



# DOUBLE TROUBLE

## INJECTION DRUG USE AND SEXUAL BEHAVIOUR

Findings from a cross-sectional qualitative study of HIV vulnerabilities among People Who Inject Drugs and their sex partners in Bihar and Manipur, India



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# Preface

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People who inject drugs (PWID) in India and elsewhere face a disproportionately high risk of contracting HIV and other blood borne viruses. India is home to at least 180,000 PWID, a large proportion of whom do not have access to sterile injecting equipment which in turn results the use of non-sterile needles and syringes and consequent rapid and large-scale transmission of HIV.

The prevalence of HIV among PWID in some states is estimated to be as high as 15%. In order to prevent new HIV infections, the National AIDS Control Organisation (NACO) has adopted a harm reduction strategy implemented under the National AIDS Control Programme IV. The strategy sets out a range of interventions, called Targeted Interventions, which are implemented by NGOs to reach PWID. With funding from Government of the Netherlands through the Community Action on Harm Reduction Initiative, Alliance India's Hridaya programme operates in the states of Bihar, Haryana, Jammu, Manipur, and Uttarakhand and delivers a range of interventions that supplement the NACO-supported programme.

The current research is one of the first qualitative comparative studies to seek an in-depth understanding of the vulnerabilities to HIV acquisition among PWID in the states of Manipur and Bihar. The study also aims to describe the factors that influence vulnerability to sexual transmission of HIV between PWID and their sexual partners. Additionally, the study focuses on logistical issues associated with the delivery of various harm reduction services to PWID and their sexual partners, as the quality of services offered to these groups has not been adequately documented in the past.

By better understanding service gaps and additional needs of PWID, we hope this study will contribute to the expansion of appropriate interventions for PWID and their sex partners under the National AIDS Control Programme.

# Acronyms

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AIDS	Acquired Immune Deficiency syndrome
ART	Antiretroviral Therapy
DIC	Drop-in Centre
FIDU	Female Injecting Drug User
ICTC	Integrated Counselling and Testing Centre
IDU	Injecting Drug User
IEC	Information, Education and Communication
KI	Key Informant
NACO	National AIDS Control Organisation
NACP	National AIDS Control Programme
NGO	Non-Governmental Organisation
NSEP	Needle and Syringe Exchange Programme
OI	Opportunistic Infection
OST	Opioid Substitution therapy
PLHIV	People Living with HIV
PWID	People Who Inject Drugs
RTI	Reproductive Tract Infections
STD	Sexually Transmitted Diseases
SACS	State AIDS Control Society
STI	Sexually Transmitted Infections
TB	Tuberculosis
TI	Targeted Interventions
WHO	World Health Organisation

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## Executive Summary

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India faces one of the largest HIV epidemics in the world. While sexual transmission remains the primary mode of HIV transmission in the country, people who inject drugs (PWID) and their sexual partners face a significantly elevated risk of HIV acquisition compared to the general population.

Spanning five countries (India, China, Indonesia, Kenya, and Malaysia), the Community Action on Harm Reduction (CAHR) initiative delivers harm reduction services to more than 180,000 PWID, their sexual partners, and their children. The programme protects and promotes the rights of these groups by fostering an enabling environment for HIV and harm reduction programming in these five countries. CAHR is supported by the Ministry of Foreign Affairs, Government of Netherlands.

In India, CAHR is called 'Hridaya' and is implemented by India HIV/AIDS Alliance in partnership with Social Awareness Service Organisation (SASO) in Manipur and a number of other community-based harm reduction organisations and networks. This programme helps build the capacity of service providers, makes harm reduction programmes more gender-responsive, and improves access to services and advocates for the rights of PWID. In addition to providing services, Hridaya has a strong capacity-building component to support advocacy, knowledge management, and improved services for PWID.

This cross-sectional study was conducted using a range of qualitative research methods to assess, in depth, the HIV-acquisition vulnerabilities of PWID in Bihar and Manipur.



Findings are presented under three categories I) vulnerability; II) barriers to implementation of harm reduction services; and III) comparison of strategies in Bihar and Manipur.

**The dynamics of vulnerability:** Drug use is primarily a social activity. People tend to use drugs in social networks and form subcultures that both shape and are shaped by the type of substances used, how the substances are used and sourced, as well as socio-economic factors and other social determinants such as access to harm reduction services and engagement with social, structural, and politico-legal systems. The research revealed normative patterns, some which worsen and others which reduce HIV vulnerability. The research showed that sexual behaviour is also subject to similar drivers to HIV infection.

Family support played a strong role in mediating vulnerability among PWID in Manipur. For example many drug users reported having strong support from their family to visit harm reduction services and undergo detoxification. In contrast, most PWID in Bihar reported that stigma from their families and the greater community made it difficult to access services, which led to increased injecting and sexual risk among PWID. While both states require more sensitisation among local communities and with the police and other stakeholders to improve understanding and increase acceptance of community-involved service provision, this need is significantly more pronounced in Bihar.

**Barriers to the implementation of harm reduction services:** Both social and political institutions created significant barriers to effective harm reduction programming. The research showed that violence and harassment by police and anti-drug organisations impeded access to harm reduction services like needle and syringe exchange programmes (NSEP). In Bihar, the study found that in addition to police harassment, discrimination against PWID and their often low socioeconomic status were major deterrents in accessing harm reduction services.

**Harm reduction programme implementation:** In Manipur, harm reduction programmes were led by PWID whose involvement bolstered access to services by other drug users. The situation in Bihar was different, where lack of engagement by PWID in service delivery was identified as a major hindrance to effective service access. Compared with Manipur, service providers in Bihar lacked the necessary experience in working with drug users.

Manipur is currently well on the way to standardising service delivery for PWID. In contrast, service delivery varies greatly in Bihar. While opioid substitution therapy (OST) services have recently been initiated in Bihar and government health care providers have received sensitivity training service, delivery remains poor and there continues to be considerable room for improvement. The current research identified, in particular, a need to improve counselling skills among outreach workers.

## Key Recommendations

The report makes the following recommendations:

### Recommendations (Both Manipur and Bihar)

1. Increase focus on the specific needs and vulnerabilities of women who inject drugs (WWID) and sexual partners of male injectors.
2. Undertake deeper investigation of the roles of HIV status disclosure and access to services in creating vulnerability. In a global environment that champions “treatment as

prevention,” projects should focus on encouraging HIV positive people to gain access to treatment as soon as possible.

3. Maintain efforts toward reducing stigma associated with drug use. However, it is recommended that we focus more attention on addressing law enforcement barriers and educating families of PWID, healthcare providers and the general community.

### **Recommendations (Manipur)**

1. Encourage new drug users to pursue health and harm reduction services before their drug use becomes problematic. This could be achieved by employing a younger cohort of peers as well as rethinking the delivery of services that are often designed for long-term drug users.
2. Work toward further reduction in costs of accessing ART as this remains a significant barrier for HIV-positive PWID in Manipur.

### **Recommendations (Bihar)**

1. Develop peer support groups among PWID and former users. These groups should also be supported to engage meaningfully in services design, delivery and evaluation.
2. Design specialised services that are sensitive to the daily routines of drug users who work long and difficult jobs, as poverty and socioeconomic isolation remain significant barriers to PWID accessing services in Bihar.



## Introduction

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### 2.1 Background

While India has achieved an overall reduction in HIV incidence in the last decade, a person who injects drugs in India is still fifteen times more likely to contract HIV than a non-injector. Several studies have described unsafe injection practices and sexual risk behaviours among people who inject drugs (PWID) in India (Eicher, Crofts, Benjamin, Deutschmann, & Rodger, 2000; Mahanta, et al., 2008; NACO, 2006a; Panda, et al., 2005), however few have investigated the socioeconomic forces that influence risk taking (De P, et al., 2007; De P, et al., 2007-b). Further, several studies have also documented the potential for HIV to spread between networks of PWID to the broader community through sexual contact (Abdala, et al., 2008; Panda, et al., 2005; Solomon, Mehta, Latimore, Srikrishnan, & Celentano, 2010).

The current study set out to gain a deeper understanding of the root causes of HIV risk taking rather than simply describing behaviour. The goal was to add to the existing literature, which has been drawn largely from small studies using convenience or purposive sampling (S. Panda, et al., 2000; Solomon, et al., 2008), snowball sampling (Eicher, et al., 2000; Sharma, Aggarwal, & Dubey, 2002), and privileged access interviews (Dorabjee & Samson, 2000).

The current study adds to foundational research conducted for the Community Action on Harm Reduction (CAHR) initiative. India HIV/AIDS Alliance (Alliance India) is implementing CAHR in India in the states of Bihar, Haryana, Uttarakhand, Delhi, Manipur, and Jammu as the Hridaya programme. The goal of the programme is twofold: to increase access to services for PWID in underserved areas; and to support the development of more comprehensive services in areas where services already exist. As in all of its programmes, Alliance India uses a human rights-based and gender-sensitive approach.

## 2.2 Rationale of the Study

In March 2012, the Hridaya programme conducted a baseline study at three sites – Delhi, Haryana, and Manipur. Findings of this study confirmed that unsafe injection practices along with low condom use were putting PWID at dual risk of HIV transmission. The vulnerability of both male and female PWID is exacerbated by the fact that they often sell sex in exchange for drugs. Females are most at risk, not just because they may be partners of PWID but also because they may lack negotiating power and awareness in relation to condom use. At the same time, in Bihar, Haryana, and Uttarakhand, the HIV epidemic is at an early stage and, in addition, services to people affected by the epidemic are still at an early stage of development. Manipur was selected as an example case study of a location where the epidemic has matured, and Bihar was selected as an example case study of a location where the epidemic is still developing.

The current study aimed to better understand how the differing environments of Bihar and Manipur impact risk behaviours in order to develop responsive customise service delivery and design more effective structural interventions aimed at improving the operational environment.

## 2.3 Objectives of the Study

The goals of the study are to gain for the states of Manipur and Bihar an in-depth knowledge of the multiple vulnerabilities to HIV infection among people who inject drugs. These vulnerabilities include unsafe injecting practices and unsafe sexual behaviours with both female and male partners.

The specific objectives are as follows:

1. To understand dynamics of vulnerability, including needle/syringe sharing and unprotected sex.
2. To understand other societal or structural factors which influence the vulnerability of the populations in question.
3. To develop evidence for appropriate interventions aimed at both individual behaviour change as well as addressing structural barriers such as stigma and service access.





# Methodology

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## Study Location: Selection of States

Out of the six states where Alliance India is implementing the Hridaya programme, Bihar and Manipur were selected as study sites. Manipur was chosen because both the HIV epidemic and the delivery of relevant services in the state are relatively mature, while Bihar was selected because its epidemic is still developing and the delivery of relevant services is still nascent.

FIGURE 1: MAP OF STATES OF MANIPUR AND BIHAR



## **Selection of Districts**

Two districts in each state were selected for this study. The study districts were Kaimur and Buxar in Bihar, and Imphal West and Imphal East in Manipur.

## **Data Collection**

Teams of researchers in Bihar and Manipur were recruited and trained in a range of standardised data collection techniques. All researchers had experience working with people who used drugs. The research employed a mixed methods design focusing on qualitative research techniques. Findings from earlier participants were used to shape enquiry with later participants in order to collect information on core issues as precisely as possible. Interview data (characterised in Table 1) were collected in three phases, with each subsequent phase building on the last.

A detailed methodology, including the sampling framework and data analysis process is presented in Appendix.

## **Ethical Considerations**

Ethical clearance was obtained from the Institutional Review Board (IRB) of the Indian Institute of Public Health-Delhi of the Public Health Foundation of India. Since the present study involved interaction with vulnerable communities (PWID, their families, and people living with HIV), a full review was obtained from the Institutional Ethics Committee (IEC).

All participants completed consent forms before being enrolled. To explain to participants the aim and purpose of the study, we used a participation information sheet (PIS), a document that exists in English, Hindi, and Meiteilon. The research assistants read the PIS to illiterate participants before the commencement of interviews.

Participants were given adequate time to reflect on the implications of joining the study and only then were they asked to sign the consent form. The participants were given the choice to withdraw from the study, if they so wished, at any point of time. Permission was received from all participants before the recording of interviews and discussions. The records of the participants were kept confidential. Data were stored in secure locations and made available only to study personnel. The identities of all participants were kept anonymous; no information obtained in the study was connected with any individual person.

## **Limitations of the Study**

Due to the brevity of the data collection period, it was impossible to pursue detailed discussion of the details of every emergent theme. However, a phase-wise discussion and review were completed (see Table 1). Furthermore, our findings should not be assumed to be representative of all PWID in India. Nonetheless, in the future, the nuanced understanding that we have developed over the course of our study may well prove critical for shaping harm reduction programmes in the communities studied and in similar communities.





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## Results and Discussion

For ease of reading, results are presented separately for each state, under the following categories: I) Dynamics of Vulnerability, II) Barriers Affecting Vulnerability, and III) Harm Reduction Strategies. A summary comparing findings from Bihar and Manipur has been included as a way of capturing key differences between attitudes and events in these states.

The data reported here are drawn from 50 separate interviews and four focus group discussions. Interviews and discussions are summarised in Table 1 below.

**TABLE 1: DATA COLLECTION IN BIHAR AND MANIPUR**

Phases	States	In-depth Interviews	Focus Group Discussions	Key Informant Interviews
Phase-I	Manipur	3	0	0
	Bihar	2	0	0
<b>Transcription, Modification of Tools, Quality Checks (I)</b>				
Phase-II	Manipur	8	1	2
	Bihar	9	2	3
<b>Transcription, Modification of Tools, Quality Checks (II)</b>				
Phase-III	Manipur	9	1	4
	Bihar	9	0	1
<b>Total</b>		<b>40</b>	<b>4</b>	<b>10</b>



## Section 1: Bihar

Data were collected from three Hridaya IDU-TI sites: Jayprabha Gram Vikas Mandal (Buxar), Gandhi Kusth Nivaran Pratisthan (Bhabua), and ECOVIC (Mohaniya). A total of twenty in-depth interviews (IDIs) were conducted with recently diagnosed HIV-positive PWID (see Table 2). Two focus group discussions (FGDs) took place – one in Buxar and the other in Bhabua – with spouses of PWID. In addition, four key informant interviews were conducted as a pathway to understanding the harm reduction programmes and to assemble recommendations and suggestions relevant to programme implementation in the future.

### Profile of in-depth interview respondents

PWID interviewed in Bihar consisted of males between the ages of 23 and 65 who were earning low incomes (through rickshaw pulling, day-wage labour, etc). All but one were married with children. Table 2 presents profiles of IDI participants. All were currently injecting, and all had tested positive for HIV between August 2012 and December 2013. Only six were on OST (Bhabua), and approximately eight were on ART (primarily in Buxar, some in Mohaniya).

### Profile of focus group discussion participants

Six women in Buxar and twelve women in Bhabua participated in an FGD at their respective location. The husbands of these women were PWID. These women ranged from 20 to 50 years of age. Most FGD women and their husbands belonged to low-income groups.

We compiled the summarised findings from each FGD as group data. FGD results described in this section do not reflect information specific to individual participants.

### Profile of key informants who were interviewed

Three key informants (KIs) from the district level (representing three TI areas) and one KI from the state level were interviewed as a way of obtaining both a detailed understanding of the provision of current services and recommendations for future implementation of harm reduction strategies in the state. KIs at the district level belonged to the NGO sector (project manager at TI-NGO), and the KI at the state level belonged to the Bihar Government State Health Services (CMO, Member, State TB-HIV Coordination Committee and State Technical Working Group for TB-HIV collaboration). The comments of the KIs were summarised and these summaries incorporated into the results chapter. In addition, their comments helped us shape the recommendations we are presenting.

**TABLE 2: PROFILES OF PWID WHO TOOK PART IN IN-DEPTH INTERVIEWS: BIHAR****Buxar**

	Approx. age	Work	Education	Marital status
1	45	Labourer	-	Married
2	50	Mason	-	Married
3	35	Labourer	Class 4	Not married
4	26	Labourer, Farmer	-	Married
5	46	Agricultural labourer	-	Married
6	40	Labourer	-	Married

**Bhabua**

	Approx. age	Work	Education	Marital status
1	45	Driver, Poultry farmer	-	Married
2	41	Rickshaw puller, Sweet shop	-	Separated
3	23	Labourer	-	Married
4	48	Labourer, Tea stall	-	Married
5	51	Mason, Agricultural farming	Village school pass	Married
6	40	Rickshaw puller	-	Married
7	60	Labourer	-	Married

**Mohaniya**

	Approx. age	Work	Education	Marital status
1	63	Labourer	-	Married
2	50	Labourer	-	Married
3	50	Labourer	-	Married
4	45	Labourer	-	Married
5	40	Labourer	-	Married
6	50	Labourer	-	Married

**1. Dynamics of Vulnerability*****(i) Poor socioeconomic conditions, manual labour, and injecting drug use form a vicious cycle***

In Bihar, many participants reported that they used drugs to help them cope with the demanding physical labour associated with their work. For example, these men worked as rickshaw pullers or labourers in the agricultural sector. Many people reported that they started to inject drugs to ‘gain power’ and ‘remain energetic,’ and thus cope with high intensity physical work. However, following the formation of dependency, PWID reported feeling trapped in a cycle of excessive labour required to finance their drug use.

“As the nature of work I am involved in demands loads of a physical activity – as I had to draw the horse for transportation, I used to get really tired. Not only that. After taking drugs, our stamina to have sex gets boosted – also that’s why I used drugs.” (PWID, Mohania)

“We take needle and syringe. Suppose this is the ampule, draw the ampule in the syringe and after that do it for the second ‘Avil.’ Also, after drawing, remove the air, and then put it in the arm. After inserting it slowly, we pull it out and press the area and after five minutes the intoxication happens. After that you can get any work done from us. And if the other friend also asks, then we give the syringe to him also – who used to wash the same syringe in the water and then draw from the same Avil ampule and insert it. If we have the drug but not the needle and syringe, then we used to ask for it – so they used to give it and we used to fix it.” (PWID, Bhabua)

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For a significant number of PWID, desire for increased sexual stamina and pleasure, as well as reduced sexual tension between partners, prompted drug use:

“When I go home under the influence of the drug, I was able to enjoy sex. So I started using it for sex.” (PWID, Buxar)

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“Drugs are taken to boost their sex lives. People (other PWID) used to come to my tea stall, sit there and smoke. We also talk and smoke. We started smoking brown sugar in the beginning. After some time, we started finding it expensive and since injection is cheaper and it was Rs 8 and we get it for Rs 30 in black market, we shifted to injecting.” (PWID, Bhabua)

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## ***(ii) Awareness and risks of injecting drug use***

**(a) Safe-injection awareness:** Participants stated they tended to use drugs in private and within tight social networks. Various myths circulated, for example, that sharing among known groups is not risky, and, for another example, that using new needles while sharing syringes or ampules is okay. These myths showed that the persons interviewed had a poor level of awareness about transmission through sharing. The myths should be seen as crucial enablers of the spread of infectious disease throughout social groups of PWID.

Although there had been regular awareness drives conducted by IDU TI-NGOs disseminating information among PWID, and although many participants knew about risks associated with sharing, they resorted to sharing drug-related equipment in some circumstances. Cleaning and reusing, as well as sharing needles and syringes within injecting networks, were casual and common practices. Injecting partners did not perceive any transmission-related threat.

“Yes definitely it happened. Like we washed and wiped and gave satisfaction to our soul that it has been cleaned. Like that I have taken 2 to 4 times. . . . .Yes it comes, so what we do, we hold it like this and keep, then it stops, the blood that has come in the needle, so we wash and wipe it and keep it. Then we use from that. . . .Not a new needle and syringe every day. You use so with that 2 to 4 days syringe only, but the needle is new, took a new needle. And why to buy new every day. I don’t lie. I am telling you the truth. Why lie?” (PWID, Buxar)

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Many participants reported that, after testing positive for HIV, they ceased sharing needles/syringes/cookers altogether. Injecting peers, however, sometimes perceived this behaviour as a sign of mistrust, thus compelling some HIV-positive individuals to conceal their infected status and resume sharing. In these cases, acceptance within the injecting group was seen as a priority greater than the importance of practicing safe injecting.

**(b) Stigma:** General awareness of the PWID community was low among other community members interviewed in this study, and stigma towards PWID remained prevalent. Widespread stigma creates a significant barrier to the effective implementation of harm reduction programmes. Novice drug injectors tend to hide their injecting behaviour which results in delayed access to health and harm reduction services and worsens dependency. This poses as a challenge for programme managers seeking to implement harm reduction programmes.

**(c) Awareness of other co-infections and vulnerabilities:** Among respondents in Bihar, there was low level awareness about hepatitis C, sexually transmitted infections (STIs), and HIV transmission among PWID. This created vulnerability for PWID themselves as well as for their wives and sex partners.

“I never used condom with my wife. Later on people told me, so after that I started realising that my health is already in deteriorated state. Then I thought, ‘Why my wife should suffer because of that?’ After, I started using condom. But now I do not have any desire to have sex, also. Before I never used condom.” (PWID, Mohania)

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“Assume that mine has gone bad so we would ask them that friend please give us a little, so we used to give it over and we used to take it from his syringe... Like four people are sitting and there is a bottle of Avil 5ml, from that we took out from the needle and our friends also will take it from that bottle only and all four people will put it in through the muscle or vein from that one syringe. There was no other syringe over there.” (PWID, Bhabua)

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### **(iii) Drug withdrawal**

Many PWID reported high vulnerability during periods of withdrawal, and engaged more frequently in risky sharing behaviours due to impromptu need to inject with little time to take preparatory measures. Hasty sourcing of drugs and equipment amounted to a much higher likelihood of sharing.

“I felt weakness. I didn’t feel like walking and speaking. My stomach used to bloat. Mouth will become dry. Water will come from nose. Even if someone says a good thing, then we will not be interested. You stay irritated in mind. When you are intoxicated then you feel hungry. When you don’t intoxicate you don’t feel hungry.” (PWID, Buxar)

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“Yes, after getting exhausted, the body get damaged and then the mind fails. And when I look at syringes then I want to take it. When I take few steps, I feel as if I will fall. That is why this mistake happened. I have imitated others and done this. After doing this I realised that I have committed mistake. But what to do? Mistake happens because of weakness.” (PWID, Buxar)

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### **(iv) Needle and syringe exchange programme (NSEP) and supply chain management**

It is well known that drug use occurs during all hours of the day, and many PWID reported that they did not have access to sterile injecting equipment because of the limited operating hours of NSEP. Such situations made PWID vulnerable to unsafe injecting practices even when they did have knowledge of safe injecting behaviours and harm reduction outreach programmes.

“No, now they are not giving, now it has been a month they have not given. When once they came, they gave all this in the garden (location of the hot-spot). They gave needle, they gave syringe.” (PWID, Buxar)

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### **(v) Sexual health**

Vulnerabilities exist not only within the injecting domain but also within sexual networks. In relation to PWID's sexual networks and the risks of transmission among 'bridge populations', it was observed that status of women in society coupled with PWID's poor understanding of sexual and reproductive health, they had the potential to create vulnerabilities for their spouses/sexual partners. Inadequate awareness of STIs coupled with a lack of awareness of opportunities for the testing of and treatment for STIs among PWID and their spouses created a threat to sexual partners.

"There is burning in urine sometimes. Like pain type. Not every day, sometimes it happens that you feel that it will go so you will die. Like this you feel." (PWID, Buxar)

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"No till now we have not had any problem, but once water was flowing off my wife (STI.) So we got her medicine. So she was fine." (PWID, Bhabua)

"Yes, my wife has leukorrhoe, a problem, and back pain also, So once I got her medicine from our local

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doctor, and now it's OK. She complains of it in winters, that her back is paining. So I showed to the doctor, who said that wear something woolen innerwear. It is catching cold, because of which back is paining. Now that's what I am thinking, that if I have 200-300 bucks then I will buy inner." (PWID, Bhabua)

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### **(vi) Lack of knowledge of risk is also a risk (spouses) - "Jokhim Ka na pata hona bhi jokhim hain"**

In a patriarchal setting, a woman's position in the family and within marriage was observed to be a vulnerability factor for the spouses/partners of PWID. Women perceiving no risk from their husbands creates risk for themselves; and this, in turn, affected both safe sex and safe injecting.

"We do not know what all health problems our husbands have. Don't think there is any problem. We also don't have any health problem. We don't know about any risks." (FGD: Spouses of PWID, Bhabua)

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### **(vii) Disclosure of HIV test results, practicing safety measures, and associated vulnerabilities**

Most PWID know the risks associated with having seropositive test results. So, given the stigma associated with seropositivity, the HIV status of the person was almost never disclosed.

This lack of disclosure emerged as a new area of vulnerability for people in the positive person's injecting as well as sexual network. There is lack of sensitisation and negotiation given the confidentiality and non-disclosure of test results in injecting and sexual networks.

This situation was particularly problematic for women of lower social status in Bihar. Also, women experienced restricted access to screening tests for STI/HIV in light of the poor awareness levels in the community.

"It is up to PWID to disclose and share their status with their family, as this process is confidential. We have come across cases where husband (PWID) had not shared the test results with wife and wife got infected. There was one case where PWID refused to accept the test results and continued to have unsafe sex with his wife. This is an area where we -- our field staff -- face problems in convincing PWID, couples, ... and bring safe sex as well as safe injecting practices." (PWID, Buxar)

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## **2. Barriers Affecting Vulnerability**

### ***(i) Social barriers – discrimination, lack of family support, stigma***

Injecting drug use is laden with stigma, and as a result, PWID face rampant social discrimination. This has huge repercussions in terms of both their accessing harm reduction services and the way the society and families cope or do not cope with drug use. Drug use, and for that matter, injecting drug use in particular, grows out of a deep-rooted socio-cultural-political milieu. Thus, discrimination and stigma create barriers affecting how users are understood and how the issue of drug use is addressed.

PWID in Bihar were discriminated against in both social and family settings, a pattern that highlights deep-rooted stigma and inadequate awareness of the circumstances affecting injecting drug use and drug users. Meanwhile, a high level of family support is required in many or most cases if PWID are empowered to successfully cope with drug-related behaviours and to seek treatment. We found that a lack of family support frequently serves as a principal deterrent for PWID accessing harm reduction services to enter rehabilitation.

*“Down. Meaning we people are worse than dogs. No respect. Even if we people will work, then people will say he must be intoxicated, he works while drinking. No other thing. No one talks to us, also. They turn their face away. At that time I felt that only that if I did not have to take intoxication, then I would have dug the person alive whose face I didn't want to see. This is what intoxication has given me that on whose door I never had to go, I go to their doorstep with this intoxication. Why don't you feel it? It feels a lot. At that time you can't think right, just like a dog.” (PWID, Buxar)*

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### ***(ii) IEC/BCC and knowledge of injecting behaviour in the community***

Information, Education & Communication/Behaviour Change Communication (IEC/BCC) services often focus on target groups or risk group populations. As a result, the community at large has not been adequately targeted and educated. Therefore, sufficient attempts have not yet been made to cover the gap in knowledge in the community. This configuration has multiple repercussions. As new PWID fail to adopt safe injecting practices, their inadequate understanding of both short-term risks and future consequences lead them to engage in risky behaviours.

*“We haven't heard much about injection or HIV before these female health workers came to our house. We never knew about all this. Also, now they tell us, but others in the village may not know all this.” (FGD: Spouses of PWID, Buxar)*

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### ***(iii) Health-seeking behaviour, reasons for testing***

Despite having some knowledge and awareness of injecting drug use and its associated risks, PWID were seen to engage in risky behaviour such as sharing needles and syringes, participating in unprotected sex, and failing to have regular health check-ups or recommended screening tests. This was reflected in their inadequate health seeking behaviour. Myths about injecting drug use continued to circulate, for example, the idea that sharing among people belonging to a well-known group is not risky; and, for another example, that it is sufficient to use new needles when syringes or ampules are shared. However, now that harm reduction services are being promoted for PWID, these drug users are becoming aware of the benefits of regular screening and testing for HIV and other co-infections. However, while we found testing for HIV was common, PWID and their spouses were not frequently seeking screening or testing for STIs. It should also be noted that some people are more likely to be tested for HIV after they have engaged in recent risky behaviour, while those same people may not look to receive routine screening tests.

“My blood has been tested for HIV. They told me to come after six months. They also told me to take care of my eating habits. They advised me not to take drugs...” (PWID, Mohania)

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#### ***(iv) Availing harm reduction services, OST and ART***

There is great need for high-risk subpopulations to access health services with greater frequency and intensity. The people in these subpopulations require regular testing, just as they should maintain safe injecting practices as well reasonable sexual behaviours. These require that they access HIV testing and ART services. Yet, such services are not always easily accessible. There is a lack of a trained workforce available within the government as well as within non-governmental settings, in addition to the fact that many in the workforce are not sufficiently sensitive to the needs of the subpopulation we are discussing. It would be important that the workforce that has received general training should be enabled and trained so they are capable of successfully offering services to PWID and other PWID high-risk subpopulations.

“TI-NGOs are so well sensitised and PWID feel happy coming to us. ART and OST services are with the hospital and there, PWID are not behaved well. They are discriminated. This is not good – as people can start defaulting, as they don’t like going there. This is not good for PWID.” (PWID, Bhabua)

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#### ***(v) Structural barriers – police harassment, pressure groups***

Injecting drug use and PWID exist in a grey area of the legal-political framework of India. PWID face discrimination and police misbehaviour. For example, false charges and unlawful detention. Such harassments affect the ability of PWIDs to access harm reduction services and also violate the basic human rights of PWID. In Bihar particularly, peddlers were taken in custody and such actions affected PWID’s sourcing of injecting drugs. This, in turn, leads to sharing among PWID, a behaviour that sometimes is related to a lack of availability of needles and syringes.

“Yes he sold the stuff also.... He washed and wiped and put....To everyone he was giving like this, after washing. Everyone. No, I didn’t have any sense, my mind was empty. I told that Bengali that Dada put it fast, I put my hand forward....” (PWID, Buxar)

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### **3. Harm Reduction Strategies**

#### ***(i) Harm reduction services for PWID recently developed in Bihar***

The issue of injecting drug use did not garner adequate attention until the problem had grown, and injecting drug use did not seem a high priority in the state’s HIV programme. Interactions with local NGO personnel have suggested that injecting drug use and issues around PWID did not drive the harm reduction programme. Rather, a top-down approach was favoured. The harm reduction programme in the state became focused only after the initiation of TI-plus interventions under Hridaya. At that point in time, IDU TI-NGOs had to scout around for PWID to enrol.

“We have listed PWID as per the listing. There are many more PWID in the community who we can’t cater as our numbers are fixed. Also, we don’t have many staff. In the community people don’t have awareness, so we need to go out and find people – literally – for the programme.” (PWID, Buxar)

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### ***(ii) Rolling out TI and TI-plus services for PWID and their families within the community***

Rolling out TI-plus services under the harm reduction programme for PWID is a great step forward, for it provides a way of understanding PWID and injecting drug use as existing within a continuum in their social and injecting networks. This development offers a holistic approach to harm reduction, as it involves a basket of services for PWID, their spouses (and sexual partners), and their children. In addition, it offers safe injecting practices with NSEP, OST, and other non-injecting health services, plus tests for HIV and co-infections. However, within the social context existing in Bihar, PWID are not sufficiently acknowledged and their families are discriminated against.

*“Now we have ration cards, and we all meet and discuss our problems. These madams and sirs help us a lot. It was not like this before. Our children are going to school, we feel better.” (FGD: Spouses of PWID, Bhabua)*

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### ***(iii) OST and ART services***

The harm reduction programme for PWID provides a set of services intended to achieve a long-term impact. But in Bihar, the programme was employed as a ‘corrective’ measure with short-term results achieved through OST and a measure to be used for referring PWID for HIV testing that would then lead to the initiation of ART. OST services were available in no more than one out of the three study sites. It was also apparent that the way NGO personnel referred PWID to OST services – as if such referral constituted a panacea – was an indication that these personnel were ignoring the socioeconomic, cultural, and political dimensions of injecting drug use.

*“Start the medicine (OST) here also, all our problem will be wiped off.” (PWID, Mohaniya)*

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## **Section 2: Manipur**

In Manipur, data was collected from the two Hridaya IDU TI sites, namely, Imphal-East and Imphal-West. A total of twenty IDIs were conducted with PWID who were diagnosed as being HIV-positive. Two FGDs were conducted, one with spouses of PWID and another with female injecting drug users (FIDUs). In addition, six KIIs were conducted as a way of understanding the harm reduction programmes and of gathering recommendations and suggestions.

In the following sections, data captured from IDIs, FGDs and KIIs are referred to as data from Manipur. However, it is important to again state that no claim is being made that the results of this study are generalisable to the entire state. (See limitation of the study in Chapter 3.)

### **Profile of in-depth interview respondents**

The PWID interviewed for this study in Manipur were males 35 to 53 years of age. All had a low income and worked in small businesses, but none had a steady or regular income. Most were married and had children. At the time the data was collected, some of them were currently injecting drugs, some were on OST, and a few were on ART. (Table 3 profiles the IDI participants.)

### **Profile of focus group discussion participants**

Seven female injecting drug users (FIDUs) and six spouses of PWID participated in the FGDs. The women were between 20 and 50 years of age. Most were from low-income families (as

was true of the male PWID). Each FGD was summarised and findings were captured as findings of a subpopulation and not as separate findings associated with individual persons.

### Profile of key informants

A total of six KI interviews were conducted, two from IDU TIs (SASO) and one each from an NGO (CONE), an academic (Manipur University), police services, and a medical research institute (RIMS). These interviews were conducted as a way of obtaining an in-depth understanding of services being provided. In addition, these interviews were used as a vehicle for creating suggestions and recommendations for the future implementation of harm reduction strategies in the state. Findings of these interviews with KIs were summarised and these findings incorporated into results presented in this chapter, as well as into the list of recommendations presented in Chapter 5.

**TABLE 3: PROFILE OF THE PWID WHO TOOK PART IN IN-DEPTH INTERVIEWS: MANIPUR**

	Approx. age	Work	Education	Marital status
1	40	-	-	Married
2	45	-	-	Married
3	40	-	-	Married
4	39	-	-	Married
5	52	Shop keeper	Graduate	Separated
6	42	Driver	-	Not married
7	30	Contract work	-	Married
8	46	Salesman	-	Not married
9	45	Shop keeper	-	Married
10	40	Labourer	-	Not married
11	32	Shop keeper	-	Not married
12	47	Mason	-	Married
13	53	Petty jobs	-	Married
14	35	-	-	Married
15	40	Vegetable seller	-	Married
16	42	-	-	Married
17	37	-	-	Married
18	35	Mechanic	-	Not married
19	40	Mason	-	Not married
20	44	Not working	-	Married

## 1. Dynamics of Vulnerability

### (i) Sharing/reusing of injecting paraphernalia (needles, syringes, substances)

Awareness of transmission of HIV through sharing among the PWID in Imphal was very high. Nevertheless, instances of risk-associated sharing have been documented. Limited access and availability were cited as the main reasons for such behaviour. Notable factors include several aspects of the socio-political situation. For example, all too frequently, there were bans and blockades barring PWID access to NSEP services and, therefore, they either reused old needles and syringes or shared among injecting partners. Syringe/needle purchase costs also

served to elevate the risk of sharing. Most respondents admitted that even though syringes were freely available within the NGOs, they sometimes had to buy them. In situations in which they were unable to obtain syringes from NGOs, they often chose to share syringes in order to save money. Since they pay Rs. 5 per dose, they often lack additional funds for needles and syringes. Furthermore, injecting patterns and frequency of usage (injecting frequency ranged from 2-4 times daily) were also cited as reasons for reusing and sharing.

“Sometime they are arguing of buying syringe, because they did not want to spend on it. I advise that I am positive, don't think of buying syringe. Sometime I buy for them, and said that if when you infected with HIV you will very sad. Some, they take the advantage of it and said buy cigarette also. At that time he said, 'I am buying one syringe, is to save life.' Don't do like that. Why you don't want to spend Rs, 5, 10? If when you infected HIV, you will very sad.” (PWID, Manipur)

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Under NSEP supply, 1 ml syringes with small needles were provided. Some FIDUs suffered from needle injuries due to accidental flesh injection. Most PWID were in the habit of injecting with bigger needles, so the introduction of smaller needles led to injuries. When needles became lodged in the veins, a surgical procedure was frequently required to remove them.

“There were times I did 2/3 times in a day. Means... this is about recent experience, so to say, once upon a time, I injected once and the kick stayed till night, means it went for a day, so to say... But later, the kick did not stay for long, it went off after sometimes. It was like that and when the kick was desired it was injected repeatedly... Like that there was time when I did twice or thrice a day”. (PWID, Manipur)

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“Yes, I have seen people sharing. When I went to Moreh for BudhaJainti, my friends has shared...” (Respondent, Manipur)

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*Having similar status - the road to other risks:* Some of the injectors perceived no risk in sharing with injectors with a similar HIV status. They believed that there was nothing to lose; they thought no other harm could result if they shared. Most of the users felt that if they had been diagnosed as being HIV-positive, nothing worse could happen to them. This shows that other sharing-transmitted infections– hepatitis C, for example – are widely ignored by injectors.

“I mean to say that we inject in the same room but do not share. They come after buying their own gun (needles and syringes) and inject together. Only sometimes when some of them who do not have enough money request to borrow the gun (needle/syringe) to inject -- in spite of informing that I am positive (HIV) – as it does not matter to them, saying: 'I too have it (HIV positive). Since I do not have money, give me your gun (needle/syringes) – as I cannot buy now. It does not matter, we both are in same condition.' That way he inject.” (PWID, Manipur)

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“To be very frank, sharing is done among those who have already been identified as HIV positive. It is injected with one gun only... But those who are new and not infected, they buy syringes or they take from NGOs or they take from peddler... I find such things.” (PWID, Manipur)

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*Reusing one's used syringes:* Reusing one's syringe was not perceived as a risk among respondents. This has the potential to lead to a major health crisis, especially in the context of what happens in shooting galleries. These are places where PWID gather in groups to inject. This behavioural pattern permits elevated opportunities for syringes to get mixed up. The result of such mix-ups would be a greater likelihood that other people might share one syringe. Additionally, PWID reported resorting to unsafe injecting behaviour during periods when they experienced withdrawal symptoms.

“Yes, repeatedly injected. Yes, there are people who use the same syringe for 2/3 times. And also the syringe is kept at the peddler's place and they come there, and the same is used for the next injection. Then, when it cannot be used again, it is thrown, like that.” (PWID, Manipur)

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### ***(ii) Availability/unavailability of drugs and peddlers***

*Injecting networks and peddlers:* Injecting drug use is a group behaviour. And injecting galleries are located either in the houses of users or nearby at the peddlers' places. Respondents stated that everyone knew of such rooms, and users were usually found taking daily doses in groups or individually in the room earmarked for this. Isolated places like toilets and bushes were also mentioned as injecting sites. Some people also injected in their own houses.

“One vacant room, after purchasing the material and then entering in such room together 20 PWID, at least. If you pay visit, there you will find 10/15 in average and in maximum there will be 20/30. Now when we enter the room we will find 10/15 always injecting drugs.” (PWID, Manipur)

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“Since it is injection not orally taken, it is hard time for us in the evening. Then after coming out there are moments we inject in the middle of the road, even we go inside sulabh and inject, like that.” (PWID, Manipur)

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### ***(iii) Vulnerability for spouse/sexual partners – STI co-infection***

In Manipur the overlap of PWID and spouse/partner vulnerability had a different context. There, sex helped finance drug habits of female PWID (FGD participants), and drug use led, in turn, to unsafe sexual practices among male PWID. In addition, there appeared myriad other overlaps among drugs and sex, and these numerous overlaps created multiple vulnerabilities for PWID.

*Sexual route of transmission:* Respondents said they had unprotected sex sometimes during their injecting days, although many also said that they practiced safe sex. The reasons cited for practicing safe sex were linked with knowing that they had tested positive and did not want to transmit the disease. Also, new users practicing unsafe sex were reported, as these new users were seen as not having an adequate awareness of the risks involved in what they were doing.

“I did not use condoms while having sex. (Interviewer: So you had sex without condoms). Yes...without condoms I had sex. About 3-4 times but I stop having sex after that, as my priority shifted to drugs” (PWID, Manipur)

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“Many times. I cannot count how many times. It had (sexual contact) happened many times. At that, not knowing about this disease, we had openly, without any hesitation, had relations openly.” (PWID, Manipur)

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“Before, I used to have pain and have burning sensation while urinating. I had gone to the prostitutes, but then I consulted a doctor. After taking medicine, I am alright now. I don’t have any problem. It was before my marriage.” (PWID, Manipur)

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*Protecting spouses and partners:* Some respondents (who are married) shared that they had unsafe sex with their wives even after knowing their status. They also admitted they were engaged in risky behaviour, and a few reported giving some form of post-exposure prophylaxis (PEP) to their wives.

“I had sex with her on the day I knew my status. I was afraid, so I gave her PEP medicine.. Once I drank milk, the one from Moreh when I took supper, I scratched on the edge of the tin and I got injured, it bled..My son’s name is Thoi..When I fed Thoi, I saw that it was bleeding..little blood was seen in his feeding..Then my mind... since he is small baby...Sister Radharani of JNIMS said nothing will happen but I still had doubt..I remained afraid and worried..When I used drugs I did not think, but when I don’t do now I feel very irritated if he would have or not. Though hep C is with him HIV may not be there. Though hep C is there, it can be treated. Means it can be treated, although it has to incur 2/3 lakhs..I have such thoughts, so to say.” (PWID, Manipur)

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“Yes, having safer sex practice, sometime not using condom. But I used condom most of the time while I was using drug. Only then I didn’t use condom.....as.....practising unsafe sometimes.....But now I have decided to use it most of the time. Because I don’t want my wife to be reactive.....children should be nonreactive. So, I was trying to have safe...in most of time.” (PWID, Manipur)

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*Condom use:* Under the influence of drugs and alcohol, a majority of the respondents who had engaged in sex with commercial sex workers reported having unprotected sex.

“Not the one with married one? Ah before?? Ah yes... there was. Although it was not frequent, I did when I got drunk. Did you use condom by that time? Was it safer sex or how was it. No it wasn’t used. (PWID, Manipur) (Note: It is the respondent who, in explaining the situation, asked these questions. These are not questions posed by the interviewer.)

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*Withdrawal:* Respondents said that under the influence of drugs, they were involved in risky behaviour. This included unsafe sex with commercial sex workers and forced sex. Also, respondents said that during withdrawal, they were more likely to reuse needles from within the network, as they needed to take the required dose. Thus, they ignored the risks involved.

“It may be because of the kick, I think. I did not think anything means when I was high. I was controlled by the intoxicant and maybe I thought it (unprotected sex with sexual worker) was done when I had to do it. It was done like that.” (PWID, Manipur)

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“When they (other PWID) have hard time, they do. I also joined once. Since we had to do, means the drug has to be injected. Knowingly they do in front of me with me.” (PWID, Manipur)

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“HIV to me. I know the person. I tried to beat him too. He is a policeman but it was because of my desire of drugs. I accept it (used syringe) even though I mind him. He made me inject the used one... by that time I also had hard time and longed for drugs, so the drug, which he already infused in the needle, was injected, so to say, with blood stained needles. Then I came to realise. I gave him a punch but I did not go for PEP. Then I disclosed it to Mr X Roger of A organisation. Since brother X also asked me not to worry, I cooled down. And then I got tested.” (PWID, Manipur)

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#### ***(iv) Undisclosed status as a risk factor***

Disclosing HIV status to one’s spouse and family was seen as a difficult matter. Many PWID preferred to remain silent about their status for fear that such information might create complications in their married life or lead to their being discriminated against in society. Nevertheless, after finding out about their status, many tried to use safety measures; but even while doing so, it frequently happened that disclosure remained an unresolved area of their lives.

“They will share it. There are some people either in young age or old who have just joined the circle of injecting. For me, I will honestly tell them point blank that I am HIV-positive – so that they don’t use my syringe. But there are some old users who will not say so. They will hide their status. I feel sad about it, why they hide their status. The reason for them hiding the status is that they feel that if their status were known by others, they will be discriminated. But in my opinion all of us are using drug. So instead of transmitting (HIV) to others, we will disclose our status. I had seen this kind of act also without naming them.” (Respondent, Manipur)

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“I think she (wife) also knows about my status. She has undergone the test but the result came out as nonreactive, even if I am positive. But I have not told her about my status with my own mouth. Probably she got to know about it from the test papers. Though I am not sure whether she has seen the test documents or not, but she has not expressed about it to me openly. But I take precautions while having sexual relationship with her. I used condoms every time I have sex with her. But I have not discussed about my status with her. But I am not sure whether she knows about my status or not.” (Respondent, Manipur)

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“Around 2008, I have undergone many tests. But I got to know about my real status in 2012. When I got to know about my status, I was sure that the test will be reactive, as that time most of my friends and network were tested positive. I was a certified positive person on 2012 (hahahaha).” (Respondent, Manipur)

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#### ***(v) Awareness and associated risks***

A person’s level of awareness affects the risks and vulnerabilities of PWID and their networks. Awareness among PWID was found to vary, a fact that created vulnerabilities in their injecting networks. Varied levels of behavioural patterns were observed, a configuration that highlighted the risks and vulnerabilities that were related to a lack of awareness or knowledge. Perceived risk also varied due to the different awareness levels. For example, this is reflected in behaviours associated with washing and reusing a person’s own syringes as compared with using new syringes.

“For the syringe we have to either pick up from the streets or ask from someone, looking at their bodily condition. Some people just assumed somebody is healthy if he is fit and fair, hmm... don’t think they will have virus. It is observed amongst a lot of youngsters. They have stopped me and asked to give me my used syringes, so that they can re-use it... They also do the same thing about me and tell me they don’t think I have any disease.” (Respondent, Manipur)

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“What I want as an injector is that NGOs should give proper awareness... Before NGOs used to go for massive awareness campaign. That's why I got to know about all the information about HIV. Now when I am encountering people who asked me to give used syringes openly, it means awareness level of the youngsters -- are now getting into injecting behaviour -- have low awareness.” (Respondent, Manipur)

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“The doubts which I had were mainly due to the past experiences, which I had when I was running a pharmacy. During that time I feel one of my friends must have infected my syringes. That is why I went to test myself for HIV, as most of my injecting network those days were HIV positive. I thought if I know about my status, I would also be able to protect others from the virus.” (Respondent, Manipur)

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*Level of awareness:* Lack of awareness was a vulnerability for spouses and sexual partners of PWID. Capacity to negotiate reflected partners' risk and vulnerability.

“As I inject, when I have sexual relationship with my wife I ensured that I used condom. If I am positive also I don't want anybody to have the disease. So I take proper precautions. I don't want any of my family to face any problem.” (Respondent, Manipur)

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“One of my peers initiate me for the first time in 1997. I began injecting heroin thinking that it might clean up the abscess or block veins. It was a myth that injecting heroin might clean up block veins amongst IDUs.” (Respondent, Manipur)

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## **2. Barriers Affecting Vulnerability**

### ***(i) Police harassment***

Police harassment of PWID was a constant issue, which created both barriers to access, as well as an assortment of risks for PWID. As reported during in-depth interviews, the forms taken by police harassment included being subject to social harassment, being victimised through unwarranted and illegal confinement, being blamed for and victimised in relation to random complaints received by local police, and being shaken down by force to hand over money to law enforcement officers. Under such circumstances, PWID ended up sharing and reusing needles/syringes, and thus increased their risk for transmitting blood-borne infections from other injectors.

“If we even want to buy syringe, we have to come out to buy. But then if we are caught in this process, then we will be harassed by the law enforcement network. In such situation, due to fear of this ordeal, I just use old ones. I don't have any other alternative.” (PWID, Manipur)

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“There is a need for sensitisation in police force, especially in the entry stage (junior positions) -- as it was observed due to lack of understanding on drug use and harm reduction. We have had instances where PWID were troubled...” (KI, Police Services, Manipur)

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### ***(ii) Distance – accessing services***

Distance was a significant factor affecting service availability. For some PWID, immense travel distances made collection of free supplies unfeasible. In such situations, users might feel forced to buy from private shops, the costliness of which encouraged them to revert to reuse of old needles/syringes.



“Now I buy and used it (syringes). Every time I have to buy and use it. It’s almost a year and so. I think it is about two years now. It is because when I go to BOC<sup>1</sup> after taking it from the NGOs, it means I have to go out of my way. Its better I go directly there. Before, it was even available there but -- I don’t know whether it is due to lack of supply -- it is not available.” (Respondent, Manipur)

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“I used to take condom from NGO. It was good. I think Jarur brand was good. But now the quality that you get from MACS, from what I hear, is not good. And the packaging is also not good. It is there but I don’t take it from them.” (Respondent, Manipur)

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“Yes, we can see the risk factors. Before, through an NGO we used to get the syringes and needle easily in North AOC<sup>1</sup> free of cost. These days we have to buy the syringe, as it is not available free of cost. We have to pay Rs 5 each for the syringes every time.” (Respondent, Manipur)

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“There was a time when the outreach workers used to provide syringes at home. If a person inject 10 times a day, we used to give them the require quantity of syringes... But back of the mind of the family members, they are hoping that their son will become clean and will get better. They do not want to entertain our staffs, because of this. But now-a-days, the trend that is seen is that it is not available at hotspots or drug joints easily. So, they just inject the same syringes twice or thrice – or probably sharing amongst themselves.” (KI, NGO, Imphal)

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### ***(iii) Stigma and discrimination towards PWID***

Stigma and vulnerability remain very high in the state of Manipur despite the fact that NGOs and government agencies have been working in the state for many years on problems related to HIV/AIDS. The general community still stigmatises PLHIV and IDUs. Despite the fact that some level of awareness of risks exists, IDUs still engage in risky behaviours. In addition, a further difficulty is that there is inadequate awareness among such service providers as paramedics, nurses, and the staff working directly with PWID and PLHIV, and therefore, stigma remains very high.

“If we organised health camps only for the spouses, nobody turns up to access the services. The reason could be mainly because they do not want to come out openly – if they do they would be recognised as the wives of the IDUs/addicts. That’s why such heath camps which we have organised earlier have failed to attract spouses.” (KI, NGO, Imphal)

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## **3. Harm Reduction Strategies**

### ***(i) Harm reduction and primary prevention - IEC***

Given the fact that injecting drug use has been a long-standing issue in Manipur, harm reduction service providers now stress primary prevention. This approach places emphasis on the need to empower youth, so as to delay or prevent the onset of drug use.

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<sup>1</sup>BOC refers to Burma Oil Corporation and AOC refers to Assam Oil Corporation. The same place is being referred to. BOC is an earlier nomenclature and AOC a more recent nomenclature. Often these two terms are used interchangeably to refer the same location, the location of a prominent oil depot.

“OST cannot be successful as a standalone programme. The failure that we see is mainly because the IDUs take it as a substitute – when they don’t have drug and it is used mostly to combat the withdrawal symptoms. Also, the failure is from the programmatic side, too. People who are working in the programme failed to deliver the core essence of the programme. The workers are not able to counsel or motivate the IDUs and are not able to explain the objectives behind the OST. The skills of the workers working in the OST are poor and hence the failure. It is both an individual failure as well as programmatic failure.” (KI, NGO)

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“Over medicalisation is an issue in the programme. As we have large number of people living with HIV/AIDS in Manipur, when they go to access services in the general hospital or private hospitals, they would be told to do multiple tests – which are not even necessary. Since the family have to bear the expenses of unnecessary test, many do not access services.” (KI, RIMS)

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### ***(ii) Harm reduction and law enforcement, health systems & communities***

Law enforcement by police created a barrier to accessing services from the DICs. The activities of various pressure groups also created this type of barrier. PWID were frequently harassed or arrested, even though they were accessing harm reduction services. It has been observed previously that the spouses of IDU/PLHIV still feel reluctant to come out openly and interact freely to demand their rights. In addition, available services lack gender sensitivity, and so they respond inadequately to the needs of these women. Generally, there seemed to be a fear of the stigma that comes with being the spouse of a drug user. Because of such fear of being stigmatised and discriminated against, access to hospitals and even health camps is limited. The general community was more accepting of de-addiction than of safer drug use behaviour. Raising awareness on the benefits of harm reduction strategies among law enforcement personnel, hospital staff, and the general population in the community could bring about needed changes in attitude and behaviour.

“Awareness level of the people is still low. The IEC material that is available in Manipur is mostly concentrating on dos and don’ts rather than giving overall sensitisation related content. The IEC is not sufficient and cannot provide the level of awareness expected to be provided.” (KI, NGO, Imphal)

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“There is a need for sensitisation and training in the police services. We need to make everyone aware on this issue of drug use and harm reduction services, it is important.” (KI, Police Services, Manipur)

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## **Section 3: Harm Reduction Programme in Bihar and Manipur – A Comparison**

### **A. Socioeconomic Status of PWID**

The PWID studied in Bihar and Manipur represented different socioeconomic groups. PWID in Manipur were literate and earned a regular (albeit low) income, whereas PWID in the Bihar sites fell under a lower socioeconomic status and worked primarily in manual labour (agriculture and masonry).

### **B. Dynamics of Vulnerability**

PWID in Manipur had relatively good family support as injecting drug use is understood in the community, and families are supported through the harm reduction processes. But in Bihar,

PWID faced challenges in this domain; such challenges further hamper their being able to negotiate safe behaviour within injecting and sexual networks.

Both sites require more sensitisation within the community, the police, and additional stakeholders as a way of achieving better understanding and acceptance of PWID and as a way to implement harm reduction services.

### **C. Barriers in Implementing Harm Reduction Services**

The socio-political situation, police harassment, availability of drugs, and access to NSEP were the major barriers in Manipur sites. In contrast, in Bihar sites, in addition to police harassment, the discrimination PWID experienced in the community and the low socioeconomic status of PWID were major deterrents in their being able to access harm reduction services.

### **D. Harm Reduction Programme Implementation**

Harm reduction programmes in the state of Manipur were led by the community and it is evident that the factor of 'being the community' or being an 'ex-user' helped to implement services among PWID. This was not the case in Bihar. And yet, community involvement is an important component of the approach now favoured, and this is especially true because harm reduction programmes and engagement with PWID require constant efforts and a long-term approach. It helps a great deal to understand injecting behaviour first hand. It should also be mentioned that in Bihar, service providers lacked the long-term experience of working with drug users.

### **E. Future Directions**

At the time the study was conducted, Manipur sites were at the stage where they were consolidating harm reduction services under 'one package' – probably because Manipur has had more time to develop its harm reduction programmes, and thus more time to understand both the merits and the problems associated with various approaches to harm reduction. Bihar has a long way to go to integrate services offered to PWID as part of a holistic package. OST services just recently rolled out and recent developments have uncovered the existence of a gap in sensitisation towards PWID among health providers in the government sector. In terms of counselling services, there is considerable scope for improvement for both male and female outreach workers.



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## Conclusions and Recommendations

The findings show that, despite significant and maintained effort by a range of social institutions, PWID remain extremely vulnerable to HIV as well as other harms. This research highlights the important role that social institutions played in mediating vulnerabilities. Conversely, the study also shows that more needs to be done to alert individuals of their vulnerabilities and to encourage positive health decisions.

Stigma towards PWID remains a significant barrier preventing access to services. The effects of stigma manifest themselves in multiple ways. First, community stigma against drug use forces the majority of PWID to hide their behaviour and delay accessing treatment or harm reduction services. Second, PWID face harassment from social institutions such as the medical system and law enforcement institutions that tend to favour abstinence over harm reduction.

Other more situational factors that increase vulnerability are now apparent. For example, many PWID reported that they were more likely to engage in risky behaviour while they were experiencing withdrawal. Similarly, untimely operating hours of NSEP centres, a consistent complaint of PWID, contributed to risky sharing behaviour despite ample risk awareness. Further, HIV status and issues around disclosure and how this status and these issues create vulnerability in injecting, as well as sexual, networks of PWID emerged as one of the critical dimensions in this research.

Group dynamics and social norms were another important driver of vulnerability. Among some groups of injectors, a reluctance to inject together (and share equipment) was viewed as suspicious. Gender played an important role in mediating sexual relationships especially for female sexual partners of male injectors who were often unaware or felt unable to moderate their risk due to power imbalances in their relationships. Simply having IEC/BCC available in the community does not increase women's access to harm reduction services. There is a huge need to create relevant and effective services that are specific to their unique needs. Together these findings show that programmes need to address multiple and complex vulnerabilities that PWID and their sexual partners face.

Comparisons between Manipur and Bihar however point to the positive changes that can occur with sustained effort, especially when the affected communities have meaningful engagement in project design and implementation.

The report makes the following recommendations:

### **Recommendations (Both Manipur and Bihar)**

1. More efforts need to focus on addressing the specific vulnerabilities that are experienced by both female injectors as well as the sexual partners of male injectors.
2. More work needs to focus on the role of HIV status and disclosure on behaviour and access to services. In a global environment that is championing "treatment as prevention" the project should focus on encouraging HIV positive people to gain access to treatment as soon as possible.
3. Efforts need to be maintained on reducing stigma associated with drug use. However it is recommended that more attention is focused on targeting key social institutions such as police, medical providers and families of PWID rather than the general community.

### **Recommendations (Manipur)**

1. Programmes need to focus on ways of encouraging novice drug users into health and harm reduction services before their drug use becomes problematic. This could be achieved by employing a younger cohort of peers as well as rethinking the delivery of services that are often designed for older more experienced drug users
2. Efforts need to focus on reducing the cost of accessing ART as it remains a significant barrier for HIV positive IDU in Manipur.

### **Recommendations (Bihar)**

1. Efforts should focus on developing peer support groups among PWID and former users. These groups should also be supported to engage meaningfully in services design, delivery and evaluation.
2. Poverty and socio-economic isolation remains a significant barrier to PWID accessing services in Bihar. It is recommended that specialised services be designed that are sensitive to the daily routines of drug users who work long and difficult jobs.

# Appendix

## Tool Development and Translation into Local Languages

Tools were designed and developed based on a systematic review of the relevant literature. The tools included in-depth interviews and focus group discussion guides. Two different sets of interview guides were developed, one for interviews with PWID and the second set for interviewing key informants at the state level. The focus group discussion (FGD) guides were developed for group discussion with spouses/FIDUs. All the tools were translated from English into Hindi, Bhojpuri, and Meiteilon.

## Field Operations

Four IDU TI-NGOs, one in Manipur and three in Bihar, provided the field logistics support that was needed to conduct the study. Further, the IDU TI-NGOs also helped in mobilising the respondents and participants.

Research associates (RAs)/research coordinators (RCs) were divided into sub-groups (two/three persons in a sub-group) to conduct interviews with PWID. Further, all the FGDs and the KI interviews were conducted by the principal investigator and the RCs. The female staff conducted the FGDs with partners/spouses of PWID, including FIDUs. Where possible efforts were made to conduct interviews in private.

During all interviews/discussions, each of the RAs/RCs recorded field notes. Following each interview a summary note was prepared. The field transcription were used in to inform subsequent data collection and during data analysis.

## Team Profile

Local research teams were selected in consultation with NGO implementing partners in Bihar and Manipur. Table 4 describes the study teams in each site. Effort was made to liaise with local drug users in selecting the research teams to ensure that study subjects felt comfortable sharing their experiences and their knowledge.

**TABLE 4: RESEARCH TEAMS IN BIHAR AND MANIPUR**

States		Field Research Assistants	Field Research Coordinators
Bihar	Buxar	3	1
	Bhabua	2	0
	Mohania	2	0
Manipur	Imphal	5	1

## Training Workshop with Field Team

A three-day training workshop was conducted with the field teams, one in each state. The principal investigator and the research coordinator provided the training. The objectives of the workshop were to provide an overview of the research, describe the concepts involved in qualitative research, and discuss and provide hands-on training on the tools developed for the study. Further, mock interviews were carried out to orient the teams about a range of interview techniques and probing styles. A session on note-taking and debriefing was also conducted.

## Sampling Framework

A total of four group discussions were organised, two each in Bihar and Manipur. The discussants of the FGDs were spouses/partners and FIDUs who were in contact with IDU TI-NGOs because of their participation in various activities. Since most of the activities implemented by the IDU TI-NGOs focus on the PWID and not directly on the spouses/partners, in both states, some women who were not direct beneficiaries but whose husbands had been beneficiaries of the TI-NGOs programme while they were alive also took part in the discussion. However, in Manipur, a discussion with FIDUs was added to the set of interventions planned in the original study design, as this permitted us to obtain different perspectives and views. In this way, we were also able to gain knowledge of multiple vulnerabilities and risks experienced by FIDUs who themselves were both spouses/partners and injectors.

## Identification and Selection of Study Respondents

### PWID Profile

The study aimed to understand the emergent, multiple risks and vulnerabilities among PWID and their sexual partners/spouses; therefore, study respondents were selected from among PWID most recently diagnosed with HIV. In each state, twenty PWID who were tested and found to be HIV-positive between November of 2012 and December of 2013 were scheduled to be included for the in-depth interviews. In fact, by our using lists maintained by the IDU TI-NGOs implementing the Hridaya programme, we found fewer than forty PWID who met the inclusion criteria in the two states. Therefore, the research team revised the time frame of the study so it included the period that extended from November of 2010 to December of 2013 in Manipur and from November of 2012 to December of 2013 in Bihar.

### Key Informants' Profile

A total of ten KIs were chosen, six from Manipur and four from Bihar. These KIs were experts from various disciplines in the fields of HIV/AIDS and harm reduction. KIs worked for or were affiliated with NGOs, government, academia, law enforcement units, medical practices, activist groups, or support networks. We received assistance from local IDU TI-NGOs and officials in state government in making these selections.

### Focus Group Discussants' Profile

A total of four group discussions were organised, two each in Bihar and Manipur. The discussants of the FGDs were spouses/partners and FIDUs who were in contact with IDU TI-NGOs because of their participation in various activities. Since most of the activities implemented by the IDU TI-NGOs focus on the IDUs and not directly on the spouses/partners, in both states, some widows who were not direct beneficiaries but whose husbands had been beneficiaries of the TI-NGOs programme while they were alive also took part in the discussion.



However, in Manipur, a discussion with FIDUs was added to the set of interventions planned in the original study design, as this permitted us to obtain different perspectives and views. In this way, we were also able to gain knowledge of multiple vulnerabilities and risks experienced by FIDUs who themselves were both spouses/partners and injectors

## Data Analysis Process

### Data Management

Audio files recorded during the interviews and group discussions were stored in a computer. Each audio file was given a unique ID. Original copies of the audio files were backed up separately. All interviews were transcribed in Meiteilon and Hindi/Bhojpuri and then translated verbatim into English. Atlas.ti software (version 7) [ATLAS.ti Scientific Software Development GmbH, Germany] was used to code and categorise the data into themes.

### Theoretical Framework

Data were analysed using a thematic analysis approach. In thematic analysis, the various themes that emerged from the interviews were analysed and categorised in such a way as to create a pattern, framework, or structure relevant to the goals of our study. Once a meaningful pattern forms, several categories emerge out of the pattern. These categories are then freely organised into an array of subcategories. The output of subcategories is then examined separately for each of the different groups of stakeholders in the study. After further information was received from the software, it was then further reorganised on the basis of the judgement of the research team; this further reorganisation was designed to fine-tune the information and group each portion of information received from various stakeholders under similar subthemes. The goal here was to identify and regularise underlying ideas or relationships across the perceptions of various stakeholders. In addition, raw data was read and re-read by the research team both to familiarise with the content and also as a way of identifying an initial set of themes and corresponding subthemes. We were then able to systematically search recurring themes and categories. The themes developed were used to prepare a codebook. The code definitions were also prepared.

Transcripts were coded using words that 'facilitate retrieval' (Pope, et al., 2006). Terminology and interesting terms used by study participants were used for coding and such coding formed the basis of analytical categories (Pope, et al., 2006). Data were thus examined for overlap and repetition among themes and subcategories.

In the initial phase, two researchers in the study team coded a few transcripts. The list of codes developed from this process was then compared and refined and in this way, we developed a single coding frame. This coding frame was then applied to the remaining transcripts. Once the coding was completed, data were grouped into higher-level themes. These themes were then compared as a way of examining relationships, specifically the multiple relationships and interrelationships that exist between the sites at which we were working, and the themes themselves. Data were also presented in the form of descriptive accounts, and these consisted of illustrative quotes taken from the interviews. These are presented in the results chapter (Chapter 4).

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