

# Women speak out:

Understanding women who inject drugs in Indonesia







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Siti spends time with her daughter during a home visit from a community-based drug dependence treatment facility.

## FOREWORD

he needs of women who inject drugs have largely been ignored by existing programmes and policies in Indonesia. The Indonesian Drug Users Network supported the implementation of the *Perempuan Bersuara* study to explore health needs, sexual and injecting risk behaviours, gender-based violence, contact with law enforcement, and harm reduction service accessibility among more than 700 women who inject drugs across multiple sites in West Java, Greater Jakarta, and Banten province.

As people who use and inject drugs and direct beneficiaries of Indonesia's harm reduction and HIV response, we feel that the complex needs of women in our community have been neglected for far too long. There is an urgent need to develop gender-sensitive, low-threshold programmes and evidence-based drug policies that accommodate and respond to the specific needs of this group.

On behalf of the Indonesian Drug User Network's national secretariat, we would like to thank all stakeholders who contributed to and supported the implementation of this study. We extend our deepest gratitude and appreciation to the peer research team and to every one of the women who shared her life story and experience with us. We recognize that it took great courage to do so.

It is our hope that the findings of this study will be utilized by all relevant stakeholders, especially those with the power to affect policy change, improve service provision, and reduce stigma and discrimination in the community. We especially encourage the use of the findings and recommendations to inform a more appropriate response to drug use and HIV in Indonesia, including through formulating evidence-based policies that support women who inject drugs to access health and support services. Most importantly, we call for the meaningful involvement of women who use and inject drugs in the formulation and evaluation of policies and services that affect them.

We hope the findings in this report will be used by our communities, service providers, and policy-makers to change the lives of women for the better.

**Edo Agustian** 

National Coordinator, Indonesian Drug User Network

## **INTRODUCTORY REMARKS**

e congratulate the research team on the completion of the Women Speak Out (*Perempuan Bersuara*) study on women who inject drugs in Indonesia and welcome the publication of the present descriptive baseline findings. This study was the result of a collaborative process involving experts across programmes and related sectors. The Ministry of Health of the Republic of Indonesia is grateful for the contribution of the *Perempuan Bersuara* study, which included more than 700 women who inject drugs, towards informing the national HIV response. The research findings are particularly useful considering that existing programmes for people who use drugs have not specifically targeted female drug users.

We recognise the importance of gender mainstreaming as part of existing harm reduction programmes. Given their complex experiences and unique needs, women who use drugs are a group that requires special, targeted attention. In the context of developing responsive programming for women who use drugs, we must consider multi-level risk factors, including individual characteristics such as mental health needs and socio-economic status; network factors such as intimate and non-intimate partner violence victimization and service accessibility; and structural and cultural factors and norms – all of which influence women's ability to negotiate safer behaviours and access prevention and treatment services.

On behalf of the Sub-directorate of HIV, AIDS and Sexually Transmitted Infections (STIs) at the Ministry of Health, we encourage the use of the *Perempuan Bersuara* baseline findings in the development of more responsive programmes, services and policies.

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We owe the deepest gratitude to the women who participated in the study and shared their experiences with us.

This report is dedicated to the memory of Sekar Wulan Sari.

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Top image: Female clients rest at a community-based drug dependence treatment facility. Bottom image: Siti speaks during a client meeting at a community-based drug dependence treatment facility.

### **EXECUTIVE SUMMARY**

ndonesia is home to about 74,000 people who inject drugs, of whom 11% are women.<sup>1,2</sup> Compared with men who inject drugs, women who inject drugs experience an elevated risk of HIV and other blood borne virus transmission, disproportionately high rates of violence from both intimate and non-intimate partners, and social exclusion. Despite their specific needs and greater marginalisation, this group has been largely neglected in Indonesia's national HIV strategy.

In partnership with the University of Oxford, the Indonesian Drug Users Network has supported the *Perempuan Bersuara* (Women Speak Out) study among more than 700 women from multiple sites in West Java, Banten, and Greater Jakarta, Indonesia. The study explored sexual and injecting behaviours, health indicators, gender-based violence, contact with law enforcement, and uptake of health and support services among women who inject drugs. The broad objective of the study was to better understand

the experiences of women who inject drugs and to inform evidence-based responses that can mitigate the impacts of drug use and HIV and AIDS on this vulnerable population in Indonesia.

The findings confirm that the needs of injection drug-using women have largely been ignored by current efforts. At the same time, inadequate access to health and support services contributes to the poor well-being of women who inject drugs in Indonesia. When women do utilize available services, they often feel unwelcome and discriminated against based on their drug use status. Existing violence-prevention and reporting programmes do not target women who use and inject drugs, and legal-aid services are often inaccessible to women who are already socially isolated and marginalised. There is an urgent need to implement and scale up a targeted, low-threshold response and evidence-based policies to address the specific needs of this group.

Based on the findings presented in this report, the Indonesian Drug Users Network recommends the following urgent actions:

#### For policy makers

- Women who inject drugs should be acknowledged as a group needing targeted attention in relevant national guidelines, strategies and policies on drugs and HIV/AIDS.
- Women who inject drugs should be meaningfully involved in developing voluntary, community-based and female-friendly drug dependence treatment programmes, and their unique needs should be prioritized in guidance on minimum standards for drug dependence treatment.
- Existing harm reduction service provision models should integrate friendly and flexible peer-driven approaches that can meet women where they are at.
- National surveillance data should include larger samples of women who inject drugs, and should be gender and age disaggregated.
- There should be monitoring and reporting systems for police-related and intimate partner violence, including legal aid for women who use and inject drugs and specialized and support counselling services.

#### For service providers

- Mainstream gender into referral systems (e.g. for sexual and reproductive health services, harm reduction, HIV prevention, violence prevention).
- Pilot a 'one-stop shop' approach through fixed-site drop-in centres or a mobile site for women who use and inject drugs.
- Implement community-led monitoring and evaluation that involves women who use and inject drugs in assessing the quality of existing local and national harm reduction services.
- Mobilize and empower women who use and inject drugs to play a greater role in advocating for better drug policy and programmes tailored to their specific needs.



A female client prays at a community-based drug dependence treatment facility in Indonesia

### INTRODUCTION

## HIV and drug use in Indonesia

ndonesia's HIV epidemic continues to escalate in contrast with a trend of stabilization in the majority of countries in South East Asia<sup>3</sup>. Between 2006 and 2011, Indonesia experienced a 10-fold increase in the cumulative number of HIV cases4. People who inject drugs, 40% of whom live with HIV5, remain one of the most affected groups. In Jakarta, HIV prevalence among people who inject drugs reaches 55%, and in some areas with limited access to harm reduction services, prevalence has been increasing<sup>5</sup>. According to the National AIDS Commission, Indonesia is home to about 74,000 people who inject drugs, with women estimated to comprise approximately 11% of all drug users<sup>1,2</sup>. In 2009, the only year for which sex-disaggregated data was reported, HIV prevalence among women who inject drugs was higher than among their male counterparts (57.1% vs 52.1%)6.

To address an expanding HIV epidemic, Indonesia introduced a national harm reduction programme in 2006, which included needle syringe exchange programmes and opioid maintenance therapy. In 2012, the programme reached 64,259 people who inject drugs, which at the time represented 87% of the injection population<sup>5</sup>. However, there are no programmes specifically targeting women who inject drugs. The absence of adequate sample sizes of women who inject drugs and sex-disaggregated data in national surveys pose obstacles to the development of female- specific programmes. When women are included in national surveillance, they tend to comprise a disproportionately small proportion of sample sizes<sup>6</sup>, further limiting the ability to draw accurate conclusions about the experiences and needs of this group.

"Women comprise approximately 11% of the 74,000 people who inject drugs in Indonesia."

## Indonesia's drug policy profile

Indonesia's response to drug use relies heavily on punitive law enforcement approaches. Narcotics Law no. 35, introduced in 2009, provides a legal framework for addressing drug-related offenses. While the policy introduced mechanisms for diverting people who use drugs away from prison and towards drug dependence treatment, it also criminalized families and communities for failing to report people who use drugs to state authorities<sup>7</sup>. In practice, the implementation of Narcotics Law no. 35 has been inconsistent and marred by systemic corruption in the police force and within the criminal justice system8. A significant proportion of people who use drugs continue to be sent to prison despite the 2009 legal provisions. As of September 2016, one third of all inmates (33% or 66,625 people ) were incarcerated for drug-related offenses, of whom the majority (63% or 41,710 people) were charged with drug possession for personal use9. Women's involvement in the drug trade as drug users and drug mules is often motivated by their social disadvantage, and often results in harsh, disproportionate sentencing due to limited access to legal aid.

Under Joko Widodo's presidency, the Indonesian government has enforced an increasingly punitive "war on drugs" that championed mandatory drug dependence treatment and increased expenditure on law-enforcement-led approaches, culminating in the execution of 14 people for drug-related offenses in 2015. Academics have criticised this approach, arguing that existing measures are costly and ineffective, and urging the government to scale up evidence-based harm reduction services such as needle syringe programmes and opioid substitution therapy<sup>10</sup>. According to preliminary research conducted by the Indonesian Drug Users Network, the government's hard-line response has posed additional barriers to HIV prevention efforts among people who use drugs and has resulted in numerous unintended consequences. These include increased discomfort and fear in relation to accessing health services among people who use drugs, and greater availability and popularity of new illicit substances in response to shortages in popular drugs11,12, which have in turn resulted in increased overdoses. Added consequences for drug-using women include engagement in risky behaviours such as sex work with high risk partners in order to procure drugs and to provide for their families, particularly as drug prices were driven up by the "war on drugs"11.

#### Women who inject drugs

Understanding and responding to the needs of drug-using women is a public health and human rights imperative. Although women comprise a smaller proportion of the overall population of people who use drugs, they face dual risk of HIV infection and onwards transmission through both sexual risk-taking and unsafe injecting practices. Existing research shows that compared to men who inject drugs, women who inject drugs experience significantly higher HIV and mortality rates <sup>13,14</sup>.

"Women who inject drugs face dual risk of HIV infection and onwards transmission through both unsafe sex and injecting practices."

Qualitative research from across the Indonesian archipelago highlights drug-using women' elevated vulnerability to HIV<sup>15-19</sup>. Many women engage in sex work in order to provide for their families and support theirs and their partner's drug use. This includes the common practice of turbo (tukar body), or trading sex with drug dealers in exchange for drugs<sup>15,16</sup>. The practice leaves little negotiating power for women, and often results in risky, unprotected sexual encounters.

Women's intimate relationships in Indonesia are strongly shaped by social stigma, cultural norms and relationship power differentials between men and women<sup>18</sup>. Such power imbalances are even more pronounced among druginvolved women. Previous research suggests that women who inject drugs experience a disproportionately high burden of gender-based violence compared with women in the general population<sup>20,21</sup>. For instance, Habsari et al. (2007) and Sari and Virgarose (2010)<sup>16</sup> identified pervasive exposure to forced sex, physical and psychological abuse perpetrated by both intimate and non-intimate partners, including law enforcement officers and health workers. Gender-based violence victimization may lead to HIV transmission through biological (e.g. tears and cuts that may occur during forced sex) and psychological mechanisms. The latter include lowering women's self-esteem and increasing vulnerability to mental health disorders, both of which impede women's ability to negotiate safer sexual and injecting practices. For example, women who inject drugs in Central Java have reported acquiescing to men's wishes to share needles and to have unprotected sex in order to avoid conflict and to "maintain" their relationship with intimate partners<sup>19</sup>.

Existing research also suggests that women are more likely to engage in unsafe injecting practices compared with their male counterparts <sup>14,22,23</sup>. According to national 2012 programme data, 22% of female and 7% of male HIV-positive injecting drug users in Indonesia reported

sharing needles and syringes in the preceding week, despite already accessing harm reduction services <sup>24</sup>. Fear of police harassment and violence leads many women to rush injections, and to inject in isolation and in unhygienic conditions. Additional barriers to accessing services include unknowledgeable healthcare staff who are unaware of women's reproductive and sexual health needs while using drugs, as well as lack of flexible opening hours and limited access to outreach workers, both of which pose obstacles for women who work or have childcare responsibilities. Elevated stigma and discrimination from the community, law enforcement, and healthcare providers<sup>25</sup> further compounds these barriers to accessibility faced by drugusing women.

These heightened risks and vulnerabilities have a negative impact on women's health and well-being, especially sexual and reproductive health. Exploratory research among women who inject drugs in Jakarta demonstrated the presence of symptoms indicative of sexually transmitted infections (STIs), substandard pre- and post-natal medical care in relation to methadone maintenance and/or active injecting drug use during pregnancy, unsafe abortions, and disrupted menstruation.<sup>26</sup> Furthermore, women who inject drugs have reported frequent experiences of drug-related arrest, police detention, and incarceration, with many also expressing difficulties in accessing legal aid throughout the arrest process. Such challenges are magnified among druginjecting women who also sell sex.

"There are currently no harm reduction programmes that specifically address the needs of drug-using women in Indonesia."

Despite the evident need for tailored services that address injection drug-using women's health and human rights concerns, there are currently no harm reduction nor drug dependence treatment programmes that specifically address women's needs in Indonesia. When women do access existing services, they often feel unwelcome and discriminated against<sup>16</sup>. Existing violence prevention and reporting programmes do not target women who use and inject drugs, and legal aid services are often inaccessible to women who are already socially isolated and marginalised<sup>27</sup>. There is an urgent need to better understand the experiences of women who inject drugs and develop appropriate responses.

### **METHODOLOGY**

baseline study was conducted to strengthen the evidence base on the experiences of women who inject drugs in Indonesia. The study was designed to generate a representative sample of women who inject drugs. A community advisory group comprised of women with an injecting drug use background provided guidance on all aspects of study implementation, including study design, development of questionnaire instruments, logistics, and ethics protocols. Additionally, an expert review committee constituted of researchers, policy-makers, and service providers peer reviewed the study protocol and advised on study implementation.

#### **Study setting**

Study sites were selected with reference to Ministry of Health surveillance data identifying areas with large numbers of people who inject drugs and high HIV rates among injectors<sup>1</sup>. These included Jakarta and surrounding suburbs Bogor, Tangerang, Depok and Bekasi; and Bandung, the provincial capital of West Java.

#### Perempuan Bersuara study implementation sites



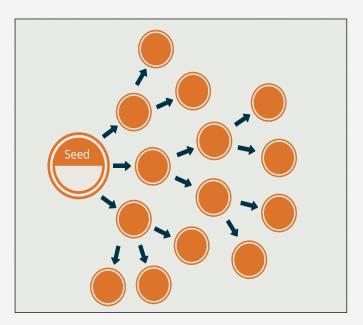
#### **Eligibility criteria**

Eligibility criteria for participating in the study included: being female; ≥18 years of age; injecting any type of illicit or illegal drugs in the previous 12 months; residing in one of the study catchment areas; possessing a referral by an existing study participant; and being able to provide voluntary informed consent.

## Data collection with peer interviewers

Eligible participants were recruited using respondent-driven sampling (RDS)<sup>28</sup> between September 2014 and May 2015. RDS is a modified form of peer-based, snowball sampling which provides access to hidden and/or hard-to-reach populations and allows researchers to conduct more generalizable analyses.<sup>29</sup> RDS uses a systematic referral procedure and a statistical model that weights the sample to reduce biases associated with non-random recruitment<sup>29</sup>, thus generating results that will be more applicable to improving services and developing interventions that target this group<sup>30</sup>.

Figure 1: Theoretical respondent-driven sampling referral chain



Female peer interviewers were trained extensively in questionnaire administration, mobile data collection, ethics, referral provision, and fieldwork health and safety. Face-to-face interviews lasted approximately one hour and were conducted at locations deemed safe by participants, such as offices of non-governmental organizations or participants' homes. Information was collected using tablets equipped with Open Data Kit, an open-source application for data

collection on mobile devices<sup>31</sup>. Recruitment was initiated through the selection of 20 initial recruits ("seeds"). Seed selection was informed by mapping and key informant interviews with local non-governmental organizations working with people who use drugs and consultations with the community advisory group. In order to increase the representativeness of the resulting sample, seeds were selected based on diversity in terms of geographic residence across study sites, age, preferred injectable drug type, levels of risk behavior, marital status and education level. Each seed was asked to refer up to three peers to the study, who in turn enlisted additional peers in a chain-referral fashion, as shown in Figure 1.

#### **Ethics and safety**

The study was completely anonymous. Voluntary verbal and written informed consent was obtained from each participant in the study; all participants were encouraged to use pseudonyms and were given uniquely coded identifiers. Strict confidentiality was maintained, except where participants requested service referrals or assistance. Researchers maximized opportunities for referral by providing all participants with a local directory of HIV, viral hepatitis, sexually transmitted infection (STI) testing and counselling, legal aid and violence prevention services. Ethical protocols were approved by the Central University Research Ethics Committee at the University of Oxford and the Ethics Board of Atma Jaya University.

#### **Data Analysis**

Data were analyzed in Stata 14.1 using the RDS package for Stata<sup>32</sup>. To account for the potential effects of RDS design on analyses, estimates of population proportions and 95% Confidence Intervals were calculated separately for each variable using a data-smoothing bootstrap algorithm. Descriptive analyses adjusted for differential recruitment and variation in participants' peer network sizes<sup>29</sup>. Unless otherwise indicated, RDS-adjusted population proportions are reported.

### STUDY FINDINGS

#### Socio-economic and demographic characteristics

**STUDY POPULATION:** 731 women aged 18-46 who actively injected drugs in the previous 12 months.

**MEAN AGE:** 31 years old. 65% of women were between 25-34 years old, 22% were 35 or older, and 14% were 24 or younger.

MARITAL STATUS: 42% currently married, 23% dating, 13% single, 15% divorced, and 8% widowed

**DEPENDENTS:** 59% had dependent children in the household or other dependents for whom they were responsible

HIGHEST LEVEL OF EDUCATION COMPLETED: 18% post-secondary education or vocational training, 61% high school, 17% junior high school, and 3% primary school

**HOUSING:** 45% lived with parents or other relatives, 44% lived in a rental room (kos-kosan) or other type of rental property, 11% owned their own property, and 1% were homeless

**EMPLOYMENT:** 47% were unemployed, 27% worked in the informal sector, 19% had temporary or short-term work, and 9% had longer-term, regular work.

**MEAN INDIVIDUAL MONTHLY INCOME:** Rp 4.3 million (approximately USD \$330). 56.5% of women had monthly incomes below the Indonesian national average of Rp 3.8 million (USD \$280).

MAIN SOURCE OF MONTHLY INCOME: 30% were financially dependent on their partner, 18% relied on their family and relatives as their main income source, 37% earned their income from a regular/temporary job, and 15% got their main source of income via sex work and drug transactions (as drug mules, or by selling drugs).

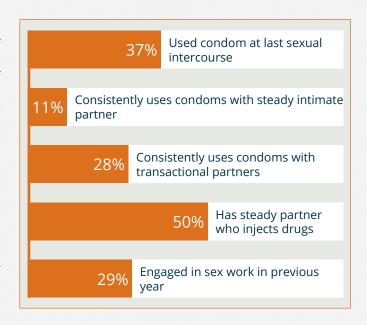
#### **Behaviours and practices**

#### Sexual behaviours

The majority of women only had male intimate partners (97%), while 3% had male and/or female partners. Unsafe sexual behaviours that placed women at higher risk of contracting HIV and other sexually transmitted infections were common in this group. A substantial proportion of women had intimate partners who themselves engaged in behaviours or had characteristics that placed them at higher risk: 50% of women had a steady partner who also injected drugs, and 42% reported knowingly having unprotected sex with a partner living with HIV. 37% of women had multiple (two or more) sexual partners in the past year.

Unprotected sex at last intercourse with any type of partner was reported by nearly two-thirds of the women (63%). Only 11% used a condom every time they had sex with a steady intimate partner such as a husband or a boyfriend of 3 months or longer in the previous year (Figure 2). Nearly one third (29%) of women traded sex in the previous year in exchange for money or drugs, to meet basic needs such as shelter and food, or to support their family, yet only 28% among them reported always using a condom for each of these encounters.

Figure 2: Sexual behaviours and consistent use of condoms



#### **Drug-related behaviours**

#### Drug injecting initiation

Mean age of injecting initiation in the sample was 21.2 years, with some women injecting drugs for the first time at 12 years of age. 29% of participants initiated drug injecting at 18 years or younger, and 74% initiated injecting at 24 years of age or younger. 96% of women were injected by someone else the first time they ever injected drugs, a practice which has been associated with increased HIV transmission risk<sup>33,34</sup>.

Drugs for women's first injection were procured by a diverse range of individuals within women's social network, including male friends (34%), female friends (24%), intimate partners (29%), family members (3%), and in a sizeable minority of cases, directly from a drug dealer by the participant herself (10%).

#### Past-year drug use and injection

Substances injected at least once in the previous year included: heroin (95%), illicit buprenorphine (19%), benzodiazepine (3%), crystal methamphetamine (1%), codeine (1%) and ketamine (0.3%). The majority of participants (86%) injected heroin as their drug of choice, while 14% indicated that they preferred buprenorphine. However, poly-drug use was common: 91% of the women used at least two types of substances in the previous year. In addition to injection drugs, participants also used several non-injection substances in the previous year; preferred non-injection drugs included crystal methamphetamine (17%), benzodiazepines, including illicit anti-depressants (15%), alcohol (13%), and marijuana (5%).

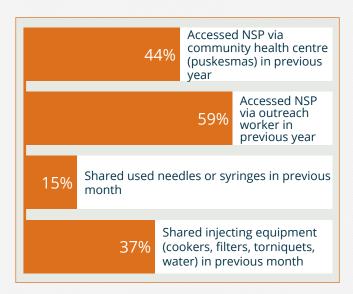
On average, women reported injecting drugs for about 10 years (range: 4 months to 24 years). Approximately 7% of the women were new injectors, injecting for 2 years or less. On average, 63% of women's incomes each month – the equivalent of Rp 2.7 million (approximately USD \$210) – was spent on drug purchases.

#### Use of sterile injecting equipment

The prevalence of receptive sharing of needles and syringes<sup>2</sup> in the past month was 15% (unweighted prevalence was higher, at 21%) (Figure 3). More than 1 in 3 women (37%) reported sharing injecting paraphernalia such as containers, filters, tourniquets and water used to prepare drugs for injection, which poses a significant, but far less prioritised, risk factor for the transmission of hepatitis C and other blood borne viruses (unweighted prevalence of injecting equipment sharing was 44%)<sup>35</sup>.<sup>3</sup>

About 41% of the women reported that they usually injected drugs together with an intimate partner. 20% of women reported that they usually require help injecting, and in most cases, they reported that it was an intimate partner who performed the injection (40%). However, the majority of participants reported being injected by individuals outside intimate relationships, such as male friends (34%), female friends (24%), drug dealers (1%), and family members (1%).

Figure 3: Accessibility and sharing of injecting equipment



## Policing and contact with law enforcement

#### Arrest and incarceration

Nearly half of the women (45%) reported a history of arrest; 93% of those arrests were for drug-related offenses. Women reported an average of three arrests during their lifetime. Thinking about the last time they were arrested, 77% of participants were charged with drug possession for personal use, 14% for aiding or assisting in a drug transaction (e.g. as a drug mule or through buying/selling drugs), 7% for other criminal offenses committed in order to procure drugs (i.e. sex work, stealing), and 3% were apprehended as part of a police raid or sweep. 14% of the women had ever been to prison or jail (unweighted 23%). Among them, 42% continued to inject drugs while in prison or detention.

<sup>1.</sup> Buprenorphine, which is marketed under the brand names Subutex and Suboxone, is a legal substitution medication used to treat opioid dependence

<sup>2.</sup> Receptive needle and syringe sharing was measured using four items selected from the injection risk subscale of the Blood-Borne Virus Transmission Risk Assessment Questionnaire (BBV-TRAQ), which assesses the frequency with which people who inject drugs engage in injection-related behaviours in the previous month. Items included: injected with another person's used needle/syringe; injected with a needle/syringe after another person has already injected some of its contents; received a needle-stick/prick from another person's used

needle/syringe; and re-used a needle/syringe taken out of a shared disposal/sharps container.

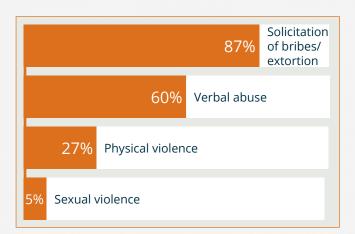
3. Sharing of drug preparation paraphernalia was measured using four items selected from the injecting risk subscale of the BBV-TRAQ. Items included: injected a drug filtered through another person's used filter; injecting a drug that was prepared in a used spoon or mixing container; injected a drug prepared with used water; and used another person's used tourniquet.

#### Police extortion, abuse and violence

An overwhelming 87% of women with a history of drugrelated arrest reported that they and/or their families experienced police extortion during the arrest process. In most cases, extortion involved solicitation of substantial sums of money by the police in exchange for a lesser charge, a referral to drug dependence treatment, or having charges dropped. Several women reported being forced by authorities to "snitch" on their drug-using peers in order to have their charge reduced or dropped. This process is known in the community as "tukar kepala" (literally, "head exchange").

We found high rates of violence and abuse perpetrated by police officers against women who inject drugs (Figure 4). 60% of women who came into contact with law enforcement experienced verbal abuse (insulted, called names, berated or put down), 27% experienced physical violence (slapped, punched, kicked or beat up), and 5% experienced sexual violence (forced to have vaginal or anal sex, perform oral sex, or touched inappropriately/groped in intimate areas against their will).

Figure 4: Police violence and abuse during the arrest process



## Self-reported health indicators

#### HIV and sexually transmitted infections

The prevalence of self-reported HIV infection in the sample was 42% (unweighted HIV prevalence was higher, at 47%). One in five women (20%) did not know their HIV status. Approximately 84% had ever been tested for HIV antibodies, of whom 86% tested more than 6 months prior

to the survey. Given that the World Health Organization Consolidated Guidelines on treating and preventing HIV infection recommends testing every 3 months for individuals at elevated risk of HIV<sup>36</sup>, it is likely that actual HIV prevalence among women who inject drugs is higher than reported here.

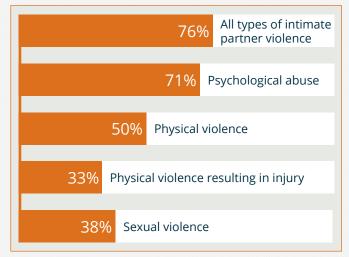
90% of women had ever heard of sexually transmitted infection symptoms (STIs). A majority (65%) reported having current STI symptoms.<sup>4</sup> The presence of STIs facilitates HIV transmission and increases the infectiousness of HIV among women already living with the virus, highlighting women's considerable risk for contracting HIV and transmitting it onwards to their sexual and injecting partners.

#### Intimate partner violence

76% of women experienced some form of intimate partner violence<sup>5</sup> by a current or former partner or spouse in the previous year. Severe psychological aggression that involved threats of violence was experienced by 40% of participants. Half of the women (50%) were exposed to some form of physical abuse, with 6% experiencing injury so severe, that they needed to see a doctor or go to the emergency room (Figure 5).

Sexual violence was reported by 38% of participants. 5% of women reported more severe forms of forced sex that involved the use of force such as hitting, holding down, or using a weapon to force them to have sex (rape).

Figure 5: Exposure to past-year intimate partner violence



<sup>4.</sup> The presence of current STI symptoms was measured using a symptomatic approach based on participant self-report of easily recognized symptoms. Participants reporting at least two of the following six symptoms at the time of interview were coded having current STI symptoms: burning sensation and/or discomfort when urinating, itching, irritation and/or discomfort in the genital area, discomfort and/or pain during sexual intercourse, sores, blisters and/or ulcers on or in the vagina, unusual vaginal discharge, such as pus or a thick and/or sticky liquid from the genital area, and/or lower abdominal pain.

<sup>5.</sup> Intimate partner violence was measured using the psychological, physical, injurious, and sexual subscales of the 20-item Revised Conflict Tactics Scale short form.

#### **Overdose**

Approximately 1 in 3 women (32%) experienced at least one overdose. On average, women experienced two overdoses in their lifetime. 73% of women had witnessed a friend or acquaintance experience a non-fatal overdose, and 34% witnessed a friend having a fatal overdose.

#### Trauma and mental health

More than half of the women (55%) had lifetime experience of trauma, such as exposure to family bereavement or to lifethreatening natural disasters. In addition, 43% experienced physical abuse, and 39% experienced sexual abuse in their

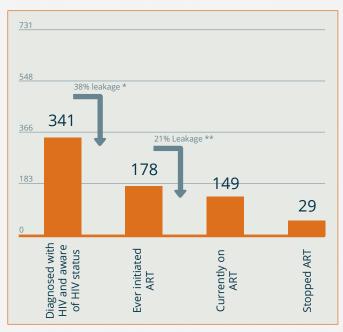
Mental health needs were widespread among the women in our sample. 65% of women reported symptoms indicative of clinical depression.7 A similar proportion, 63%, had symptoms of post-traumatic stress disorder.8

#### Access to health and support services

#### Antiretroviral treatment for HIV

Among women living with HIV who were aware of their positive status, the majority (62%) had initiated life-saving antiretroviral treatment (ART) (unweighted figure was lower, at 52%). At the time of the survey, 21% of these women had stopped taking ART (Figure 6). Reasons for stopping ART included: being tired of taking medication daily or multiple times a day (62%), experiencing severe side effects (35%), often forgetting to take the medication/being worried about developing viral resistance (45%), not having time to go to the clinic/hospital (14%), not being able to get to the clinic/ hospital due to geographical distance (14%), and feeling "healthy" without medication (21%). Participants also raised concerns about lengthy and complicated bureaucratic processes related to ART access after moving to another area, financial constraints, and concerns about family/ relatives finding out about their status.

#### Figure 6: Antiretroviral treatment among women who inject drugs (n=731)



\* Unweighted: 48%. \*\* Unweighted: 16%.

38% (unweighted 48%) of all women living with HIV in the sample had never initiated ART. Women's reasons for not yet starting ART included: feeling "healthy" without medication (50%), having a high CD4 count (34%), feeling worried about side effects (28%), and receiving medical advice against initiating ART (13%). Financial constraints (3%) and large geographical distances to the clinic/hospital (5%) posed additional barriers to ART uptake, particularly for women residing outside the Greater Jakarta area.

#### Sexual and reproductive health

23% of women accessed testing for sexually transmitted infections in the previous year, among whom approximately one third (34%) received STI treatment (Figure 7).

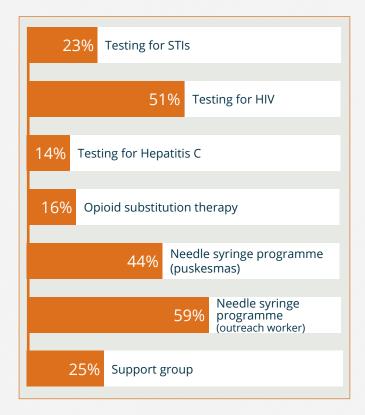
More than 1 in 4 (26%) women reported having an abortion, with women having on average at least two abortions in their lifetime, and some women having up to five. Although abortion in Indonesia is illegal and highly stigmatised, many women terminate their pregnancies in unsafe ways, leading to serious complications and sometimes death.

Lifetime history of trauma and childhood abuse was measured using The Early Trauma Inventory Self Report-Short Form. The instrument consists of 27 items in the four domains of childhood physical, emotional, and sexual abuse, as well as general lifetime traumas such as exposure to life-threatening natural disasters and family bereavement. Depressive symptoms were measured using the 20-item Revised Center for Epidemiologic Studies Depression Scale, and assessed using key components of depressive symptomatology (i.e. depressed mood, feelings of guilt and worthlessness, feelings of helplessness and hopelessness, psychomotor retardation, loss of appetite, and sleep disturbance). A cut-off score of 16 or more, indicative of "significant" or "mild" clinical depression symptomatology, was used to assess the existence of depressive symptoms.

Post-traumatic stress disorder was measured using the PTSD Checklist Scale, a 17-item tool. Participants were coded as PTSD-symptomatic if they met the median Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) cut-off score.

Participants highlighted sexual and reproductive health as a priority need that remains largely unmet. A particular challenge was accessing quality, accurate sexual health and pre- and post-natal care that did not discriminate against women based on their active drug use or their non-married status, and which is integrated within existing services. Women also reported disrupted menstruation, and raised concerns about the lack of reliable information and limited knowledge of drug and HIV service staff in relation to this common issue.

Figure 7: Past-year access to health services



#### Antiviral treatment for Hepatitis C

70% of the women were unaware of their hepatitis C (HCV) status. Among the 33% who knew their HCV antibody status, self-reported HCV prevalence was 43% (unweighted prevalence was 49%).

Among women with self-reported positive HCV antibody status, only 15% had ever accessed antiviral treatment with pegylated interferon and ribavirin. The treatment was successful (i.e. resulted in sustained virologic response) for 64% of these women.<sup>9</sup> Reasons for not initiating treatment among the remaining 88% of women living with HCV included: feeling "healthy" without medication (34%), prohibitive cost of treatment (32%), prohibitive cost of supporting tests such as fibroscan, genotype testing, viral load (17%), and fear of side effects (6%).

#### Needle and syringe programmes

In the previous year, most women accessed needles and syringes through outreach workers (59%). 44% accessed sterile injecting equipment from fixed sites in community health centres (puskesmas).

## Opioid substitution therapy and drug dependence treatment

16% of the women were enrolled in opioid substitution therapy (OST) at the time of interview, of whom 85% accessed methadone and 15% accessed buprenorphine (Subutex or Subuxone). On average, the women had been on OST for three years and eight months (range one month to 144 months).

26% of the women had previously attended a drug dependence treatment programme. On average, participants had attended drug dependence treatment at least twice, with some women reporting attending as many as 20 times. When asked about the last drug dependence treatment programme they ever attended, only 36% of women reported that they had enrolled voluntarily. The majority (60%) had been forced to enter treatment by their families, while only 4% were referred to treatment via legal processes such as the criminal justice system. When thinking about which type of drug treatment worked best for them, the largest proportion of women (30%) indicated that community-based drug dependence treatment<sup>10</sup> was their preferred option.

<sup>9.</sup> Note: this figure is based on a small subsample of 14 women who ever accessed antiviral treatment for HCV.

<sup>10.</sup> In the Indonesian context, community-based drug dependence treatment (CBBDT) refers to a model established in 2009 by the National AIDS Commission in cooperation with 11 community-based organisations. CBDDT comprises a short-term individualised in-patient programme and a longer-term outpatient programme aimed at improving clients' quality of life and minimising risky behaviours associated with the transmission of blood borne viruses. For more information, see Wijoyo E, Sarasvita R, Rachman A. Evaluation process for community-based drug treatment program in Indonesia. 2014.

## Discrimination, exclusion and social support

Women who inject drugs tend to face greater discrimination than men who inject drugs. In Indonesia, women's drug use is commonly viewed as "immoral", reflective of personal failure, and incompatible with the expected gendered roles of women as wives and mothers<sup>16</sup>.

These perceptions were confirmed by the experiences of the women in this study, many of whom felt socially excluded and lacking the social support they needed from their families and peers. 50% of women did not feel that they could talk about their problems with their family, nor that their family provided emotional help and support. Exclusion from women's own social circle was also common: approximately 50% of the women felt that they could not talk to or count on their friends when they had a problem. Considering the high levels of relapse and limited access to voluntary, community-based drug dependence treatment, there is a particular need for greater community and social support to ensure better outcomes for women on OST and those in drug dependence treatment.

In addition to concerns identified by previous qualitative research regarding women's lack of comfort in accessing public health care due to discrimination by medical staff<sup>16</sup>, participants in this study also noted the need for friendly, integrated services in the community that accommodate childcare needs and provide a "safe" space run by women for women. Many participants particularly noted the need for integrated health services that address their drug-related, sexual and reproductive health needs compassionately and holistically, and where their active drug use status is addressed in a non-judgemental manner.



### CONCLUSION

his study's findings confirm that women who inject drugs in Indonesia experience multiple negative health outcomes and vulnerabilities. High rates of inconsistent condom use, engagement in sex work, and injecting equipment sharing highlight women's double risk of contracting and transmitting HIV, HCV and other blood borne viruses through both unsafe sexual and injecting practices. Women's dual sexual and injection-related risk is compounded by elevated exposure to intimate partner violence and widespread harassment and abuse from the police.

Self-reported health indicators demonstrate high rates of HIV and sexually transmitted infections, overdose, trauma, and mental health needs. Sexual and reproductive health was emphasised as a key area of concern where urgent action is required. Participants highlighted a significant gap in existing services that are sensitive and appropriate to the needs of drug-using women. Social exclusion, lack of support from families and peers, and discrimination from service providers further adds to drug-using women's marginalisation.

The 2016 United Nations Political Declaration on HIV and AIDS: On the Fast-Track to Accelerate the Fight against HIV and to End the AIDS Epidemic by 2030 encourages countries to "reach all women, adolescent girls and key populations with comprehensive HIV prevention services, including harm reduction, by 2020".

Earlier this year, Indonesia was one of 193 United Nations member states that unanimously adopted the 2016 United Nations Political Declaration on HIV and AIDS: On the Fast-Track to Accelerate the Fight against HIV and to End the AIDS Epidemic by 2030. The Declaration encourages countries to "reach all women, adolescent girls and key populations with comprehensive HIV prevention services, including harm reduction, by 2020"<sup>37</sup>. This goal cannot be realized, particularly among key affected populations such as people who inject drugs, without addressing the disproportionate burden of HIV-related vulnerability faced by women who inject drugs. This study's findings suggest that Indonesia must do more to fulfil this commitment for women who inject drugs: utilisation of harm reduction services, voluntary

community-based drug dependence programmes and antiretroviral treatment uptake remain limited among this group. Reaching all women and girls also means addressing the high rates of violence and victimization perpetrated by both intimate and non-intimate partners and encouraging an enabling policy environment that supports rather than criminalises drug-involved women.

## Strengths and limitations of the study

This study has several limitations. First, due to the cross-sectional study design, no conclusions about causation can be made; follow-up research employing longitudinal study design is required to test any causal assumptions. Second, the use of self-report may be subject to recall and reporting bias, especially in relation to sensitive information about illegal behaviours. This limitation was minimized by using peer interviewers<sup>38</sup>, which has been shown to enhance the validity of self-report data<sup>39</sup>.

Despite these limitations, the study has important strengths. This is the largest study to examine baseline health indicators and other key characteristics among women who inject drugs in Indonesia. Importantly, the collaborative nature and diverse partnerships between Indonesian and international academic institutions, networks of people who use drugs and local civil society organisations ensured that findings will be used in advocacy for evidence-based policies and to improve existing programmes. Notably, the active involvement of the female drug user community was integral to the project's human-rights based, participatory approach, and provided an important opportunity to build research capacity among women with a drug use background and collaborating community-based organisations.



Siti participates in a client meeting at a community-based drug dependence treatment facility.

### **RECOMMENDATIONS**

espite evidence of overlapping vulnerabilities among women who inject drugs in Indonesia, there has been no comprehensive response to addressing their unique needs. Tailored, low-threshold programmes and conducive, evidence-based policies need to be implemented and scaled up to address the specific needs of this group. We recommend the following urgent actions:

#### For policy-makers

- 1. Women who use and inject drugs should be explicitly included in national guidelines, HIV/AIDS and drug strategies and other relevant policy documents as a specific group needing targeted attention.
- 2. National guidelines for opioid substitution therapy (OST); including methadone and buprenorphine should be developed with the meaningful participation of women who use drugs. Guidelines should include:
  - Clear instructions for doctors and other medical staff on drug dependence including dosing and sexual and reproductive health and rights: menstruation, pregnancy, abortion, and contraception.
  - Provision of psychosocial support for women on OST.
- **3.** Guidance on minimum standards for drug dependence treatment and rehabilitation should meaningfully involve women who use and inject drugs and address their specific treatment needs. In particular, these include:
  - Voluntary, client-centered women-only programmes that provide evidence-based, individualized treatment plans and flexibility regarding communication and interaction with women's children and families.
  - Meaningful involvement of women who use and inject drugs in existing drafting and negotiation processes at the national level.
- **4.** Actively report and disaggregate existing national surveillance datasets and other research information based on gender and age. Specifically:
  - Include larger samples of women who use and inject drugs in national surveillance.
  - Utilize peer-driven recruitment method in research and harm reduction programmes.
- **5.** Establish monitoring and reporting systems for police-related and intimate partner violence including legal aid for women who use and inject drugs followed by providing special counselling services post-violence for women who use and inject drugs.

#### For service providers

A package of interventions and related guidance, including adjustments to existing programmes, that addresses harms related to drug use, unsafe sex and human rights violations are required:

- **1.** Mainstream gender into referral systems for services related to sexual and reproductive health, harm reduction, HIV prevention, treatment and care, and violence prevention services.
- **2.** Pilot a model 'one-stop shop' approach through fixed-site drop-in centres or mobile sites to facilitate service access for women who use and inject drugs:
  - Improve the friendliness of existing harm reduction and other HIV/AIDS prevention and care services for women who use and inject drugs by providing discreet, separate locations for women-only service provision; involving more women in programme design, monitoring and evaluation; providing flexible hours for fixed-site services; and implementing mobile, peer-led services, in recognition that many women have child care and/or work responsibilities;
  - Implement peer-driven outreach among women who use and inject drugs within existing outreach programs, including by having a quota of female staff including outreach workers, counsellors and peers to manage women's cases;
  - Engage women's families and local communities in programes and events with the aim of reducing stigma and increasing social support for drug-involved women.
- **3.** Implement community-led monitoring and evaluation for existing services that involves women who use and inject drugs in assessing the quality and effectiveness of local and national harm reduction services.
- **4.** Mobilize and empower women who use and inject drugs to play a greater role in advocating for better drug policy and programs tailored to their specific needs.



Clients at a community-based drug dependence treatment facility undergoing a traditional massage to relieve stress.

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