ways ... I mean... roughly saying, in NGO we don't mention that as "sell sex for drugs" ... We [mention that as] use drugs together. For example, "Can I use etep, please?"... well, then, we use it together. We cannot guess the meaning of "use together". Whether after use, we do another thing [like having sex], it's up to each person.*

(Dwi)

*Well, if I wasn't married, I could be worse than this because I am a woman. Why? Well I see my friends' experiences. If they were experiencing withdrawal, they could do anything just to get drugs so that they were no longer experiencing withdrawal. It was like "you give me one injection then it is up to you to ask anything from me, you want to "ride on me, it is fine". That means it is okay if the person who gives them the drugs ask them to have sex with the person. Well I know how it feels to be experiencing withdrawal; I can give and do anything just to get injected. It is different for men, they don't sell their bodies, and there is no one to sell to. But for women, the worse thing of experiencing withdrawal is they are willing to sell sex. Well someone will want them. Moreover, if the woman is clean and pretty, anyone will want them. That's the difference between men and women. Men will go as far as stealing things then they can sell the things to get money to buy drugs. Woman's only shortcut is to sell sex to get money.*

(Bunga)

In response to the policing of drug markets, drugs were purchased via a system of calling a dealer by telephone, transferring money to a bank account, and picking up the drugs in a public location. This system meant that people sometimes injected in a hurried manner in non-sterile conditions such as in a rice field.

*In [this city], we don't use face-to-face kind of transfers because we got caught a lot by doing that. Now, the trend is by transferring. We transfer money, and then we get texted where the drugs are. Usually when we transfer the money we are in withdrawal. So, we don't have the strength to drive back home to inject. So, we usually inject in the place where the drugs are. We often inject in the rice field. For example, the address of the drug is over there, and then we will inject there too. Sometimes a rice field, sometimes by the river.*

(Bunga)

Drugs were usually bought and used with friends or a partner, not with strangers. The reasons for sharing were partly for financial reasons (to share the cost of the drugs) and partly because it was more pleasant to use with friends/partner. Sharing appeared to be related to the Javanese culture *pekewuh* (feeling of shame or reluctance to do something in front of anyone else). That is, it is culturally more comfortable to use drugs with someone than to use drugs in front of them.

*If you are determined to use it yourself, it's better for you to not go to your friend's place. Just go to the ATM (Automatic Teller Machine) yourself, use it yourself. But if when you're using it alone, then your friend comes... it's kinda feel awkward, then you must say "you want to use this or not, how much millimetre, just use it a little, okay"... You must feel awkward if you use it alone, while your friend is there.*

(Ade)

However, some women expressed a preference to inject alone so they would not have to share their drugs. Injecting alone can be a risk factor for fatal overdose as there is no one to respond in the case of an overdose.

### **Obtaining injecting equipment**

The women in the study obtained injecting equipment from a variety of sources. A minority usually obtained

needles by themselves, independently of people they knew. Most relied on other people, mostly male partners and male friends, to access needles. The main direct sources were outreach workers (for 13 women) and pharmacies (for five women, only two of whom preferred pharmacies to outreach workers). Outreach workers either delivered the needles to the homes of the women on demand, or provided the needles from the NSP service.

Some barriers to obtaining needles from outreach workers were mentioned. Some said that it was sometimes difficult to contact the outreach worker when they wanted a needle or the outreach worker took too long to get the needle to them. One woman mentioned that she felt reluctant to ask for needles from outreach workers because she felt ashamed that she had not stopped injecting drugs.

*The [outreach workers], they usually offer us [needles]. But sometimes, we don't feel comfortable with them. All junkies want to quit, but we sometimes feel embarrassed when they find out we still use drugs. So, we only ask them for needle once in two months or once a month or twice a week. We usually say "send us some needles please," then they answer "oh you're using again?" They sometimes ask that. We can only say "yes, we want it now." But if we ask from them all the time, we still have shame. But actually it's okay.*

(Nana)

Some women purchased needles from pharmacies. However, to do so, they would generally need to hide the real reason for wanting the needles or else the staff would not sell them the needles and/or they would feel shame. Generally they would provide a fictitious reason for wanting the needles; for example, saying that the needles were needed to inject a pet with vitamins or for a diabetic relative. A number of other barriers to purchasing needles from pharmacies were mentioned. These included practical problems (the cost of needles at pharmacies, or that local pharmacies were not open when a needle was wanted) as well as fear (fear of exposure as an injecting drug user and that this will be gossiped about or reported to parents).

## Sharing of injecting equipment

Among the women in this study, a minority reported that they had recently shared injecting equipment. Four of the 19 women said that the last time they injected drugs, they used a needle or syringe that had previously been used by someone else.

Three of the 17 women who answered the question said that in the past one month, they had given, lent, sold or rented a needle or syringe to someone else, after they had already used it. However, most of the women mentioned during the in-depth interview that they had shared a needle within the previous six months. When needles were cleaned, they were generally cleaned with just water.

When women did share needles it was generally with male partners and/or friends.

Some would share only with their boyfriends. There was no clear pattern of sharing with a partner: sometimes the partner suggested sharing, sometimes the woman did, sometimes the partner always went first, sometimes the woman always did, sometimes it varied. Women did not typically report being pressured to share needles by partners or friends. Rather, the Javanese culture of avoiding conflict and not forcing others to do anything they do not want to do prevailed.

The women were often unable to articulate clear answers to questions about why they shared needles. However, with probing, a range of reasons for sharing were given. These included those issues around access to needles that are often reported in the research literature such as there being no quick way to obtain a needle (e.g. the local pharmacy being closed, it taking too long to get a needle from an outreach worker), hanging out to use so not wanting to delay use, and not carrying a needle for fear of being caught by police with injecting equipment (although, contrary to other research, fear of police was not a strong theme in the discussions). Also consistent with the literature, those who were HIV positive would share with a friend or partner if they knew that person was also HIV positive.

The strongest theme to arise around reasons for sharing related to trust and bonding. The women tended to have small social networks, mostly with other injecting drug users who were mostly male – generally either their boyfriends or the male friends of their boyfriends. Using drugs and sharing needles was restricted to

partners and/or this small group. The women generally felt very close to their group and trusted their friends. At the same time, they were isolated from non-injecting people as they felt unsafe or lacked affinity with such people:

*I don't have too many friends.... I don't really care what other people do. The priority is me, my boyfriend, and my clique also. People usually hang out together, chat. Well I don't really like doing that, hanging out together to kill time. Well, I just like to be with my close friends. That's all. People who can be trusted.*

(Sulis)

Some were disconnected from family, which is a significant loss within the family-focused culture of Java. Thus, the woman's boyfriend or small group were important to the woman not just for obtaining drugs (as discussed above), but they constituted the entire social world for many of these women. Sharing was a way to bond with one's boyfriend and friends. Clearly bonding with this group was important as they constituted the source of drugs and the women's whole social circle.

*If we share together, and share needle, it feels like we are really soul mates.... even if we have two needles, we only use one of them.*

(Melati)

Furthermore, to refuse to share could be regarded as a sign of arrogance, which is contrary to traditional Javanese values:

*If someone uses the needle alone, he/she is afraid that our other friends will consider him/her arrogant... and then we use the needle together.*

(Icha)

The women talked about feeling safe to share with friends or boyfriends because they felt they could trust them:

*I don't want to share needles. But, it's different if I am injecting with my boyfriend. If I am with him, I trust him. But I don't trust other.*

(Desi)

*It is very seldom if each of us uses our own needle, because he has no relationship anymore with other women.*

(Maya)

**Indah** *Yeah, he doesn't know if I use drugs with my friends also. He gives me some advice... "don't share your needle with someone else" but actually I shared with my friends, my own friends.*

**Interviewer** *what do you mean share – share what?*

**Indah** *I mean the needle ... Well, it's only with the three of them, all women ... "so what?": (My husband said, "what will you do if you get affected by some disease?" yeah, but I know that they are all clean, so they don't have any risk of disease.*

(Indah)

Trust, however, was not always complete. A number of women talked about how they could not really trust their partners or friends, particularly as men in general and injecting drug users in particular were considered likely to have casual sex. Some also noted that one could not just trust another person because it was not possible to tell if someone was HIV positive by their appearance and a person might want to hide their HIV positive status:

*For a few months I hooked up with him [previous boyfriend who was an injecting drug user], I had sex with him. And I realised that no junkie was a healthy person. I used a condom whenever we had sex... I didn't want to get pregnant... So, with drugs, the same applied. (I asked,) "Is the needle clean?"... "That's still in the pack"... The injecting equipment was still in the pack, which meant it was sterile. So I used it.*

(Dwi)

*The needles must be sterilised, I never use other people's ... Because we have no evidence whether one of the needles may perhaps be infected by a virus or not, information like that will be kept a secret by other people, nobody want to let other people know, so that's why we will not know...that person may look healthy and fit but then perhaps that person may have already been infected, there is no way that we may know. So, it is better to avoid getting a disease.*

(Sulis)

In fact, as mentioned above, most of the women did not share needles most of the time and there were multiple reasons for this. One was that, while there were some misconceptions, they all knew about HIV and that HIV could be transmitted by sharing needles. Some managed to maintain a good supply of needles, albeit often via male partners or friends. For some, the male partner was reportedly a strong and protective figure in safe using. For example, Bunga and her partner were both HIV positive. Bunga's partner went to great lengths to ensure that his partner and friends did not share needles. Such consideration for others is consistent with Javanese values:

**B** *So, when we were in the rice field, my husband said: "If you use my needle, you will get infected." Even when his friend said that it was okay, my husband still insisted so his friend didn't use his needle. Even though my husband was in withdrawal, he was still willing to ride his motorbike to buy a needle with his own money because he didn't want his friend to get infected. Although his friend said it was okay, he still refused to lend his needle...*

**I** *Have you ever shared a needle when injecting drugs?*

**B** *Never, never.*

**I** *Not even once?*

**B** *I haven't. He always handles me, he advises me. He observes me so when I go too far he can remind me to not use a needle together, to not share a needle even if there is only one needle. He said: "No, this belongs to you, and this one to me, we have a different condition". He's the one who always reminds me....*

(Bunga)

Consideration for others was also evident among the women who were HIV positive, who asserted that they never shared after discovering their status.

Some women were cautious due to a fear that having HIV could expose them as an injecting drug user. That is, concern about the social stigma of being discovered as a women who injects drugs, or disappointing family, were strong incentives for safer injecting practices within Javanese culture:

*I'm scared of getting affected by that ... if we share our needles, what if someone from that other group is affected by HIV? So I don't want to. I am afraid. I don't want my parents to find out ... they will pass out.*

(Melati)

In contrast to literature that has traditionally portrayed women as lacking agency in negotiating injecting practices, many of the women in this study described being quite assertive in this regard:

**I** *Has your boyfriend ever said to you, "let's use together with me"?*

**S** *Yes, we use together, but we never share needles.*

**I** *Oh, he never shares with you?*

**S** *I don't want to.*

**I** *Oh so you are the one who don't want to?*

**S** *The point is I say to him "if you want to use together with me, bring your own needle. If you don't want to bring your needle, then don't use together with me".*

(Sulis)

It was not clear why women felt able to be assertive. However, at least two factors are possible. One is that it appeared to be the older women who were economically independent that were able to be assertive, rather than younger, less experienced women who were not economically independent. The second is that Javanese culture does not condone confrontation or forcing people to do things. So the social environment is one in which people would not want to force a woman to share needles if she said she did not want to do so.

Some of the women described behaviour that was not assertive, but aggressive which is quite contrary to Javanese culture. This could have been a survival skill for these women:

The problem is, they really know who I am. "It could make some trouble if we push her" they think like that.. so they allow me to do what I like, because they know what will happen if I get angry. (Indah)

From small things. I'll get mad easily. And my friends already know about that. Moreover, to share needle... They already know me well, that if I get mad, I'm mad like crazy. I can beat someone he...he..... Yes, it's true. I can hit someone. Well, it's me, that's who I am, because I don't want it. (Sephia)



## Condom use

During the year prior to the interviews, 15 of the 19 women had been sexually active and this was mostly in the context of an ongoing relationship, mostly with a man who also injected drugs. All of the 15 women had a regular sexual partner in the past year: ten had lived with their spouse or boyfriend, and seven had a boyfriend with whom they did not live. Two had both over this time. Only one woman reported that she had a casual sexual partner in the past year. Three women reported a commercial sexual partner in the previous year.

The interviewees tended to not use a condom with any type of partner. The main barrier was that they reduced sexual pleasure for the women and their partners. Some added that sex with their partners did not often occur because their drug use reduced their libido, so when it did happen, they did not want to lose the moment or reduce the enjoyment by using a condom.

As was the case with sharing needles, most of the women, particularly those who lived with their partners, tended to say it was reasonable to not use a condom because they trusted their partner. However, most then said that they did not completely trust their partner.

*It's trust. I really trust my boyfriend. I strongly believe that he never has sex with another girl. Well I am not really sure about it, but I rarely know that he has sex with another woman. I've never seen or heard before that he slept with other girls. Actually, he always stands by me, whenever I need him; he's always there for me. Well, we live in one boarding house [in one room], Miss.*

(Desi)

**I** *But, are you also sure that he only has sex with you?*

**R** *Yeah, I am sure. But I don't know actually, whether he has affair or not. Well for me, a man is a man, it's just so impossible if a man never cheats on his partner, right? But with him, I can only trust. I just trust him.*

(Rosa)

The women did not tend to report being pressured to not use a condom. Rather, women talked about wanting to be considerate of their partner's feelings and, to a lesser extent, of partners being considerate of their feelings. This is consistent with Javanese cultural values around avoiding confrontation as well as norms of women pleasing men.

HIV was not a major issue for many of the women, whereas shame was. They were more concerned about becoming pregnant, which would have substantial negative social repercussions in Javanese society than with HIV. Pregnancy was prevented by means other than condoms and which did not interfere with sexual pleasure.

While access was not a major barrier to condom use, it is worth noting that the women interviewed did not like to buy condoms as they experienced shame when they did so. In fact, there appeared to be more shame in buying condoms than buying injecting equipment:

*If we have a condom, people will think we are going to have sex... so if I buy condom, I am shy... yeah.... just afraid if I have to buy condoms... if I buy condoms, people think I am a bad girl... and I am afraid of thinking such a thought like that.*

(Icha)

*It feels awkward, if women buy condoms, even though if a woman brings children there, but they still think bad things ... Yeah, because some people will think something like ... sometimes if I buy alone, people will think that I am a, the term is bad girl.*

(Indah)

*It's kind of awkward. If I buy condom in a store and the seller is a boy, [it's] kind of shameful, isn't it? It's one of the reasons why I'm reluctant to buy one ... Well, it's kind of shameful for a girl to buy it. Well, actually, if a female customer wants to buy condoms, the seller would be ... It's like an assumption, afraid of being seen as ... If the seller smiles, we're already upset. It's not that I'm lazy or scared. It's different between being ashamed and being scared.*

(Dwi)



As discussed above (in the section: 'HIV Knowledge') some misconceptions also contributed to not using condoms; for example, thinking that it is safe to not use a condom if a person looks clean.

Older women who were more worldly and had friends who had contracted HIV or an STI were more likely to use condoms than younger, less experienced women. This suggests that younger women are more vulnerable to unsafe sex than older women:

- I** *Have you ever had sex before you got married without using condoms?*
- B** *Yes, I have.*
- I** *And why was that?*
- B** *Because I was so naïve. Then, when I didn't use condoms, I was still so naïve, I didn't know anything. I didn't know and I didn't dare to ask to partner. Because most women are more passive, for their first time having sex. First time is always like that, everywhere, even though she watches blue film [pornography] more often, or she is a virgin, but in every girl's first time, she is more passive.*
- (Bunga)

### Sex work

Only three of the nineteen women interviewed in this study said that they had sold sex. One of these women was not doing sex work at the time of the interview, but had done so within the previous month in a different city. All three had regular partners who also injected drugs and male partners had played an important role in the initiation of sex work. One woman, Desi, was tricked into engaging in sex work and was unable to escape:

- D** *I worked in a brothel before because the boss wanted to find some girls from the north area, Miss. But he told me that I would work in some place, but not in a brothel, he said "you will be happy working there, you'll meet a lot of people". But, I was young and I didn't understand right, Miss? That's all, I just said, "Yeah, I will go". But then, after I got here, and worked, I found out what kind of job here – serving men who want sex. I didn't understand before...I was not allowed to go anywhere. The bodyguard always guarded us.*
- I** *Oh, really, they had bodyguard?*
- D** *Yeah, I kept being watched by the bodyguard wherever I went. They always followed me. I couldn't escape at all. Then, the only way I could do was to put myself in the business. That's what I did. (Desi)*

However, Desi later willingly engaged in sex work to purchase drugs.

- While he [boyfriend] was at the prison, I had to earn the money with whatever way that I could. The important thing was I could use drugs every day even though I had to have sex with other men.*
- (Desi)

The partners of the two women who were currently engaged in sex work condoned and urged them to do so.

*For example, there is someone who negotiates a deal with me, my husband encourages me. Every time there is a person offering me big money, he always says “accept that, mom”. But if there is someone who bargains, but (with a small amount of money)... well, he just says “no, don’t accept it”.*

(Maya)

*He knows that I sleep with some guys. But he just says “you can do whatever you want to, but the important thing is you get the money”. Yeah, he thinks like that.*

(Desi)

None of the three women who had engaged in sex work expressed concern about HIV. Desi had a live-in partner and a boyfriend with whom she did not live, as well as her clients. She always used a condom when she had sex with her commercial partners, but this was only because the clients wanted to do so. She did not use a condom with her partner because she trusted him and they did not like using condoms, but she did use a condom with her boyfriend because she did not trust him:

**I** *Did you always use condoms with clients?*

**D** *Yeah, I always do.*

**I** *You never don’t use a condom?*

**D** *Yeah, the clients are the one who don’t want to have sex without condom, they usually ...*

**I** *So, they ask that?*

**D** *Yeah, sometimes the clients ask me to do something because they have the money, right? So they can do everything they like, right? They will always win. They want to keep safe. They think like that, maybe they think that a street person is like that. They are afraid to get disease, they think like that. Yeah, they always are like that, they want to use condom, so, I also prepare myself with condoms.*

(Desi)

Maya, who also had multiple sex partners (husband and boyfriends), never used condoms during sex with her commercial partners. She said she always felt rushed and wanted to end the process as quickly as possible. Maya was more concerned that clients were clean than with using condoms:

*It was also because I felt hurried – my mind said, “let it be [not using a condom]”. That happens when I have sex with guys who pay me. Only with the ones who pay me, I don’t think that much; I am in need of the money, right? So, let it be, hehe... whether or not he is clean. For me, it is kind of important, Miss. Clean. First thing is he must be clean.*

(Maya).

Rosa, who had engaged in sex work in the past, never used condoms with her partner or her clients, mainly because she did not like using them:

*Well, with the [client], I don’t know whether he had another affair or not, but I didn’t use condom with him also ... Yeah, actually [he] had said to me before we had sex, he advised me to use a condom. But I got angry that time. I said to him: “If you want to use condoms, then use it, but with another woman. Don’t have sex with me.” That’s what I said.*

(Rosa)

## Harm-reduction services

The harm-reduction programs in all three towns included a needle exchange program, condom distribution, HIV education and information, counselling, HIV testing, referral to STI and drug treatment programs. Methadone programs were available in Yogyakarta and Solo, but not in Salatiga.

In Yogyakarta, the harm-reduction program had recently moved from an NGO to the National AIDS Commission (NAC) Yogyakarta branch. Needles were distributed from the primary health care service, and outreach workers distributed them to the injecting drug users on demand. That is, injecting drug users would call the outreach worker and the outreach worker would deliver the needles to them. In the other

two cities, harm-reduction programs were operated by NGOs and outreach workers worked for these NGOs. In Solo, there was one NGO called Mitra Alam. Mitra Alam's working area was not limited to Solo, but extended to other cities in the area. In Salatiga, there were two NGOs working with injecting drug users, both branches of larger organisations: Mitra Alam and Performa. Injecting drug users were able to hang out at the NGOs in Solo and Salatiga, but there was no such space in Yogyakarta.

During the previous 12 months, 12 of the 19 women had been given condoms and 15 had been given sterile needles and syringes by an outreach worker, a peer educator or a needle exchange program.

Generally speaking, women in this study were positive about the NGOs and the outreach workers. They reported that they received a range of services including needle exchange, HIV testing, referral to methadone and HIV information and advice. The NGOs also provided a space for other social, recreational and vocational activities:

*Well it helps, what I mean in helping is that we are given guidance, we are guided to do more positive things, we are requested... well usually...well I usually tend to ... mmm ... if well.. usually, when junkies don't have any money, they will do criminal acts. Well, by being here we tend to think that it is better being here because here they have games, there's a billiard table, those kind of things.*

(Sulis).

*When I was at the NGO, I didn't just chat, or gossip... not like that. I learnt there, we could join a seminar, we could meet students who do their internship and write thesis there, so we could read and see their theses, like that. So, don't take the negative side of being in the NGO... There are many positive things, there. I couldn't operate a computer... There are three unused computer, so I thought why didn't I use it?*

(Dwi)

*The NGO does not stop injecting drug users from using, it is only a place where they can find shelter to share, a place to tell stories, and a healing process. Instead of hanging out in the street, the NGO provides them a place, or garage like a billiard place for them, just to keep them busy. They can provide counselling if you want to be cured - just find the information there.*

(Dwi)

Only one woman expressed dissatisfaction with harm-reduction services. Her main concern was that the services were established to 'cure' people (help them to stop using drugs), but people who use the services continue to use drugs. She was also concerned about the apparent contradiction between drugs being illegal and needles being distributed to use drugs. This view reflects that often found in community surveys in countries that have introduced NSPs, particularly early in the life of the programs.

Most women were introduced to the harm-reduction services by their male partner or male friends.

Those who were introduced to the NGO by their male partners usually relied on those partners to get them clean needles from the NGO.

Outreach workers in some sites had close relationships with the women who inject drugs, sometimes predating the outreach workers' positions at the NSP. Women who knew outreach workers well and had friendships with other clients of the NGO tended to go more routinely to counselling, attend seminars or get information regarding HIV.

However, not many women spent a lot of time at the NGO. Shame about injecting was the main barrier to accessing harm-reduction services. For most women, the shame of being exposed as a woman who injects drugs was such that they did not want to access the services at all.

The fact that the services were dominated by male clients (i.e. there were few women using the services) was not mentioned as a barrier to service use. However, one woman did report some sexual harassment from men who inject drugs at the NGO which made her feel bad about herself:

*There are about thirty junkies in the NGO. But I only do that thing [have sex] with those two boys [boyfriends]. There are lots of other boys, so every night I receive many SMSs from them, asking me to have sex... They promise me to buy me this and that... That makes me think of how low I am in the NGO.*

(Dwi)

For Dwi, the NGO was a social environment that contributed to drug use, so if she wanted to not use, she avoided it:

*I want to break loose from the environment. So, I seldom go to NGO now... I don't want to go to the NGO, anymore. I'm afraid of meeting my old friends.*

(Dwi)

## HIV testing

HIV testing was available via NGOs in Solo and Salatiga only. It was available in all three sites via community health centres and hospitals.

Fourteen women said that they knew where to get an HIV test but only half of the women had ever undergone an HIV test.

Among the nine women who had done so, seven had been tested multiple times; however, six had been tested a year or more ago. Of the nine participants who were tested, five were HIV negative, two were HIV positive, one woman did not want to declare her status and one did not get the test result. Testing was generally done at an NGO rather than a health service where that was available (Solo and Salatiga).

The overwhelming reason for not being tested for HIV was fear of getting a positive result. The fear was largely related to the likely social repercussions of a positive result because of the stigma attached to HIV and to drug use by women. There was also some concern about being exposed as a drug user if they get tested for HIV.

*I am afraid of taking the test... If I took the test, then the result was positive... it would make my heart beat faster... then after receiving the result... it feels like my heart beats faster so it's better for me not to take the test... Well, sometimes, I feel so afraid; afraid if some day, I will get infected by... oh my God, what am I supposed to do if I am infected? What about my family, what will they do to me? What will my friends do to me? Will they still be my friends?*

*I just thought like that... I felt ashamed. Why, I need to go there (Community Health Centre), because people who goes there must be getting counselling right, then some people will say "Oh my God, she used drugs"... so, I never join the counselling.*

(Icha)

*I'm just scared of the result... it's better not to take the test at all. If my result was HIV positive, I couldn't imagine what would happen next... so, I prefer not to have HIV test.*

(Indah)

Some also had not been tested because they were convinced that they did not need to do so, that they were not at risk of HIV.

*I have not taken an HIV test yet because I am sure that I am clean, so that I never take the test.*

(Susi)

## Methadone

A methadone maintenance program was available only in Yogyakarta and Solo, so the seven women from Salatiga had no access. In Yogyakarta, methadone cost 5,000 rupiah (approximately 0.60 Australian dollars) per day, in Solo injecting drug users were given money to participate in the program. Among the 12 women who could access methadone, two were in a methadone program, and one had previously been on methadone, but had stopped. Thus, there was very little experience of methadone within the sample.

One significant reason for not participating in the methadone program was that five of the 19 women had never heard of the methadone program. Other reasons related to stigma and concerns about the program itself. In relation to stigma, they were afraid of being seen and identified as a drug user while accessing methadone at a community health centre, as this would cause great shame.

In relation to the program itself, some of the reasons were consistent with barriers to using methadone in other countries: concern about being able to stop using methadone as the methadone withdrawal was reputed to be severe, and wanting to avoid the social scene of injecting drug use around a methadone clinic:

*No, I don't like methadone. I have my own point of view... it's like synthetic. If you use it, when you feel withdrawal syndrome, you will feel pain, until to the bone. But if it is etep, add it with Alganax, it will be great... I've once been asked to try methadone, but then my friend from Malaysia said, "withdrawal symptom of methadone is more severe than to etep". It hurts more, so I don't use it. If my friends say "Let's take methadone", "Oh go on, I'll take etep, instead and Alganax, it is already nice".*

(Ade)

*And if I consume methadone, I have to go to the Community Health Centre where it becomes place for the junkies to hang out. Junkies from the NGO. It is held at 8 am to 11 am, and I meet them there... Well, I don't want to meet them. I'd better buy Alganax. 20 for some days*

(Dwi)

Concern was expressed about the sustainability of the program: that the program is subject to international funding so it could cease at any time.

*Then, what if the program of methadone is stopped? Where would you find it? America? Haha... But if you consume etep, it will always be available. The dealers are everywhere. But methadone? Where will you look for it? You don't know yet. Looking for at the government? Haha...*

(Ade)

## Principal findings

While high levels of unsafe injecting and unsafe sex were not described, there were indications that many of the women in this study were at risk of HIV. Most of the women had shared needles at some time, generally with partners and/or friends. When the needles were cleaned, they were generally just cleaned with water which provides little protection from HIV. Most of the women did not use a condom every time with sexual partners; however, most sexual partners were husbands or boyfriends. While few admitted to sex work, providing sex for drugs was not uncommon and likely to have been underreported because of the great stigma and shame associated with commercial sex or providing sex for drugs. Among the small number who said they had done sex work, condom use with clients was not the norm unless the client wanted to use one. Less than half the women reported that they had ever been tested for HIV. Of those who had been tested, most had been tested more than a year ago. Consequently, some women might have been HIV positive and not known this was the case. Very few women were engaged in a methadone program.

Consistent with theoretical frameworks that identify that HIV risk arising from a multitude of individual and social factors,<sup>26-28</sup> a number of factors contributed to the HIV risk for these women. At an individual level, there was excellent knowledge about the role of sharing injecting equipment in transmitting HIV and reasonably good knowledge about sexual transmission. However, there were some misconceptions that contributed to HIV risk. In particular, a few women thought that people who looked clean and healthy would not have HIV so it was safe to share a needle or have unprotected sex with such people.

As is well established, knowledge does not determine behaviour. Attitudes are important, and HIV was not a primary issue of concern for many of the women in the study. Issues that were of greater importance were social issues: avoiding shame by keeping drug use and sexual behaviour hidden and maintaining relationships with friends who inject and/or partners. While it is not true to say that the women were not concerned about HIV, it was generally not as important as these other issues. It was apparent that the women lived in a world where injecting and extramarital sex were so taboo that keeping these behaviours hidden was paramount.

And the strategies for doing this were to socialise only with other injecting drug users, who tended to be male partners or friends, and to do nothing that could possibly expose her as a woman who injects drugs (e.g. going to a harm-reduction service) or has sex (e.g. becoming pregnant). While avoiding pregnancy could be a vehicle for promoting condom use, this is unlikely to have traction as alternate means of contraception are possible that do not reduce sexual pleasure for the woman or her partner. Furthermore, the relationship with one's partner was more important than concerns of HIV, and sex without a condom was a demonstration of trust and a way to please one's partner. Similarly, despite knowledge that HIV could be transmitted by sharing needles, sharing needles was a means of bonding with friends and/or partners. In short, HIV was a lower priority than other social and relationship issues.

Access to condoms and needles was not a major barrier to practising safer sex and drug use. They were generally available if wanted, mostly via males. Having said that, there were still barriers to access which warrant attention. In particular, pharmacists provided an alternate source of needles for a small number of women. The benefit of pharmacies is that there are many of them across the cities and going to a pharmacy does not necessarily identify a woman as an injecting drug user. However, they were only a means of access if: they were open, the woman had sufficient money, she did not fear being recognised or identified as an injecting drug user and the pharmacist would sell injecting equipment to her. This reportedly happened when the woman could convince the seller that the needle was for another purpose (e.g. to inject a pet with vitamins) or the woman knew the pharmacist. Purchasing condoms was found to be even more difficult as it was impossible to pretend that the condoms were for any other purpose than to have sex. Even married women with children found purchasing condoms difficult as it was assumed that she wanted the condoms to have an affair. Policies that support pharmacists to contribute to harm reduction could assist women to directly access injecting equipment and condoms.

From the discussion so far, it is already clear that HIV risk behaviours are shaped by the context in which the women lived. From the discussions with the women, it was the Javanese cultural context that was most evident. This is not to say that Javanese culture is a



'problem' or warrants criticism. In fact, as outlined in the Introduction to this report, Javanese culture produces a generally cohesive and considerate society. However, there were a number of themes here, some specific to women, others that were applicable to men and women, that related to HIV risk. In relation to gendered expectations, Javanese women are expected to be polite, gentle, bland and graceful. Since early childhood, girls are taught to do domestic work; whereas boys are allowed to be more active and playful. Girls are more likely to be punished for naughty behaviour than boys. Hence, when women engage in socially unacceptable behaviours according to Javanese norms, they tend to be more reproached than men. Furthermore, the Javanese character of *pekewuh* (fear of disappointing others who are respected) and *isin* (a sense of 'uneasiness' with respect to behaviour and expression which is counter to social values) amplifies concerns about breaching traditional gender roles. Within this local context, which is situated within a national context of strong religious and legal stances against drug use and extramarital sex, few women inject drugs or have sex outside marriage. Consistent with Room's discussion of the stigmatisation of drug use,<sup>29</sup> there appears to be some public health benefit to social disapproval of these behaviours: most Indonesians, women in particular, do not use illegal drugs at all. However, among those who do, there is a strong sense of shame, and their number-one priority is to hide these behaviours. This has led to women who inject drugs restricting their social life to other injecting drug users. Consequently, they are socially isolated. Further, they are reluctant to be associated with harm-reduction services and fearful of buying condoms or obtaining sterile needles as to do so could expose them. Even the relationship of these women with outreach workers was limited by the Javanese culture of *pekewuh*. Although sometimes they had a relatively close relationship with outreach workers, they still felt disinclined to ask for needles from them as it would identify that they are still injecting drugs and this caused them to feel ashamed of themselves.

While there was evidence of HIV risk and some explanations for these behaviours, there were also factors that were protective of the women in the study. One was that there was a greater level of assertiveness and less exposure to violence than expected from the international literature. Some women talked about

being able to insist upon condom use or not sharing needles. When we looked at who was assertive and who was not, it appeared that women who were financially independent, older and more experienced were the ones who were being assertive. In fact, these older women talked about how younger women were naive and submissive. Apart from these individual factors, how were these women able to be assertive within a society that expects women to be passive and subservient? One possible factor is that the women's friends and partners were accommodating, so it was not difficult to be assertive. There was, in fact, evidence of considerate behaviour from friends and partners. Given that women were often the only female within a group of injecting drug users, there might have been a level of protectiveness from friends and their partners. Partners or friends who had initiated women into injecting drug use might even have felt a sense of responsibility towards their welfare. Javanese culture places emphasis on being empathetic and considerate, so this conducive environment might simply be a product of broader cultural values. An alternate explanation is that the women were not assertive at all, but were motivated to tell the interviewers that they were able to be assertive. This could be because they did not want to admit to being forced to do something against their will, because they did not want to say anything negative about friends or partners, or because they wanted to give an impression of being in control (social desirability bias). It is possible that, to some degree, all of the reasons posited have a role in the assertiveness that was evident in the discussions.

A second protective factor was that the women in the study tended to inject with a small number of friends and/or their partner. Previous research has demonstrated that smaller social networks are associated with less needle sharing as there is a smaller number of available sharing partnerships.<sup>30</sup> So, these small closed groups reduce the number of people with whom the women share.

## Implications

There is substantial literature on HIV prevention to guide policy and programs.<sup>31</sup> United Nations agencies have recommended a comprehensive package of core interventions for preventing HIV among people who inject drugs. These include NSPs, opioid substitution



therapy, HIV testing and counselling, condom programs for injecting drug users and their sexual partners, targeted information for injecting drug users and their sexual partners as well as interventions related to STIs, hepatitis and tuberculosis.<sup>7</sup> The Indonesian government has committed to addressing HIV through such programs.<sup>6</sup> However, the coverage of such programs is universally low, particularly in developing countries, and Indonesia is no exception:<sup>32</sup>

*In Thailand, Indonesia, Myanmar, Nepal, India and Bangladesh it is estimated that less than 12,000 (1.5 per cent) of the estimated 800,000 people who inject drugs have access to opioid substitution therapy... The UN Secretary-General reported that, in 2005, 92 per cent of people who inject in 94 low and middle income countries had no access to HIV prevention services of any kind. (pp 17-18)<sup>33</sup>*

The women in this study were not routinely accessing harm-reduction services or being reached by harm-reduction interventions. But, is it just a matter of providing more services and interventions? To some degree: yes. But not completely. Women who inject drugs are clearly so hidden because of their concern about being exposed as an injecting drug user that some creative strategies for accessing them need to be considered. They are unwilling to attend programs at sites where they can be exposed as an injecting drug user or to obtain condoms or needles for the same reason. Interventions that challenge the social stigma of injecting by women in Indonesia might have some value, and such interventions are recommended by UNAIDS as an essential part of a national AIDS strategy.<sup>25</sup> In particular, the women should not be experiencing shame or hurt as a result of the behaviour of health service providers. The development of leaders and injecting drug user community organisations that include women are likely to be pivotal to addressing stigma.<sup>34</sup> However, changing such long-held and deeply entrenched cultural values will take time and women who inject drugs in Indonesia need to be accessed now. Women-only group discussions or social activities might be a means of encouraging women to access harm-reduction services. Such activities would also benefit women as issues that are difficult to discuss in front of men might be able to be discussed among women.

Given the connection of most of these women to a male partner or friend, the evidence of caring and closeness among these small groups, and the effectiveness of peer interventions in developed and developing countries,<sup>35-36</sup> interventions to encourage and assist men who inject drugs to act as peer educators and suppliers of needles and condoms might be one element of a strategy. However, it would be dangerous to perpetuate female dependence on men, and we cannot assume that the women have no agency in obtaining needles and condoms. There is still a need to make direct access to needles and condoms easier for women. Given that some women already go to pharmacies for needles and condoms, the role of pharmacists in harm reduction could be expanded as has occurred elsewhere.<sup>37</sup> However, it would require substantial training and policy development to change the existing views of pharmacists so that they can take on a role that supports harm reduction.

The culture of caring for each other that was evident among the women, their partners and their friends is consistent with Javanese values around caring for others and putting the needs of others before individual wants. This is a protective factor that HIV prevention efforts can build upon. Health promotion activities could foster a culture of not sharing needles within communities of drug injectors.

Given that the women in the study tended to be socially isolated, particularly from other women, there could be value in helping women who inject to network with each other, so that the younger women might learn from the older women. It is likely that the women would be more comfortable discussing issues about relationships and sex with other women than with men. Older women could act as mentors to younger women, encouraging financial independence and assertiveness. This is a role that may give some women pride and status and that is consistent with Javanese notions of respect for older people.

### Study limitations

While the study has provided important insights into drivers of HIV for women who inject drugs in central Java, the study had a number of limitations. First, the sample was small so some behaviours or situations were not well represented. In particular, there were very few who admitted to having engaged in sex

work, living with HIV or with children. These are very important groups about which more needs to be known.

Second, the interviewers were trainee researchers so they were developing their interview technique during the course of this study. However, during the course of the study, the interviewers' technique improved, and some women were reinterviewed so that richer information could be obtained. This was done after the transcripts of the first interview had been reviewed by a senior researcher.

Third, while women in western countries are often comfortable to disclose personal information to others, it was uncomfortable for the women in this study to talk about sexual behaviour and drug use, given the social sanctions on such behaviour. It is likely that their full stories were not given. One woman who had said that she had never done sex work admitted in a second interview that she had done sex work. Thus, it appears that subsequent research would benefit from an approach that allowed for repeat visits over time to build rapport.

Lastly, given how hidden women who inject drugs are in this area, those who agreed to participate in the study might be different to those who did not. For example, as discussed above, the assertiveness that was evident in the group might be a selection effect rather than representative of the study population.

### **Further research**

Research is needed to obtain more detailed information on subgroups of women who inject drugs, including those who have engaged in sex work, those who are HIV positive, and those with children.

This study was restricted to small cities in central Java. Similar research in other areas of Indonesia where injecting drug use is prevalent would identify how common or unique is the experience of women who inject drugs in central Java.

By speaking only to women, it was not possible to compare the views and experiences of women who inject drugs with those of men who inject drugs. In-depth interviews with men as well as women would enable this comparison.



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