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Department of AIDS Control  
Ministry of Health & Family Welfare, Government of India  
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# Barriers to and Opportunities for Uptake of HIV Testing and Antiretroviral Treatment among Injecting Drug Users (IDUs) in the Context of Targeted Interventions

Diagnostic Study

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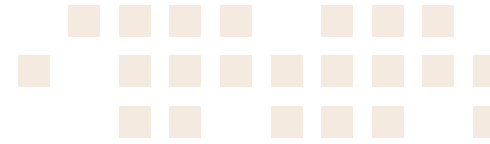
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## Diagnostic Study:

### Barriers to and Opportunities for Uptake of HIV Testing and Antiretroviral Treatment among Injecting Drug Users (IDUs) in the Context of Targeted Interventions

“Currently ‘Injecting Drug Users’ (IDUs) are referred to as ‘People Who Inject Drugs’ (PWID). However, the term ‘Injecting Drug Users’ (IDUs), has been used in this document to maintain consistency with the term used presently in National AIDS Control Programme”.

**Supported by The Global Fund to Fight AIDS, Tuberculosis and Malaria- Round-9 India  
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## Preface

Improving access to antiretroviral treatment among injection drug users (IDUs) remains an urgent public health concern. Though the overall trends in terms of number of people infected with HIV in India seems to be indicating of a downward trend. The infection rates continues to rise across several new pockets, and with the epidemic largely concentrated in certain sub-populations, including primarily injecting drug users, men who have sex with men, and their sex partners. Further the levels of undiagnosed HIV infections may still be high specially in emerging high risk pockets.

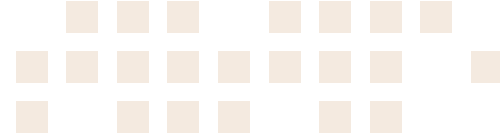
Owing to the above factors many people with HIV remain undiagnosed until late in the course of infection and therefore cannot benefit from earlier treatment that reduces morbidity and mortality. It is also recognized that persons diagnosed early are less likely to transmit the virus because of lower infectivity and changes in risk behavior. Thus HIV testing, early diagnosis and treatment may have both individual and public health benefits.

In India, Targeted Intervention (TI) under the National AIDS Control Programme (NACP) framework is one of the core strategies for HIV prevention among injecting drug users (IDUs). Primary health services, health education, abscess management, treatment referrals and provision of harm reduction services such as Needle Syringe Exchange Program (NSEP) and Opioid Substitution Therapy (OST) are some of the critical services provided as part of the NACP strategy to reach out to IDUs. The services are executed through peer based outreach and Drop-in Centre (DIC) based approaches.

To further strengthen these established mechanisms under the NACP and to expand the reach to vulnerable IDUs, the United Nations Office on Drugs and Crime (UNODC) in India provides technical assistance to the National AIDS Control Organisation (NACO) through the Global Fund Round 9 Project (i.e., Project HIFAZAT), amongst others, to undertake the following:

1. Conduct Operational Research & Diagnostic studies
2. Develop Quality Assurance SOPs
3. Develop Capacity Building/Training manuals
4. Training of Master Trainers

It is in this context that a diagnostic study on “Barriers to and Opportunities for Uptake of HIV Testing and Antiretroviral Treatment among Injecting Drug Users “(IDUs) in the context of Targeted Interventions in India has been conducted.



The study aims to describe the individual, situational and structural factors influencing HIV diagnosis and treatment services (especially HIV testing and antiretroviral treatment) uptake by IDUs. It will assess the gaps in service access and use – by collecting information on the number/proportion of IDUs in targeted interventions who are in need of core HIV-related services, testing and antiretroviral treatment and number/proportion actually using those services. It is hoped that the study will form the necessary basis for policy/decision makers, donors and programme implementers to remove the barriers and consequently also improve the opportunities for uptake of HIV Testing and Antiretroviral Treatment by IDUs in India.

Contributions from the Technical Working Group of Project HIFAZAT which included representatives from NACO, Project Management Unit (PMU) of Project HIFAZAT, SHARAN, Indian Harm Reduction Network and Emmanuel Hospital Association were critical in articulating and consolidating the inputs that helped in finalizing this module.



## Acknowledgement

The UN Office on Drugs and Crime, Regional Office for South Asia (UNODC ROSA) in partnership with national government counterparts from the drugs and HIV sectors and with leading Non- Governmental Organisations in the countries of the South Asia is implementing a project titled “Prevention of transmission of HIV among drug users in SAARC countries” (RAS/H13).

As part of this regional initiative, UNODC is also engaged in the implementation of the Global Fund Round -9 IDU- HIV Project (i.e. HIFAZAT). Project HIFAZAT aims to strengthen the capacities, reach and quality of harm reduction services among IDUs in India. It involves providing support for scaling up of services for IDUs through the National AIDS Control Programme.

We would like to acknowledge the invaluable feedback and support received from various stakeholders which includes NACO, Project Management Unit (PMU) of Project HIFAZAT, Emmanuel Hospitals Association (the Principal Recipient of the grant “Global Fund to Fight AIDS, Tuberculosis and Malaria- India HIV-IDU Grant No. IDA-910-G21-H”), SHARAN, Indian Harm Reduction Network and individual experts who have contributed significantly in the development of this document.

Special thanks are due to the UNODC Project H13 team for their persistent and meticulous efforts in conceptualising and consolidating this document. We would also like to thank co-lead consultants Mr. C. Bangkim, Mr. Brijesh Dash, Ms. Kanudeep Kaur, Mr. Debashish Das and Mr. Shiva kumar, as well as to all the NGOs from where the data was collected.



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## Abbreviations

<b>ART</b>	Anti-Retroviral Treatment
<b>BSS</b>	Behavioural Surveillance Survey
<b>DIC</b>	Drop-In Centre
<b>FGD</b>	Focus Group Discussion
<b>FIDU</b>	Female Injecting Drug User
<b>HIV</b>	Human Immunodeficiency Virus
<b>ICTC</b>	Integrated [HIV] Counselling and Testing Centre
<b>IDI</b>	In-depth Interview
<b>IDU</b>	Injecting Drug User
<b>NACO</b>	National AIDS Control Organisation
<b>NACP</b>	National AIDS Control Programme
<b>NGO</b>	Non-Governmental Organisation
<b>NSP</b>	Needle Syringe Programme
<b>ORW</b>	Outreach Worker
<b>OST</b>	Opioid Substitution Therapy
<b>PE</b>	Peer Educator
<b>PLHIV</b>	People Living with HIV
<b>TI</b>	Targeted Intervention
<b>UNGASS</b>	United Nations General Assembly Special Session on HIV/AIDS
<b>UNODC</b>	United Nations Office on Drugs and Crime





# Executive Summary

## Background and Objectives

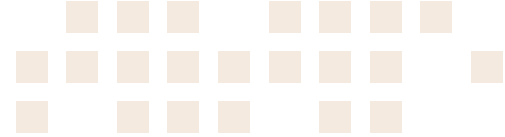
Available studies have shown that injecting drug users in India face several challenges in accessing and using HIV-related services including HIV testing and antiretroviral treatment. Often the findings of these studies which are conducted in one or more sites have limited applications in other parts of India. Hence, this national level multi-site study was conducted to diagnose the challenges encountered by male and female IDUs at several stages of the HIV services pathway. The USP of this study is that perspectives and suggestions of both IDUs and their service providers (staff of targeted interventions and health care providers in government hospitals) have been analysed, thus enriching the findings and providing an insight into the problems on the ground.

**Following are the research objectives:**

- Delineate and describe the individual, situational and structural factors influencing HIV diagnosis and treatment services (especially HIV testing and antiretroviral treatment) uptake by IDUs
- Gather perspectives and experiences of injecting drug users as well as key stakeholders including staff of IDU TI and health care providers in ICTC and ART centres
- Assess quantitatively the gaps in service access and use – by collecting information on the number/proportion of IDUs in HIV targeted interventions who are in need of core HIV-related services (i.e., HIV testing and antiretroviral treatment), and number/proportion actually using those services

## Methodology

Data was collected from qualitative field research (focus groups and stakeholder in-depth interviews) and review of service delivery statistics available in IDU TIs and government HIV service centres (ICTC and ART centres). Qualitative field research was conducted in 18 study TI sites that covered five regions of India. Sites were selected on the basis of urban/semi-urban nature, presence or absence of opioid substitution treatment (OST) and presence of separate TIs for female IDUs. Qualitative data was gathered from 39 focus groups (n=239 participants: 200 males; 39 females) with low socioeconomic IDUs (aged 19-58 years) and in-depth interviews of 101 stakeholders by the staff of IDU TI (project coordinator, counsellor, outreach workers, peer educators) and doctors/counsellors in ICTC, ART centres and community care centres (CCCs). For focus groups, purposive sampling was used to include males and females, HIV-positive and HIV-negative/unknown HIV status persons, current and former injecting drug users, and OST users.



Focus groups and interviews were recorded and translated into English. Transcribed data was analysed thematically through framework approach - using NVivo7 software. Major categories and themes, related to barriers and opportunities for service access and use, were identified and inferences drawn from both qualitative data and review of service delivery statistics.

## Findings

Several barriers to and opportunities for improving service uptake have been identified in the study. Stigma related to HIV, drug use and sex work (in the case of some female IDUs) all posed barriers for IDUs to get tested for HIV or access ART. Participants had the fear of disclosure of their HIV and/or drug use status with adverse consequences to their financial and emotional support.

Another common problem related to the consequences of active drug use. Active injectors could not comprehend the importance of HIV testing and ART, and did not have either the patience to wait in HIV testing and counseling centers or didn't want to go and get registered in ART centres.

At the health care centers (ICTCs and ART centres), several barriers exist. Right from registration; problems are faced, especially by homeless IDUs who do not have address proof and whose basic needs of shelter and food are not met. Since many current users develop withdrawal symptoms and easily become irritated, they do not want to wait for long and demand immediate attention. This is often not appreciated by health care providers as drug users are a difficult population to deal with. Without any job or financial support, many IDUs are not able to visit HIV testing centres (first-time or repeat testing) or ART centres on their own; they expect TI staff to bear their travel expenses and to accompany them. Self-referrals are rare.

Across the sites, negative experiences with health care providers were narrated - making it a key barrier for IDUs to access services for the first time or to continue to use services. Lack of privacy and confidentiality during HIV test, counseling and delay in getting back HIV test results, in some sites, led some IDUs to be reluctant to come back for repeat testing or to collect test results. Since OST is not available in all sites, HIV-positive IDUs could not make use of the 'stabilising' effect of OST to help them in adhering to ART. Use of alcohol by some former and current users also contributes to limited attention to one's health and ART non-adherence. In most sites, CCCs are under utilized by IDUs living with HIV because of negative interactions between CCC staff and IDUs.

While referrals from IDU TIs to ICTCs and ART centres are satisfactory in most sites, reverse referrals from government sector (ICTCs, ART centres) to IDU TIs were very limited. Differences in rapport (professional personal relationships) between TI staff and ICTC/ART staff seem to account for much of the differences between sites that were doing well and those which were not.



## Recommendations

### 1. Common recommendations for HIV testing and treatment services (ICTCs, ART centres and CCCs)

#### ***Sensitisation and training of health care providers***

Anticipated and actual discrimination of IDUs (former or current) by health care providers prevent them from accessing HIV testing or ART. Even if IDUs had used that service previously, negative experiences prevented them from coming back to collect test results and to come for repeat testing, or to be regular in follow-up when they are on ART. Hence it is crucial that health care providers need to be sensitised on the issues faced by injecting drug users (males and females, including those who engage in sex work) and trained to provide competent clinical and counselling services for these populations.

#### ***Financial support for travel costs to visit ICTCs and ART centres***

Majority of the IDUs, reached through TIs, being from lower socioeconomic class, and a considerable number being unemployed, are reluctant to go to hospitals on their own even if referral slips are given to them. Accompanied referrals have been known to increase HIV testing uptake or registration in ART centres and follow-up visits. Thus, support for the travel costs of IDUs and the accompanying TI staff (outreach worker or peer educator) to visit/accompany ICTCs or ART centres is needed in the TI budget or through other means (e.g., through ICTCs or ART centres).

#### ***Provide training to health care providers to address psychological and other individual level barriers to HIV testing or ART initiation***

Psychological barriers such as lack of self-efficacy in drug adherence, fear of side-effects and fatalism prevent some IDUs from initiating ART. Similarly, factors such as fear of being tested HIV positive, and fear of adverse consequences such as family or partner rejection prevent some IDUs from getting tested for HIV. Hence outreach workers, counsellors, and doctors need to be trained to be competent in eliciting and providing tailored counselling to address various psychological barriers to initiating ART or getting tested for HIV.

#### ***Strengthen linkages and referral mechanisms across various service providers***

Some broad guidelines for IDU TIs on referrals exist but often there are no reverse referrals from government centres (ICTC or ART centres) to IDU TIs as it is unclear when and where to refer. Detailed guidelines need to be developed for IDU TI, ICTC, and ART centres – on when and how to refer IDUs from one service to another service, e.g. when to enrol an HIV-positive IDU in OST; when to refer an HIV-positive IDU person to CCC rather than to a government hospital. Also, to ensure continuum of care for negative and HIV-positive IDUs across the HIV-related service pathways, mechanisms (e.g., meetings, cross-referral slips) need to be strengthened for better coordination among various service providers (HIV testing; OST; ART registration, initiation and follow-up; linking with PLHIV networks).



***Strengthen routine service delivery data collection and documentation systems at IDU TI, ICTCs and ART centres to help monitoring and improving service performance***

Even though, in general, adequate and reliable data on service uptake was available from most study sites, not all necessary data is available in some sites to assess optimal use of referrals, gap between referrals and registration, and follow-up of ‘pre-ART’ and ‘on ART’ IDUs and from the IDU TIs. Hence, it is crucial to strengthen routine service delivery data collection and documentation at IDU TIs, ICTCs and ART centres – to help in monitoring whether recommended processes (e.g., 100% of HIV-positive IDUs identified in ICTCs are referred to ART centres) are followed and to help improving service performance.

## **2. Recommendations to remove barriers to accessing and using HIV testing (first time and repeat testing)**

***Creating a positive and welcoming image of government ICTC centres, and ensuring privacy and confidentiality***

Ensuring privacy and confidentiality during counselling (e.g., in private rooms where counselling process is uninterrupted by others) would greatly help in improving the effectiveness of the risk reduction counselling and in increasing the chances of uptake of first-time or repeat HIV testing among IDUs.

***Expediting HIV testing process for core populations including IDUs***

To avoid problems due to withdrawal symptoms experienced by active IDUs when they wait for HIV testing and counselling, fixing a particular day and/or time for IDUs alone can be considered. One can consider giving priority to key populations being brought by TI staff to ICTCs, so that the waiting time can be reduced. Possibility of providing results on the same day – as practiced in some centres – needs to be strongly considered.

***Introducing rapid, non-invasive (non-blood) or dried blood spot tests at the field or drop-in centre level***

Having a rapid, non-invasive HIV test (such as saliva or urine) needs to be considered as it can then be done at the field level without the need to worry about the distance, time, and travel costs. In any case, adequate pre- and post-test counselling should be ensured. The national working group for IDU TIs of NACP-IV too has suggested rapid tests such as dried blood spot (DBS) as it does not require any special specimen-transport arrangement.

***Introducing mobile HIV testing and counselling units***

Some sites have successful experience of having mobile ICTC units. Where there is high concentration of core populations including IDUs, a mobile unit can visit the field or drop-in centres at regular intervals to collect blood, and provide proper pre- and post-test counselling.

### 3. Recommendations to remove barriers to ART access and adherence

#### ***Relax stringent requirements for address proof that prevent or delay initiation of ART***

In some sites, many IDUs living with HIV are homeless or do not want to reveal their real address for fear of disclosure. While an address proof is required for follow-up, lack of appropriate address proof should not pose barrier to needy persons from receiving ART. If NGOs working with IDUs or PLHIV networks are willing to take responsibility for follow-up of those persons then, as an interim measure, addresses of those agencies can be used to follow-up IDUs living with HIV.

#### ***Consider using mobile phone text messages to remind people about follow-up appointments for HIV testing or follow-up in ART centres***

Not all IDUs reached through TI may have mobile phones. However, after getting the permission of IDUs to send health-related messages to their (or their friend's) mobile phones, reminders can be sent to them regarding next appointment for HIV testing or follow-up visits to ART centres. Mobile phone reminder calls have already been in vogue in several sites – both in IDU TIs and in ART centres. Considering an outreach team from ART centre for follow-up of people living with HIV (including IDUs) can also be pilot-tested.

#### ***Address active drug and alcohol use among IDUs living with HIV***

Active drug use and alcohol use poses direct and indirect risks for HIV transmission and acquisition. IDUs living with HIV who are currently drug dependent need to be linked with needle/syringe programmes or drug dependence treatment such as opioid substitution treatment (OST). Even though, ideally all HIV-positive IDUs be enrolled in OST program to help them in 'stabilising' and ensuring proper follow-up and adherence, not all active IDUs living with HIV can be immediately enrolled in OST and thus require access to clean needles/syringes until then. As heavy alcohol consumption damages liver, current alcohol use among IDUs living with HIV (former or current) should be actively screened and linked with alcohol dependence treatment.

#### ***Provide comprehensive ART education to IDUs living with HIV to facilitate ART uptake and adherence***

Provide and reinforce HIV treatment messages to HIV-positive IDUs in different forms and avenues (pamphlets and posters in local languages in drop-in centres and ART centres); and through different providers (peers, outreach workers, doctors, and counsellors).

#### ***Educate all IDUs about ART (irrespective of HIV status and CD4 count)***

Treatment messages should not be restricted only to those who are known to be HIV-positive. Giving ART-related treatment messages to all (irrespective of their HIV status) helps diffusion of this information among the IDU community and avoids labelling people who receive treatment messages from outreach workers as being HIV infected.



# 1. Background

As per the sentinel surveillance conducted by NACO in 2007, HIV prevalence among Injecting Drug Users (IDUs) is 7.2%, one of the highest among the high risk groups in India.<sup>1</sup> The surveillance data for 2008-2009 suggest declining HIV infections among female sex workers but many states show increasing trends of HIV prevalence among IDUs and men who have sex with men.<sup>2</sup>

The technical guide developed jointly by the World Health Organization (WHO), United Nations Office on Drugs and Crime (UNODC), the Joint United Nations Programme on HIV/AIDS (UNAIDS) for countries to set targets for universal access to HIV prevention, treatment and care for injecting drug users has recommended a comprehensive package of core public health interventions. The package includes Needle Syringe exchange Programme (NSP), Opioid Substitution Therapy (OST) and provision of Anti-Retroviral Therapy (ART) for HIV-positive IDUs as the essential package among the nine interventions. There is strong evidence that these interventions are effective in reducing injection-related HIV risk behaviours – preventing HIV infections and ensuring access of essential care and treatment services for IDUs.

National AIDS Control Organisation (NACO) in India has adopted a harm reduction approach in the third phase of National AIDS Control Programme (NACP-III) to prevent HIV among IDUs through HIV targeted interventions (TI) implemented by Non-Government Organizations (NGOs). As part of this strategy, through its IDU TIs, NACO gives significant thrust towards ensuring that the IDU clients are linked to the Integrated HIV Counselling and Testing Centres (ICTC). Further, given that a significant proportion of the IDUs are vulnerable and often found to be HIV positive, the IDU TIs have to therefore work in tandem with the government ART centres and SACS-supported community care centres (CCC) where people living with HIV are provided short-term in-patient care for minor illnesses.

## ***Data on HIV testing rates and ART access among IDUs in India***

A global review on HIV prevention, treatment and care services for IDUs estimated that an average of four (range 2–18) per 100 HIV-positive IDUs receive ART. There was no estimate of HIV-positive IDUs on ART reported for India in the review<sup>3</sup>. However, anecdotal evidence does not suggest an encouraging trend amongst IDUs receiving ART in spite of a major expansion in ART services in the country. This makes it prudent for necessary information to be made available for evolving any response for ART provision for the HIV-positive IDUs in India. NACO's 2010 report<sup>4</sup> to UNGASS notes that the percentage of IDUs, who were tested for HIV in the last 12 months and who know their results, range from 2.9% in Uttar Pradesh to 20.7% in Manipur. Data from the Behavioural Surveillance Survey (BSS) 2006 of NACO showed a wide range of 3 to 70% across survey locations for the same indicator.



### ***Gaps in understanding the barriers to HIV testing and ART access***

Linking IDU clients to the HIV-related services – especially HIV testing and ART – has been a challenge. Small scale studies in some parts of India have documented some reasons that include individual, structural, and system barriers. Studies conducted among IDUs in Chennai and Manipur revealed several barriers to service uptake that include (but not limited to) lack of adequate knowledge regarding HIV and ART, lack of concern regarding their own health status, fear of rejection due to HIV positive status, perceived and actual discrimination at the referred centres<sup>5 6 7</sup>. Another study, conducted and published in 2007, for Manipur, reported low treatment adherence as per self-report of the IDU clients enrolled into ART<sup>8</sup>. There are no national level studies that determine the challenges along the pathway to HIV diagnosis and treatment services. In this context, it was decided to conduct this study to diagnose the challenges encountered by IDUs at several stages of the HIV diagnosis and treatment services pathway.

Accordingly, the research objectives are:

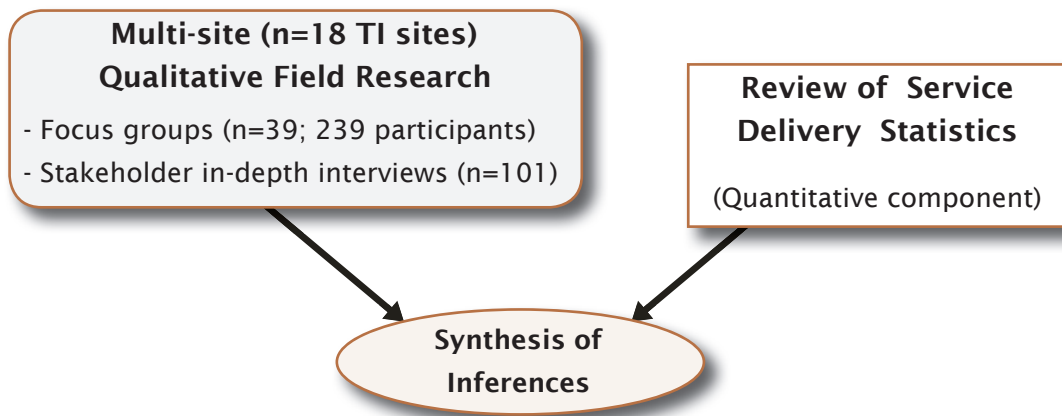
- Delineate and describe the individual, situational and structural factors influencing HIV diagnosis and treatment services (especially HIV testing and antiretroviral treatment) uptake by IDUs
- Gather the perspectives and experiences of injecting drug users as well as key stakeholders including staff of IDU TI and health care providers in ICTC and ART centres)
- Quantitatively assess the gaps in service access and use – by collecting information on the number/proportion of IDUs in HIV targeted interventions who are in need of core HIV-related services HIV testing and antiretroviral treatment and number/proportion actually using those services

This report provides necessary information on the barriers and challenges faced by male and female IDUs in relation to HIV diagnosis and treatment uptake and provide programmatic recommendations - based on the fieldwork carried out by the research team and available service delivery data. The recommendations are expected to be used to fine-tune the existing activities to promote HIV testing and ART service uptake among IDUs by removing the barriers at the individual, health care system and structural levels.

## 2. Methodology

Development of the report was based on qualitative field research data (focus groups and key informant interviews) and review of available documents on service uptake and referrals of IDUs. Following are the details:

**Diagram 1: Summary of the research design**



### A. Qualitative Field Research

Focus group discussions with IDUs and in-depth interviews with key stakeholders were conducted to understand their views and perspectives and also get their suggestions in relation to challenges and opportunities.

#### ***Sampling Plan for Qualitative Field Research: Selection of study sites and justification***

By using Multiple or collective case study design (Yin, 2003<sup>9</sup>; Simon, 2009<sup>10</sup>, Stake, 1995<sup>11</sup>), multiple sites were chosen to examine certain issues such as barriers to and facilitators of access to HIV-related services for IDUs. In selecting the study sites, a sampling strategy called ‘maximum variation sampling’<sup>a</sup> – a kind of purposive sampling used to choose sites that have diverse characteristics (see next paragraph) - was used for collecting information about how the study issues were experienced in different sites (Patton, 1990<sup>12</sup>). There is, however, a commonality to all the study sites: exclusive IDU targeted interventions (TIs) supported by SACS/NACO.

In accordance with the maximum variation sampling strategy for selecting sites, 18 study TI sites were selected for their different key characteristics (heterogeneity): regional representation – northeast, north, east, west and south; HIV prevalence among IDUs in the state; number of IDUs in the state/site; experience of the states in relation to IDU TIs

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<sup>a</sup> This involves purposefully picking a wide range of sites that maximize the diversity relevant to the research question. The aim is to sample for heterogeneity.

– relatively new and well experienced; level of experience of TI-implementing agencies – experienced and relatively new NGOs/CBOs (See Table 2). A mix of OST sites, including the major ones catering to female IDUs, was deliberately included to help compare and contrast similarities and differences among these sites and to answer the research questions. Based on the logic of replication<sup>b</sup> in multiple case study design, similar data collection and analysis procedures were used in all study sites (Yin, 2003).

**Table 1: Study sites and their key characteristics**

Note: All these sites had IDU TIs, ICTC, and ART centre; together they constitute a sampling unit. Some sampling units did not have OST or CCC. Four sites catering exclusively to female IDUs were also included

Region/State and Cities	HIV prevalence among IDUs in the state	Presence of OST project in the site	Presence of exclusive TI site for female IDUs
<b>Northeast:</b> 2 sites (one male and one female IDU TI unit) each in Manipur, Nagaland, Meghalaya, Mizoram ( <i>total 8 units</i> )			
Imphal	High	Yes	Yes
Dimapur	High	Yes	Yes
Shillong	Moderate	Yes	Yes
Aizwal	High	Yes	Yes
<b>North:</b> Uttar Pradesh, Punjab, Delhi ( <i>total 3 units</i> )			
Lucknow	Low	Yes	-
Amritsar	High	Yes	-
Delhi (NCR)	High	Yes	-
<b>East:</b> West Bengal, Orissa, Chhattisgarh ( <i>total 3 units</i> )			
Kolkata	High	Yes	-
Bhubaneswar	High	Yes	-
Raipur	Moderate	Yes	-
<b>West:</b> Maharashtra, Madhya Pradesh ( <i>total 2 units</i> )			
Mumbai	High	Yes	-
Narsinghpur	Low	No	-
<b>South:</b> Andhra Pradesh, Kerala ( <i>total 2 units</i> )			
Hyderabad	High	No	-
Calicut	High	Yes	-

### ***Focus group discussions***

In each site, two or three focus group discussions were conducted, with at least one focus group aimed at only HIV-positive IDUs. In each focus group, six to eight persons participated. Purposive sampling was used to recruit participants.

<sup>b</sup> In this study, ‘theoretical replication’ is referred in the sense that similar methods are used in different sites for having contrasting results for predictable reasons (e.g., high HIV prevalence, maturity of HIV epidemic among IDUs, experience of service providers)

### Stakeholder in-depth open-ended interviews

In-depth interviews focused on understanding the views of key stakeholders in relation to the barriers to and facilitators of service uptake among male and female IDUs, best practices and lessons learned, and suggestions/recommendations for filling any gaps in improving service uptake. In each site, about 5 to 7 stakeholder in-depth interviews were conducted. See Table 4 for information on the categories of stakeholders interviewed.

**Table 2: Qualitative component: Study Methods and Sample size**

Region (M=IDU TI catering to males; F = IDU TI catering to females)	Study sites	No. of FGDs		No. of stakeholder in-depth interviews
		FGD among HIV-positive IDUs	FGD among IDUs of mixed HIV status	
North	Lucknow	-	2	6
	Amritsar	-	2	7
	Delhi	-	2	5
Northeast	Imphal (M)	1	1	5
	Imphal (F)	1	1	7
	Dimapur (M)	1	1	7
	Dimapur (F)	1	1	3
	Shillong (M)	-	2	5
	Shillong (F)	1	1	3
	Aizawl (M)	1	1	4
	Aizawl (F)	1	1	3
East	Kolkata	1	2	7
	Raipur	1	2	7
	Bhubaneswar	1	1	7
South	Hyderabad	1	1	6
	Calicut	-	2	7
West	Mumbai	1	2	7
	Narsinghpur	-	2	5
Total		12 FGDs	27 FGDs	101 interviews
Total number of participants = 340 (239 FGD participants + 101 in-depth interview participants)				



## B. Quantitative Component: Review of Service Delivery Statistics

In each site, the research team reviewed relevant records in the TI site, ART centre, ICTC centre, and community care centre. Information was collected from IDU TIs, ICTCs and ART centres on various aspects of service delivery. For example, from IDU TI: number of referrals for HIV testing, ART centres, and CCCs; and enrolment of HIV-positive IDUs in OST. The information gathered was used to identify the gaps in the coverage of services of needy IDUs (See Tables 5, 6 and 7).

## C. Ethics

An internal technical and ethics review group comprising experts from UNODC, New Delhi, provided technical inputs on research design and analysis, and also examined the ethical issues. Data was collected from the participants after getting written informed consent from them.

## D. Data Analysis

### *Qualitative component (FGDs and in-depth interviews)*

FGDs and in-depth interviews were digitally recorded with permission, and detailed notes (with verbatim quotes that illustrate key concepts) were taken. Sometimes, where participants did not consent for audiotaping, interviewers just took active notes and expanded the same soon after the interviews were completed. Coding was done through NVivo7, a qualitative data analysis software and a preliminary code book was developed based on the information available in the literature. These codes were applied when conducting targeted analysis of the text segments. Focused coding and a constant comparative method (Charmaz, 2006; Glaser & Strauss, 1967) were used initially. Themes were identified by looking for similarities, differences and relationships between categories (Gibson & Brown, 2009). Illustrative quotations (corresponding to inferences) were drawn from the interviews and FGDs.

### *Data analysis from service delivery statistics*

Based on the available data, indicators were developed to find out whether referrals were sufficient, and whether the referrals resulted in registration and testing in ICTCs and registration and initiation of ART in ART centres.

### *Synthesis of inferences*

For proposing recommendations to improve service, both the findings from the views/perspectives of stakeholders and community members as well as from the records review (service delivery statistics) were taken into consideration.



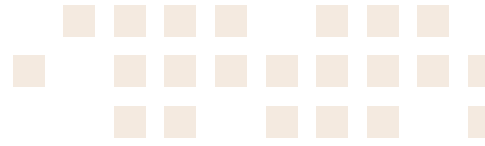
## E. Validity (of the qualitative component)

### ***External validity (Generalisation) and authenticity***

From the perspective of researchers who engage in qualitative policy-oriented research, the generalisation potential of qualitative research can be enhanced by having multiple sites, including study locations that vary in certain key characteristics as well as including sites that are typical and representative (Larsson, 2009<sup>13</sup>; Falk & Guenther, 2007; Stoddart, 2004; Heriott & Firestone; 1983). Hence, as explained earlier, for generalisation of the qualitative study findings from this perspective, 18 sites were selected for their different key characteristics. Even though the site selection was not random, by including sites with diverse characteristics – maximum variation sampling, a kind of purposive sampling – the generalisation potential of this study is likely to be enhanced.

### ***Internal validity (Trustworthiness)***

Data source triangulation (using three different data sets: records, IDUs, stakeholders) and methods triangulation (two different methods – FGDs and interviews) enhanced the validity/trustworthiness of the findings (Glaser & Strauss, 1967; Lincoln & Guba, 1985; Mays & Pope, 2000).



### 3. Findings

#### Sociodemographic characteristics of Qualitative field research

A total of 39 FGDs (n=239 participants: 200 males; 39 females) and 101 stakeholder in-depth interviews were conducted.

##### *FGDs*

Participants' ages ranged from 19 to 58 years. All participants were recruited through IDU TIs and hence have been accessing TI services. Almost all participants were from lower socio-economic status. About 14% were illiterate and only 7% were graduates. About 28% were unemployed, 24% worked in NGO or government sector and 5 women reported their occupation as sex work. About 28% (n=67; males-48, females-19) were openly HIV-positive. More details are available in Table 3.

##### *Stakeholder in-depth interviews (KII)*

Stakeholders included experienced IDU TI staff (project coordinators, project managers, outreach workers); counsellors in ICTCs, ART centres and CCCs; and doctors in ART centre. Most of these participants had several years of experience in working with IDUs.

Details of site-wise stakeholder interviews are shown in Table 4.

**Table 3: Socio-demographic profile of FGD participants**

Site name (M=IDU TI catering to males; F = IDU TI catering to females)	No. of FGDs (Total no. of participants)	Mean age (Range)	Marital Status M: Married U: Unmarried/ S: Separated/ Divorced	Educational qualification					Occupation					% of participants on OST	% of participants registered in TI
				1	2	3	4	5	1	2	3	4	5		
Lucknow	2 (12)	32 (21 – 40)	M – 75% (9) U – 25% (3)	25%	17%	41%	8%	8%		83%		17%		0	100
	2 (17)	48 (23 – 49)	M – 76% (13) U – 24% (4)	12%	35%	47%	6%		5%	52%		42%		65	100
	2 (12)	32 (22 – 40)	M – 75% (9) U – 25% (3)	17%	17%	33%	25%	8%	8%	58%		33%		0	100
Imphal (M)	2 (10)	36 (31 – 42)	M – 50% (5) U – 50% (5)			40%	40%	20%	60%	40%				20	100
Imphal (F)	2 (9)	32 (30 – 44)	M – 89% (8) U – 11% (1)	44%	11%	33%		11%	100%					0	100
Dimapur (M)	2 (10)	36 (38 – 42)	M – 50% (5) U – 50% (5)			40%	40%	20%	60%	40%				50	100
Dimapur (F)	2 (9)	28 (26 – 34)	M – 55% (5) U – 45% (4)	55%		45%			11%	22%	55%	11%		0	100
Shillong (M)	2 (11)	30 (24 – 33)	M – 45% (5) U – 55% (6)	9%	9%	18%	55%	9%	27%	73%				100	100
Shillong (F)	2 (10)	31 (22-36)	M – 40% (4) S – 40% (4)		20%	30%	50%		40%	20%		40%		100	100
Aizawl (M)	2 (14)	32 (19 – 41)	M – 36% (5) U – 50% (7)		7%	36%	36%	21%	72%	21%				57	100
Aizawl (F)	2 (11)	32 (24 – 42)	M – 36% (4) S – 55% (6)		36%	28%	36%		36%	25%		36%		45	100
Kolkata	3 (21)	39 (25-55)	M – 57% (12) U – 43% (9)	10%	52%	38%			10%	80%				100	100
Raipur	3 (21)	35 (28-58)	M – 90% (19) U – 10% (2)		14%	33%	29%	24%	19%	24%				38	100
Bhubaneswar	2 (16)	40 (22 -53)	M – 63% (10) U – 33% (6)	6%	19%	69%	6%		6%	38%				87	100
Hyderabad	2 (9)	33 (24 – 41)	M – 33% (3) U – 55% (5)	22%	22%	55%			22%					0	100
Calicut	2 (10)	46 (33-67)	M – 70% (7) U – 30% (3)	10%	20%	70%			20%	70%				30	100
Mumbai	3 (25)	34 (21-58)	M – 36% (9) U – 64% (16)	40%	28%	20%	8%	4%	56%					88	100
Narsinghpur	2 (12)	32 (24-48)	M – 50% (6) U – 50% (6)	8%	50%	17%	25%		8%	42%				0	100

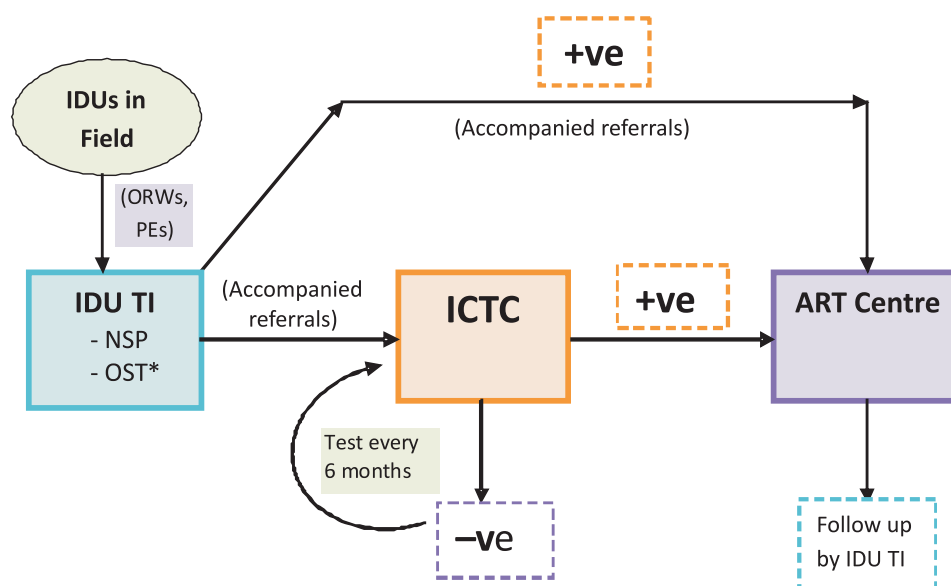
**Table 4: Site-wise details of in-depth interviews with key stakeholders**

Site name	No. of IDIs	Categories of key stakeholders (ORW = Outreach Worker; Coun = Counsellor; PM = Project Manager; PCO = Project Coordinator; Dr = Doctor)										
		TI ORW	TI Coun.	TI PM	ICTC Coun.	ART Coun.	ART Dr.	CCC Coun.	CCC PCO	CCC Dr.	OST Dr.	OST Coun.
North												
Lucknow	6	1	1	1	1	1		1				
Amritsar	7	1	1	1	1	1		1				1
Delhi	5	1	1	1	1	1						
Northeast												
Imphal (M*)	5	1	1	1		1						1
Imphal (F*)	7	1	1	1	2	1		1				
Dimapur (M)	7	1	1	1	1	1		1				1
Dimapur (F)	3	1	1	1								
Shillong (M)	5	1		1	1	1						1
Shillong (F)	3	1	1	1								
Aizawl (M)	4	1			1	1						1
Aizawl (F)	3	1	1	1								
East												
Kolkata	7	1	1	1	1		1		1		1	
Raipur	7	1	1	1	1		1	1			1	
Bhubaneswar	7	1	1	1	1		1		1		1	
South												
Hyderabad	6	1	1	1	1	1		1				
Calicut	7	1	1	1	1	1				1		1
West												
Mumbai	7	1	1	1	1		1		1		1	
Narsinghpur	5	1	1	1	1	1						
Total	101	18	16	17	15	11	4	6	3	1	4	6

\*M=IDU TI catering to males; F\* = IDU TI catering to females

## A. HIV-Related Service Pathways of IDUs

Diagram 2: Commonly reported HIV-related service pathways of IDUs

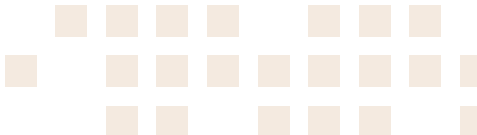


(\*If a person is tested HIV-positive, then TI staff enrol her/him in OST program as well. This pathway is not shown explicitly. Referral pathway from IDU TI and ART centre to community care centre is not shown as well.)

### *From ‘field’ to IDU TI to ICTC, ART centre and CCC*

Often entry of IDUs into HIV prevention services (IDU TI) is through peer educators or outreach workers of NGOs working with IDUs. Rarely IDUs or their families directly approach IDU TIs. Once an IDU is registered in an IDU TI, his or her HIV-related risk behaviours are assessed by the TI counsellor who then refers him or her to ICTC. Often outreach worker or peer educator accompanies IDUs to ICTC. In ICTC, after pre-test counselling, blood for HIV testing is taken and the client is asked to come after a couple of days. Usually the ICTC counsellor then asks TI staff (ORW or PE) to bring the client for collecting HIV test results. Occasionally, test results may be given to NGO staff, but this is rare. If a person is found to be HIV-negative then he/she is asked to come for HIV testing at least every six months thereafter or before that 6-month period if they engage in risk behaviours. If a person is found to be HIV-positive, then often TI staff accompanies the client for registration in ART centre and then follows-up with the client. Similarly, sometimes IDU TI staff directly refers needy HIV-positive IDUs to CCC.

Ideally, all new clients need to be referred for HIV testing and registered negative clients need to undergo HIV testing every 6 months. Data from IDU TI show that about 40 to 100% of referrals made to ICTCs result in HIV testing (See Table 5). Only 3 out of 18 study sites had 100% of their referrals resulting in testing. No major differences were found between male and female IDU TIs, while more percentage of referrals resulted in testing in urban sites and NGOs with long-term experience. Similarly, about 50 to 100% of referrals of HIV-positive IDUs from TIs resulted in registration at ART centres.



Data from ICTCs in the study sites (See Table 6) showed that 98 to 100% of IDUs registered in ICTCs had undergone HIV testing. In 6 study sites<sup>c</sup>, 100% of registered IDUs were referred from study TIs; it shows that self-referrals by IDUs are almost nil in these sites.

(As data on the number of HIV-positive IDUs on NSP and whether TI meets those persons' daily needs of clean needles/syringes were not available readily, inferences related to access and use of NSP by HIV-positive IDUs could not be made. Otherwise, access to and use of NSP by IDUs reached through TIs is good. As NSP access and use is not the focus of this study, NSP data from the study TIs are not discussed in this report)

### ***From ICTC to ART centre and IDU TI***

If a person is found to be HIV-positive in ICTC, then usually ICTC counsellor refers that person to ART centre. However, often HIV-positive IDUs do not go to ART centres on their own and hence ORW or PE then accompany and help them to get registered in ART centres. In the ART centres, after CD4 testing, doctors decide the eligibility of an IDU to be initiated on ART and all eligible persons are initiated on ART.

If a person is currently not found to be eligible, then he or she is asked to come for regular follow-up and as soon as they are found eligible, they are initiated on ART. Again, in the absence of dedicated outreach staff for ART centre, doctors and counsellors of the ART centre rely on ORW or PE of IDU TI to follow-up with HIV-positive IDUs for regular follow-up and adherence to ART. In IDU TI, all HIV-positive IDUs, if they are currently injecting, are counselled to get enrolled in OST as it helps in stabilising a person to be initiated on ART and helps in adherence. No reliable data is available on the number/proportion of newly identified IDUs referred from ICTCs to IDU TIs.

### ***From ART centre to IDU TI and CCC***

From the ART centre or IDU TI, some HIV-positive IDUs are referred to community care centres (CCCs) if IDUs require some care during initiation of ART or short-term care for minor illness.

Data from ART centre shows that about 50 to 100% of eligible IDUs were initiated on ART in the last one year. In eight out of 18 sites, 100% of eligible IDUs were initiated on ART (See Table 7). About 10 to 29% of IDUs were lost to follow-up. Reliable data is not available about these persons who were lost-to-follow-up. Hence, it is not known whether or not these persons were initially referred by IDU TIs.

Out of the 6 sites where we had data on the number of reverse referrals of HIV-positive IDUs from ART centre to IDU TIs, four ART centres referred none to IDU TIs and only two ART centres referred two persons each to IDU TIs (See Table 7). This means, very weak reverse referral from ART centre to IDU TIs unless all the HIV-positive IDUs in those ART centres were referred from IDU TIs.

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<sup>c</sup>For remaining sites, data on this item were not available.

**Table 5: Data from IDU TIs: Key indicators to demonstrate access to and use of HIV testing and ART services**

Sites (TI)	IDUs served	Total (cumulative) number of IDUs registered in the TI in the past year (April 1, 2011 – March 31, 2012)	I. % of referrals made by TI to ICTC that resulted in testing	II. Among referred IDUs, % of IDUs who have been tested at least once	III. HIV prevalence among unique persons (IDUs) tested	IV. % of HIV-positive IDUs referred from TI who were registered at ART centre	V. % of eligible unique individuals initiated on ART	VI. % of persons registered at ART centres (not initiated on ART yet) regularly followed-up by IDU TIs
<b>North</b>								
Lucknow	M	254	84	73	11	85	0	0
Amritsar	M	856	71	NA	NA	100	100	13
Delhi	M	422	53	NA	NA	NA	NA	NA
<b>Northeast</b>								
Imphal (M*)	M	1536	100	57	3	100	NA	NA
Imphal (F*)	F	109	100	100	20	100	NA	67
Dimapur (M)	M	566	77	77	4	50	NA	75
Dimapur (F)	F	94	69	59	10	100	100	62
Shillong (M)	M	279	100	100	0.8	NA	NA	NA
Shillong (F)	F	63	57	40	10	100	100	62
Aizawl	M	406	100	53	13	92	NA	NA
	F	55	100	71	0	0	NA	NA
	Total	461	100	54	12	92	NA	NA
<b>East</b>								
Kolkata	M	275	81	66	6	100	66	10
Raipur	M	508	40	NA	0	100	0	0
Bhubaneswar	M	319	73	39	0	82	66	83
<b>South</b>								
Hyderabad	M	601	87	53	0	100	43	166
Calicut	M	536	73	57	0	0	NA	NA
<b>West</b>								
Mumbai	M	517	92	NA	NA	100	100	0
	F	16	100	NA	NA	NA	NA	0
	Total	533	92	NA	NA	100	100	0
Narsinghpur	M	706	47	35	0.3	100	100	0

\*TI that serves males only indicated as 'M', and that serves only females is indicated by 'F'. Some TIs serve both males and females, and are not indicated by any special notation. (NA=Data not available)

**Table 6: Data from ICTCs: Key indicators to demonstrate access to and use of HIV testing, and referral patterns (NA=Data not available)**

Sites (TI*)	Gender of IDUs	No. of IDUs (former/current) registered at ICTCs	No. of IDUs referred from local 'study TI'	XI. % of IDUs registered in ICTC belonging to study TI	XII. % of IDUs who have undergone HIV testing	XIII. HIV-positivity rate among IDUs in that ICTC	XIV. % of IDUs who know their HIV test results	XV. % of IDUs referred to ART centre
<b>North</b>								
Lucknow	M	135	135	100	99	23	98	90
Amritsar	M	261	251	96	96	8	99	100
Delhi	M	137	137	100	100	5	NA	57
<b>Northeast</b>								
Imphal (M*)	M	664	77	12	100	14	NA	100
Imphal (F*)	F	77	77	100	100	6	NA	NA
Dimapur (M)	M	390	390	100	100	3	100	100
Dimapur (F)	F	112	112	100	100	6	100	100
Shillong (M)	M	119	NA	NA	NA	NA	NA	NA
Shillong (F)	F	29	NA	NA	100	14	NA	NA
Aizawl	NA	NA	NA	NA	NA	NA	NA	NA
<b>East</b>								
Kolkata	M	89	84	NA	100	2	93	NA
Raipur	M	558	558	NA	97	1	NA	NA
Bhubaneswar	M	NA	127	NA	NA	0	NA	NA
<b>South</b>								
Hyderabad	M	20	20	NA	100	10	100	NA
Calicut	M	290	289	NA	100	0.3	83	NA
<b>West</b>								
Mumbai	M	267	121	NA	98	7	NA	NA
	F	7	1	NA	100	14	NA	NA
	Total	274	122	NA	98	8	NA	NA
Narsinghpur	M	568	NA	100	100	0.18	86	NA

\*TI that serves males only indicated as 'M', and that serves only females is indicated by 'F'. Some TIs serve both males and females, and are not indicated by any special notation.

**Table 7: Data from ART centres: Key indicators to demonstrate access to and use of ART, and referral patterns**

Sites (TI*)	Gender of IDUs	No. of IDUs (former/current) registered at ART centre	Among registered IDUs, number of IDUs who were found to be eligible for ART	Number of IDUs who were initiated on ART	XVI). % of IDUs who were initiated on ART	Number of IDUs who were lost to follow-up	How many of those IDUs lost to follow-up were referred by IDU TIs	Number of referrals of HIV – positive IDUs from ART centre to IDU TIs
<b>North</b>								
Lucknow	M	17	NA	NA	NA	5	5	0
Amritsar	M	NA	NA	NA	NA	NA	NA	
Delhi	M	NA	1	1	100	1	1	0
<b>Northeast</b>								
Imphal (M*)	M	143	93	93	100	NA	NA	NA
Imphal (F*)	F	3	3	3	100	NA	NA	NA
Dimapur (M)	M	37	23	22	96	5	NA	NA
Dimapur (F)	F	3	1	1	100	1	NA	NA
Shillong (M)	M	14	8	5	96	1	NA	2
Shillong (F)	F	4	4	2	50	1	1	0
Aizawl	M	11	11	11	100	1	NA	NA
<b>East</b>								
Kolkata	M	12	12	12	100	NA	NA	NA
Raipur	M	2	2	2	100	0	NA	NA
Bhubaneswar	M	32	6	6	NA	0	NA	NA
<b>South</b>								
Hyderabad	M	4	0	0	NA	NA	NA	NA
Calicut	M	2	0	0	NA	NA	NA	NA
<b>West</b>								
Mumbai	M	10	4	3	75	1	27	0
Narsinghpur	M	2	0	0	NA	0	0	2

**Table 8: Illustrative quotes: Barriers and facilitators to HIV testing**

Individual-level barriers	
Fear of being tested HIV-positive	<p>[IDUs] who come first time for the [HIV] testing are afraid of being detected reactive. We feel helpless at times. (IDU peer educator, FGD)</p> <p>We are always afraid of getting tested. We are scared what if our test result is [positive]? And if it is positive, we are worried that then there will be a lot of restrictions on food and our life style. (IDU, FGD)</p>
Fear of disclosure of HIV-positive status or drug use behaviour	<p>There is also a problem that people from the locality are there at times at the ICTC centre as its in a hospital premises and if the IDU is also from the same locality, they don't want to go there as they know that they may meet some of their family and friends and they may think or various questions may arise in their mind as to why this person has come to the ICTC centre? Does he have AIDS? Does he take drugs? And this is also a reason why the clients don't want to go to the nearby ICTC centre. At times, we send them to the other ICTC centre which is far off and not in this locality. (ORW)</p> <p>The biggest of all challenges in attending the Government ICTC is the apprehensions about status being disclosed and fear of being seen by any relative while at the hospital as it might end up disclosing their drug abuse status also. (ICTC counsellor)</p>
Active drug use	<p>[IDUs] always take drugs and postpone their visits to the ICTC centre as they are interested more in drugs than anything else. Another factor is money, if they have less money and have to come in auto for ICTC, they would prefer buying drugs with that money rather using it for auto. (ICTC counsellor)</p> <p>IDUs always want to lead an isolated life and they don't want to visit hospital for any tests. They constantly want to be under the influence of drugs. That is the main issue for getting tested. (ORW)</p>
Distance and need for travel money	<p>[ICTC] centre is very far away from the city and we do not have money to travel. (IDU, FGD)</p> <p>Some IDUs stay far away from the city. And, we have to pay Rs. 20 each for their travel and food every time they go to ICTC centre. IDUs who live nearby, come on their own to ICTC. (ORW)</p> <p>If TIs provide travel support to IDUs, referrals to HIV testing will improve. (PM)</p>
Waiting time and withdrawal symptoms	<p>IDUs do not like to wait for long hours to get tested. This is the major issue that we face while referring female IDUs to ICTC. They are always in hurry. Similarly, most of the time they go away before getting the results. (ORW)</p> <p>As most of the time they need their dose of drugs, they are restless and they can't wait (ICTC counsellor)</p> <p>One needs to assess the condition of patients and find out how long they can wait. They need to give us some painkiller if we are in pain and also provide some food as we feel very hungry and also provide us some monetary help to boost our morale (IDU, FGD)</p>
Health-care system level barriers	
Negative experience with health care providers	<p>I was asked to draw blood by myself by [lab technician]. He passed a snide remark: "Being an IDU you must be an expert in injecting." (IDU, FGD)</p> <p>Without finding proper vein, they injected many times. When I complained, they commented, "Being an IDU you should not feel pain." (Female IDU, FGD)</p>

<b>Perceived lack of satisfactory post-test counselling</b>	<p>I did not receive any counselling after getting [HIV testing] results. [ICTC counsellor] just took information and filled-in some forms. (Female IDU, FGD)</p> <p>[ICTC counsellors] should do intensive counselling for IDU clients. It is hard for them to counsel a person for more than 10 minutes. Counselling should not be 'time-based'; it should be need-based. (ORW)</p>
<b>Lack of privacy and confidentiality (counselling room)</b>	<p>Blood is drawn in the same place where counselling is done. Further, in the same place other staff members hang around. At the time of counselling, [IDU] clients cannot openly tell their problems. (TI counsellor)</p> <p>Counselling room is very small. Also, partitions of the room are thin. We believe others can overhear us and confidentiality cannot be maintained. (IDU, FGD)</p> <p>More than the services, the infrastructure and location of the ICTC ought to be looked into. Spacious waiting room (as the clients have to wait for counselling) is necessary. Counselling room should be soundproof so that confidentiality can be maintained. (TI counsellor)</p>
<b>Delay in the process (of getting tested and collecting HIV testing results)</b>	<p>After waiting for a long time, I got my test result. The counsellor told me to get my cough test done and gave me a bottle and then the next day I went to give the cough. But, till date, I have not got my test result. (IDU, FGD)</p> <p>I went to ICTC centre with a group of IDUs. We waited for a long time as the staff did not turn on time. We were all very tired after waiting for long time. As soon they came, without any proper counselling blood was drawn quickly. (IDU, FGD)</p>
<b>ICTC working hours – inconvenient</b>	<p>The timings are a major problem. The [hospital] follows very strict timings. They do not take sample after 11.30 [am] and they send the clients back. But in another ICTC no such problem is encountered. They entertain the clients even after lunch time. (IDU, FGD)</p> <p>The timings for ICTC centre is written as 9.30 am – 2 pm. But ICTC was not open after 1 p.m. Even yesterday we went to ICTC around 1'o clock, but the staff told that time for testing was over. (Female IDU, FGD)</p> <p>Though the ICTC timing is from 10 am to 4 or 5 pm, the staff do not come before 11 am and won't attend any client after 2 pm. It is quite challenging to convince the clients to go for blood test. (TI counsellor)</p>
<b>Interruption in availability of HIV testing kits</b>	<p>At times the centre does not have testing kits and the clients have to return back without getting tested. (TI counsellor)</p> <p>There is always a shortage of kits and we have to go back without getting tested. Once a client goes back without getting tested it's very difficult to bring him the next time. (IDU, FGD)</p>
<b>Same-day test results</b>	<p>We take extra pain to get the testing done and to give the report on the same day. (ICTC counsellor)</p>
<b>Accompanied referrals and support for travel expenses</b>	<p>At times, we get travel allowance to go to ICTC and if someone is very sick, then one person from the TI accompanies us. (IDU, FGD)</p> <p>Even if [peer educator] accompanies, in the mid-way they tell the PE that I will be back in a moment after having paan (betel) or I just have to go and meet my family and come back and then they don't come back. They just want to take drugs and they flee away to get themselves injected in case they have withdrawal. (ORW)</p>
<b>Structural level barriers</b>	
<b>Stigma related to drug use and sex work (female IDUs)</b>	<p>Most female IDUs also engage in sex work. So they face stigma in the society. Also, family disowns them out of fear of society. As a result, they are more sensitive to other people's view and attitude. So they hardly accept to come to the ICTC for HIV testing. (ICTC counsellor)</p>



## B. Barriers to and Facilitators for HIV Testing

Several barriers to HIV testing were identified at the structural and policy level, health care system level, and the individual level. (See Table 9 for themes and Table 8 for illustrative quotes)

### Individual level barriers

#### *Active injecting drug use*

Peer educators and ORWs reported that the first thing many IDUs do is to have a ‘fix’ in the morning and when they approach them at that time to go for HIV testing, they tend to ignore them. Also, when they are ‘high’, ORWs too are reluctant to accompany them to ICTCs because they feel IDUs may pose problems to others in ICTCs. And once in ICTC, IDUs who have consumed or injected drugs in the morning do not want to wait for a long time (to avoid experiencing withdrawal symptoms or they want to leave to earn for the day) and want to be attended immediately by counsellors. Drug dependence is thus considered by stakeholders to be a major barrier to HIV testing for IDUs. IDUs who are already tested HIV-negative do not see the need to undergo testing after 6 months as they have ‘already been tested’. For repeat testing, IDUs demand money or ‘fix’ from the TI staff as a ‘bribe’ to come for testing.

#### *Distance and travel expenses*

IDUs in some sites (Amritsar, Lucknow, Raipur, and Narsinghpur) reported ICTCs being located in distant places and they found it difficult to go on their own and to pay for the travel expenses. They expected IDU TI to provide them travel expenses and many reported that they preferred ORW or PE to accompany them since it quickens the procedures.

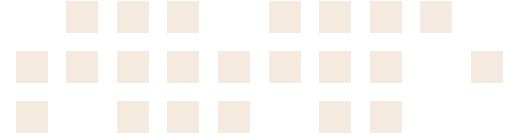
#### *Fear of adverse social and familial consequences*

Participants also had fears about being tested HIV-positive and thus being rejected by family members, friends, and peers. Moreover, they were also afraid that others might find out that they engage in stigmatized behaviours such as drug use or sex work (female IDUs). These fears prevent or at least delay some participants from getting tested. TI staff shared incidents of IDUs who get tested, but then do not want to collect their test result.

### Health care system level barriers

#### *Lack of cultural competence among HIV testing centre (ICTC) staff and health care providers*

Experiences with ICTC counsellors were mixed. Although some positive experiences were reported, participants across several sites shared examples about how they themselves or peers were discriminated against, and treated poorly by ICTC counsellors and other government hospital staff. Such negative experiences, either direct or indirect, act as a strong deterrent for some IDUs to seek testing services from these centres, and not wanting



to come for repeat testing. Positive experiences in these testing centres were generally described as because of good rapport developed by IDU TI staff with the ICTC staff. Some felt that ICTC counsellors lack cultural competency in working with IDUs. While some male IDUs were comfortable with discussing with female ICTC counsellor, some other male IDUs reported that they could not share HIV-related risk behaviours, especially sexual risk, with female counsellors.

### ***Opening hours and registration procedures***

Accessibility of HIV services in terms of time was seen a major issue. In most sites, HIV testing services are not available after noon, but IDUs come only around that time or prefer coming later. Female IDUs who engage in sex work and who work at night find the current hours of operation inconvenient, especially if they have children for whom they need to find someone to babysit.

Participants also reported that registration procedures were bureaucratic and intimidating to individuals seeking testing for the first time. Long queues and waiting time for undergoing counselling and testing were other concerns of IDUs. In addition to being unresponsive to the needs of IDUs, these experiences caused embarrassment, and feelings of stigmatization, and discouraged individuals from seeking testing, receiving test results and/or returning for testing (which is usually recommended at least every 6 months).

## **Structural and policy level barriers**

### ***Stigma***

HIV-related stigma and the stigma related to being a drug user or sex worker (female IDUs) were overarching barriers to HIV testing. Participants thought that being diagnosed HIV-positive would mean discrimination, which generally lead individuals to question the merits of HIV testing. This contributed to apprehensions about HIV testing. Participants were concerned about them being recognized while entering or leaving a HIV testing centre, which could mean that others will assume their involvement in risk behaviours or their drug using peers suspecting that they might be HIV-positive. Stigma was reported as a barrier in several sites but more so in Amritsar, Kolkata and Dimapur.

### ***Lack of availability of rapid HIV tests at the field level***

Participants suggested that having rapid HIV tests at the field level would greatly increase the acceptance for HIV testing especially for repeat HIV testing, but the project staff expressed apprehension about the challenges that it might pose in terms of providing counselling and ensuring confidentiality. Some participants suggested considering mobile vans (similar to 'Mitwa [friends] vans' in Delhi) that can be used for collecting blood for HIV test and providing counselling.



## Facilitators of uptake of HIV testing and ART

### ***NGOs: Outreach efforts and support services***

NGOs that implement TIs among IDUs have a pivotal role in encouraging IDUs to seek out testing services, which were described as highly beneficial in increasing HIV testing uptake. In most cases, services include ORWs accompanying clients to HIV testing sites and sometimes even covering transportation costs (in spite of lack of budget for the same in the 'TI budget' of SACS/NACO). The general perception was that peer ORWs were trusted to keep clients' HIV status confidential, which encouraged clients to undergo HIV testing. These comprehensive services, particularly the one-on-one approach, were considered to be strong motivators of HIV testing uptake.

### ***IDUs: Drug treatment, recovery and support***

Participants highlighted how many former drug users became concerned about their health and wanted to know their HIV status after they entered recovery from their drug dependency. Participants reported that after drug treatment – either on OST or de-addiction treatment, individuals could prioritize their own health and that of their sexual partners and former drug-sharing partners.

### ***Accurate knowledge about HIV testing and treatment options***

Even though not explicitly stated in many sites, accurate knowledge about HIV was generally seen to facilitate testing uptake (and getting enrolled in ART centre). In general, across several sites, research team found that participants had reasonably good knowledge about HIV transmission, testing services, and treatment options. Participants were appreciative of the important role of outreach workers in promoting HIV testing (and ART uptake).

**Table 9: Barriers to HIV testing access (first-time and repeat testing):  
Themes identified in study sites**

Barriers	North		Northeast				East			South			West	
	LUC	AMR	DEL	IMP	DIM	SIL	AIZ	KOL	RAI	BHU	HYD	CAL	MUM	NAR
<b>Individual-level barriers</b>														
Fear of being tested HIV-positive		+			+			+						
Fear of disclosure of drug use behaviour			+			+	+		+					
Fear of disclosure of HIV-positive status		+	+	+			+							
Active drug use	+									+			+	+
Distance and need for travel money	+	+				+			+	+		+		+
<b>Health-care system level barriers</b>														
Negative experience with health care providers				+		+		+	+		+	+	+	
Perceived lack of satisfactory post-test counselling				+		+								+
Lack of privacy and confidentiality (counselling room)	+			+	+		+	+	+	+		+		+
Delay in process (for getting tested and collecting HIV testing results)			+	+				+	+			+	+	+
ICTC working hours - inconvenient		+	+	+	+		+	+	+				+	+
Interruption in availability of HIV testing kits						+			+				+	+
<b>Structural and policy barriers</b>														
Stigma related to drug use and sex work (female IDUs)	+	+	+	+	+	+	+	+	+	+	+	+	+	+
LUC = Lucknow; AMR = Amritsar; DEL = Delhi; IMP = Imphal; SIL = Shillong; AIZ = Aizawl; RAI = Raipur; BHU = Bhubaneswar; HYD = Hyderabad; CAL = Calicut; MUM = Mumbai; and NAR = Narsinghpur														

**Table 10: Barriers to ART access and adherence among IDUs:  
Themes identified in study sites**

Barriers	North		Northeast				East			South			West	
	LUC	AMR	DEL	IMP	DIM	SIL	AIZ	KOL	RAI	BHU	HYD	CAL	MUM	NAR
<b>Individual-level barriers</b>														
Active drug use	+	+		+	+		+				+	+		
Fear of disclosure of positive HIV status						+	+							
Fear of side-effects							+		+	+	+	+		
Lack of self-esteem				+						+		+		
Insufficient and incorrect knowledge about ART	+	+		+	+		+				+	+		
Poverty Homelessness			+					+					+	
Distance and travel costs		+	+		+									
‘Mobile’ nature			+	+			+							
<b>Health-care system level barriers</b>														
Stringent registration procedures (address proof)	+	+	+	+			+	+	+	+	+	+	+	+
Negative experiences with health care providers	+			+	+	+	+	+	+		+		+	
Long waiting time	+	+		+			+	+		+	+			
Privacy and confidentiality issues (counselling room)				+					+		+			
<b>Structural barriers</b>														
Stigma related to HIV, drug use & sex work (female IDUs)	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Lack of family support	+	+				+	+	+	+	+			+	+
LUC = Lucknow; AMR = Amritsar; DEL = Delhi; IMP = Imphal; SIL = Shillong; AIZ = Aizawl; RAI = Raipur; BHU = Bhubaneswar; HYD = Hyderabad; CAL = Calicut; MUM = Mumbai; and NAR = Narsinghpur														

**Table 11: Illustrative quotes: Barriers and facilitators to ART initiation and adherence**

Individual-level barriers	
Active drug use	<p>IDUs always want things in an instant. They want instant pain relief. They don't understand the concept of ART much but [NGO] and their ORWs do a lot of follow up. I have also heard that they demand money to come to ART centre. Their primary aim is to secure drugs - not ART. <b>(Doctor, ART centre)</b></p> <p>IDUs always want to lead an isolated life and they don't want to go to a doctor for any tests and they constantly want to be under the influence of drugs and that is their main concern. <b>(ORW)</b></p> <p>Most IDUs are quite weak and have very low stamina due to daily drug use. They are not in position to visit the centre periodically. They visit only when their condition deteriorates. <b>(IDU, FGD)</b></p>
Fear of disclosure of positive HIV status	Some of the IDU say that if they take the medicine, then their family will get to know of their status and further, there is one medicine where on the cover, it is written 'HIV' and that if anyone sees, will figure out that it's a HIV medicine and those are the issues faced by IDUs <b>(ART counsellor)</b>
Fear of side-effects	Many HIV-positive IDUs afraid to start ART medicines due to their perception about side effects of ART medicine. <b>(IDU, FGD)</b>
Fatalism and Lack of self-esteem	HIV-positive IDUs clients are generally not feeling any meaning in life and they are not interested in treatment. Most HIV-positive IDUs clients suffer from low self-esteem. <b>(OST counsellor)</b>
Insufficient and incorrect knowledge about ART	First of all, it is really difficult for us to understand when one person is started on the medicine and not the other - when we both have HIV. Secondly, if we are not started on ART, why we are required to turn up on a regular basis. If you really care for us, we should be started with the medicine. <b>(HIV-positive IDU, FGD)</b>
Poverty – Homelessness and Hunger	<p>Some HIV positive IDUs do not even take all three meals in a day. Without proper food the whole effort of accessing ART medicine becomes meaningless. <b>(IDU, FGD)</b></p> <p>Some HIV positive IDUs live in streets. And they use public toilets for bathing. In this case, there is a possibility that the ART medicine might get spoiled or lost. <b>(IDU, FGD)</b></p>
Distance and travel costs	<p>Conveyance is a big issue with them. They always say that they do not have money to visit ART centre. <b>(TI counsellor)</b></p> <p>Distance is a real problem. [ART centre] is very far away from the city. The clients feel depressed after a long travel. <b>(TI PM)</b></p>
'Mobile' nature	Follow-up is one big challenge that we face while working with IDUs not only in the case of ART. They are very mobile in nature and only depend on their 'drugs'. <b>(TI counsellor)</b>
Health-care system level barriers	
Accompanied referrals to ART centre	<p>When an IDU is found [HIV] positive he is referred to the ART centre from the ICTC directly. But very few of us go by themselves. We usually return back home after hearing the news. And it is when the NGO comes to know about the result from the centre, they try to track us and register us at the ART centre. We [IDUs] don't have the tendency to go ourselves and get registered at the ART centre. We are very much dependent upon the NGO. <b>(IDU, FGD)</b></p> <p>It is really difficult to motivate the IDUs to go for ART. Need to counsel them several times before they give consent to go for the ART. They never go alone; even if the family member accompanies them they still want us to come. Also, the registration process is very lengthy and takes at least 2 days to complete the process. <b>(ORW)</b></p>



## C. Barriers to and Facilitators for ART Access and Adherence

Several barriers as well as facilitators to ART access and adherence were discussed by both the IDUs as well as stakeholders including health care providers. Various themes identified across the sites are summarised in Table 10. (Also see Table 11 for illustrative quotes)

### Individual level barriers

#### *Fear of adverse consequences of disclosure of HIV status*

In several sites, most IDU participants reported being afraid of negative consequences of disclosure of their HIV-positive status. These include: rejection by spouse, family, and friends (including other drug users); and eviction from home. For female IDUs who engage in sex work, revealing their HIV-positive status will then affect their livelihood as they would not get clients.

#### *Poverty and homelessness*

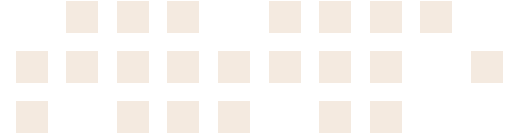
Most IDU clients served by IDU TIs in places such as Delhi are rag-pickers and/or homeless, and thus have problems meeting their daily basic needs. Even though some IDUs may be from middle-class or well-to-do families, often they do not have a job of their own and hence are dependent on others for their daily needs. There is also reluctance among some poor and homeless IDUs to be initiated on ART because they believe that one needs to have nutritious food if they are to be on ART. For some IDUs who have a history of arrest or imprisonment, getting a job becomes a problem and in turn they remain poor irrespective of their educational qualification – as seen in Northeastern study sites.

#### *Insufficient and incorrect knowledge about ART*

IDUs, in general, seem to have relatively good knowledge about HIV. However, many seem to have lack of in-depth knowledge about ART, including benefits and when to initiate therapy (medical eligibility criteria for initiating ART). In some places, IDUs could not understand why some are initiated on ART and some are not – which they see as discrimination. Some IDUs are also afraid that since their liver might already be damaged by hepatitis, taking ART might further damage liver and can be fatal.

#### *Alcohol and drug use*

Alcohol and active drug use was reported explicitly as a barrier only by health care providers, even though some ex-injecting drug users (outreach workers and peer educators) alluded to it. Health care providers wanted IDUs not to consume alcohol while taking ART in order to ensure ART adherence. For IDUs who also consume alcohol, the challenge is even greater. Key informants reported that the main priority of IDUs living with HIV was obtaining drugs (to avoid painful withdrawal symptoms) and thus they are not concerned about initiating ART. Furthermore, even though health care providers did not have explicit criteria to deny ART to eligible IDUs, their emphasis on the need for HIV-positive IDUs to be on OST may at



least delay some IDUs' access to ART. One TI service provider was critical about the need for all the HIV-positive IDUs to be on OST. He argued that some of them do not get enrolled in OST and continue to inject drugs and hence they should not be part of NSP.

## Health care system level barriers

### ***Negative experiences with healthcare providers***

Across several sites, participants - both IDUs and TI staff - noted an increasing trend of relatively positive attitudes among government health care providers. However, several incidents of discrimination in some ICTCs and government ART centers were still reported. Judgmental attitudes, perceived substandard treatment, and perception of deliberate delay in attending to an IDU living with HIV were reported by some participants. Often, it is not clear whether the actual or perceived discrimination was because of HIV-positive status, drug use status, or engagement in sex work (female IDUs in sex work). A service provider reported that a doctor was mainly concerned about the lack of hygiene of homeless IDUs and hence did not properly treat them.

### ***Lack of comprehensive and adequate counseling***

Some participants thought that counseling services in ART centres have substantially improved over the years. Some expected more time and thus more details to be given to them on ART (side-effects, tips for adherence, etc.) and sexual behaviors. Some expressed concerns about lack of privacy and confidentiality in counseling, while in some sites the participants were satisfied with the infrastructure and counseling.

### ***Unfriendly administrative procedures (enrollment and admission)***

To facilitate follow-up of patients on ART, a valid proof of identity/address is required for enrollment in government ART program. Very often, those who are homeless are affected by this requirement as it prevents or delays registration. Although TIs usually vouch for the IDUs they bring to ART centres, requirement of address proof delays registration as well as ART. Some NGOs help IDUs in getting address proof signed by local councilors. In some sites, ART centres use the address of the NGOs as the address proof because those NGOs take care of follow-up of patients.

### ***Lack of access to OST (in some sites) create problems in ART adherence***

In spite of the benefits of opioid substitution treatment (OST) to help IDUs living with HIV to become 'stabilized' and eventually drug abstinent, not all sites have OST projects. Some TI sites that cater to female IDUs have OST centres located within male IDU TI premises, which pose problems for female IDUs to access OST. Key informants stressed the need for establishing and strengthening linkages among the needle/syringe programs, OST programs, and detoxification/de-addiction and rehabilitation centers to create a continuum of services.



### ***User fees for blood tests***

In some sites (such as Delhi), blood tests other than CD4 testing are charged – even in government hospitals. This means that IDUs who can not afford these costs, are reluctant to come for follow-up. Sometimes NGOs bear some expenses, in spite of the lack of any support for such expenses in the TI budget.

## **Structural level barriers**

### ***Societal and community discrimination***

Across the sites, stigma is still an important issue that prevents IDUs living with HIV from accessing services. IDUs living with HIV face double or triple stigma and discrimination due to their HIV-positive and marginalized status (drug use and sex work [female IDUs]). In addition to societal stigma, they also face discrimination even from their own peers – other drug users or female IDUs in sex work. While lack of strong linkages between NGOs implementing IDU TIs and mainstream PLHIV networks might be the reason for less referrals of HIV-positive IDUs to PLHIV networks, it is possible that fear of discrimination on the basis of drug use status (current or former) prevent IDUs living with HIV from using PLHIV network services.

### ***Lack of family support***

Most participants reported lack of family support for IDUs once they know of their drug use or HIV-positive status. Some IDUs kept their drug use or HIV status a secret and hence they could not obtain any family support which might have been available to them had they revealed it. Some IDUs are rejected by their family for being drug users and thus are homeless. Also, female IDUs living with HIV who engage in sex work often do not have any support from their own or their husband's family members.

**Table 12: Barriers to accessing and using community care centres:  
Themes identified in study sites**

Barriers	North			Northeast				East			South			West	
	LUC	AMR	DEL	IMP	DIM	SIL	AIZ	KOL	RAI	BHU	HYD	CAL	MUM	NAR	
Individual-level barriers															
Fear of disclosure of positive HIV status									+						
Active drug use (poses challenge in admission for days together)	+			+					+		+		+		
Lack of knowledge about CCC and services				+	+										
TI-level barriers															
Unwillingness to refer to CCC – as IDUs have reported negative experiences with CCC	+	+							+	+		+			
CCC-level barriers															
Lack of adequate infrastructure (beds)	+	+		+	+		+	+							
Negative experiences with health care providers in CCC				+			+								
Perceived lack of poor quality food							+		+	+					
Inadequate treatment facilities (lack of OI treatment/ medicines)					+		+		+		+				
CCC staff experienced difficulties in managing active drug users		+								+					
Structural barriers															
Lack of family support (during admission)	+	+		+	+		+			+	+		+		
LUC = Lucknow; AMR = Amritsar; DEL = Delhi; IMP = Imphal; SIL = Shillong; AIZ = Aizawl; RAI = Raipur; BHU = Bhubaneswar; HYD = Hyderabad; CAL = Calicut; MUM = Mumbai; and NAR = Narsinghpur															

**Table 13. Illustrative quotes: Barriers to using community care centre services**

<b>Individual-level</b>	
<b>Active drug use (poses challenge in admission for days together)</b>	As soon as IDUs get admitted in CCC they say, 'I could not stay here as I inject drugs twice a day, and I would need my drugs'. (CCC counsellor)
<b>Lack of knowledge about CCC</b>	In my experience I find many IDUs and their family members do not have any information or knowledge about CCC. (CCC counsellor)
<b>TI-level</b>	
<b>Unwillingness to refer to CCC (as IDUs have reported negative experiences with CCC)</b>	According to the IDUs, the food is not good and the doctor is not always available and the distance is also a major problem as it is minimum 20 kilometres and after staying there for 1 or 2 days, they come back as they tell that the food is not good and they also can't take drugs there. This is what I have heard of but I have not referred any one there. (ORW)
<b>CCC-level</b>	
<b>Negative experiences with health care providers in CCC</b>	Nurses do not treat IDUs especially female IDUs properly. They do not respond quickly even in case of emergency. And they do not want to touch them. (PM)
<b>Perceived inadequate treatment facilities</b>	On the other day CCC ran out of oxygen, and unfortunately one of the clients who needed oxygen died. (ORW)  My mom was fed up so much as they [CCC] always wanted us to buy medicines from our own money. My mother told that it was better to stay at home instead of visiting CCC. (IDU, FGD)
<b>Experiences and perceptions of CCC counsellors in having IDUs as in-patients</b>	The IDUs are a very difficult lot. They misbehave with people and the nurse if we try to control them. They smoke Cannabis and it is problematic. They act as per their free will and they tell us that we want some medicines which we cannot provide as per NACO guidelines. This is not a drug de-addiction centre... We have no idea about OST or other medical requirement of IDUs (Counsellor, CCC)  They come here and break rules like going to the paan [betel leaves] shop for cigarettes and other drugs. They also throw the food that we give them. They don't listen to us. They tell us that we don't eat this kind of food. (Counsellor, CCC)  It is difficult to admit the drug users as due to their drug habit they become very problematic at times and it becomes difficult for the staff to manage and handle them. (ORW)
<b>Structural-level</b>	
<b>Lack of family support (during admission)</b>	IDUs seeking admission in CCC were asked to bring their family members along with them for staying with them at night and none of their family members were willing. "TI PM"  Drug users themselves are not willing to go there for five days. And it is mandatory for one of the family member to stay with them at the CCC and the family member is not willing to stay. (ICTC counsellor)

## D. Barriers to and facilitators for using Community Care Centres (CCCs)

Not all the study sites had CCCs and not in all sites that have CCCs do TIs and ART centres refer IDUs living with HIV. A range of reasons for this apparent underutilisation of CCCs were offered by IDUs, TI staff and the staff of CCCs (See Table 12 for themes and Table 13 for illustrative quotes).

Staff of CCCs were of the view that there was no difference in terms of the admission process for the 'general' people living with HIV and IDUs living with HIV. However, discussion with CCC staff revealed that they were concerned about the drug use of IDUs within the CCC premises and about the temperament of IDUs who often get into brawls with co-patients and staff of CCC. While staff of CCC complained that IDUs did not want to have the food that was given in CCCs to everyone else, IDUs in FGDs complained about the bad quality of food, poor status of beds and other infrastructure. Staff of CCC acknowledged that, because of limited number of beds, sometimes they ask persons to leave within five days so that they could admit other relatively more needy persons. Staff of CCC also asked for further training on taking care of IDUs and thought visits by a counsellor from a de-addiction centre would be helpful.

In some sites, TI or ART centre staff did not want to refer IDUs to CCCs either because the distance was too far or IDUs did not want to go there after hearing about the negative experiences of other HIV-positive IDUs. Staff of CCC actually attributed the decreased number of IDU referrals to CCCs to the rumours spread by former in-patients of CCCs about the way IDUs are treated there.

### Box 1: Specific issues of female IDUs in accessing HIV testing and ART

Most of the issues of female IDUs are found to be similar to that of male IDUs. However, some of the specific issues that directly or indirectly posed barriers to uptake of HIV testing and/or ART include:

- Lack of separate OST project for female IDUs (lack of accreditation) and hence the necessity to use OST facilities that are available only in male IDU TIs
- Multiple stigmas associated with drug use, HIV-positive status, widowhood and sex work
- Harassment from police, for being a sex worker as well as drug user and extortion of money from police and local goons
- Lack of child care services or lack of supportive people who can look after their children in case of emergencies (such as overdose or serious illness)
- Unaddressed mental health issues such as depression, lack of social and emotional support and lack of mental health counselling support

In almost all sites, TI staff found it difficult to reach female IDUs. Also, in Northeast, female IDUs were observed to have comparatively less knowledge about availability of HIV-related services, and more resistant to use government services when compared with men. Service delivery statistics, in this study, however, could not find any marked difference between male and female IDUs in terms of access to and use of HIV testing and ART.



## 4. Discussion

### Referral systems and linkages

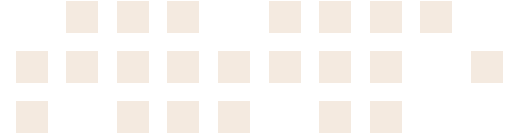
We identified that, although formal referral systems do exist between IDU TIs and ICTCs and ART centres, differences in the rapport (professional personal relationships) between TI staff and ICTC/ART staff seem to account for much of the difference between sites that were doing well and those were not. This means that, apart from having formal mechanisms (such as referral slips) active steps need to be taken to promote linkages between TI and ICTC/ART staff so that the focus is on the outcome for IDUs and not just a mechanical check of whether IDUs have passed through the system and whether testing and registration have been done or not.

A common understanding on the relative contributions of NGOs and government sector in improving the health status of IDUs and their partners/families need to be realised by the staff of both NGOs and government sector so that they also understand the need to work together as a team in spite of the sectoral differences and having different authorities to report to. Putting the onus of bringing IDUs to ICTC/ART centre and following them up for repeat testing and ART adherence on only the NGOs mean that government sector does not own its share of responsibility in improving access and continued use of the HIV testing and ART facilities. For example, government hospitals can avoid discrimination and negative attitude towards IDUs and improve efficiency of procedures (registration and initiation of treatment) and referrals of newly identified IDUs to IDU TIs (i.e., reverse referrals).

Experience shows that providing referral slips alone to the IDUs often do not result in IDUs going to HIV testing or getting registered in ART centre. Almost always accompanied referrals – where ORWs or peer educators accompany active IDUs – are required. While this creates a dilemma of whether NGOs are actually making the IDUs to be entirely dependent on them, the lack of support for IDUs from families or friends, and lack of self-dependency (job or income) mean that this dependency of at least active injecting drug users seem unavoidable. In the long term, however, active drug users can be connected to drug dependence treatment and both active and former users can be linked to employment and income generation schemes.

### Barriers at different levels

Among current users, a key issue is active drug use itself which creates a major barrier to access HIV testing and ART. Active users require a ‘fix’ almost on a daily basis – often the first thing in the morning without which they develop withdrawal symptoms. Also, to meet their daily drug needs, they need to work on a daily basis (e.g., rag picking in Delhi). In such a scenario, ORWs and peer educators have great difficulty in convincing them to come for HIV testing or to get registered in ART centre. Because IDUs may be in an intoxicated state (drug or alcohol) when they come to ICTC or ART, IDUs expect the process to get over quickly as the more the time they spend in ICTC or ART centre, the chances of experiencing withdrawal symptoms are high and also they could not earn for the day. Consequently, IDUs



may want to be given priority in getting tested or getting medications, and may get into brawl with co-patients, TI staff or the staff in the ICTC or ART centre. The issue is similar for female IDUs who are in sex work (whether they are current injectors or not). Thus, the problems related to waiting time, operating hours, and reactive negative attitude of staff are also from the active drug use of IDUs – which needs priority attention in the form of linking them with drug dependence treatment – either in OST or in other drug de-addiction programs.

The operational issues in ICTC and ART centres in relation to the waiting time, counselling duration, infrastructure that ensure privacy and confidentiality, and staff attitude and interactions with IDUs all are important for service acceptability<sup>d</sup> (or client satisfaction) as well as for making them to come back and regularly use the services (whether it is HIV testing or ART adherence and follow-up visits after registration in ART centre). Hence, taking steps to decrease the waiting time by having adequate staff, ensuring adequate infrastructure and dealing in a professional non-judgemental manner with IDUs – all are important to improve service acceptability or client satisfaction.

Sometimes the locations of ICTC and ART centres may not match the location of drug using sites or concentration of IDUs in a city. Hence, distance and travel become issues for many IDUs who often can not afford travel cost. In such scenarios, the possibility of supporting or subsidising travel-related costs of at least HIV-positive IDUs can be considered.

While sensitization programs by TIs with police have to some extent decreased police harassment of IDUs and outreach workers, it is still a reality in some sites because of a variety of reasons (change in police force, and IDUs stealing goods and selling drugs, etc.). Some IDUs who are taken in police detention or imprisoned can not continue their OST or ART. Such interruptions in treatment can be solved only if there are concrete guidelines for ensuring uninterrupted treatment (OST or ART) for IDUs in detention or prisons.

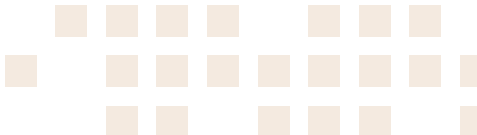
## Facilitators of service uptake

IDU TIs in certain sites have established good relationships with the ICTC and ART centres, which could account for the relative lack of complaints from IDUs and TI staff about the staff attitude and efficiency of procedures in ICTC and ART centres. Including TI staff in the sensitisation and training of ICTC and ART centre staff is claimed to have contributed to this good relationship, apart from the professional relationship developed between the staff of TIs and ICTC/ART centres over time, by implanting the common concern that they work as a team for IDUs' health.

Once such a rapport is developed between NGOs and government centres, then the government staff can ensure that IDUs (and other at-risk groups) when they come to ICTC or ART centre, are given priority as they now understand the mind set of IDUs and do not

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<sup>d</sup> Service 'acceptability' was identified by measures such as clients' return or follow-up rate (in the quantitative component); and perceived friendliness of and/or ease of communication with staff (qualitative component).



want to lose them by keeping them waiting for more than what is necessary because of the work load. Also, by seeing NGOs as partners in ensuring the follow-up of IDUs on ART and as a guardian for IDUs, ART staff can register even those IDUs who otherwise do not have any address/identity proof (e.g., rag pickers).

Former injectors (not currently injecting drugs) and those on OST are seen more capable of understanding the need for HIV testing and registration/follow-up at ART centres, and hence both TI staff and health care providers at ART centres should insist that IDUs be enrolled in OST. For facilitation of easy access to syringes/needles, some TIs have appointed 'secondary distributors' (e.g., small-shop owners, road-side vendors, etc.) so that IDUs – including HIV-positive IDUs – can get uninterrupted supply of needles/syringes whenever they need.

## **Challenges in availability of crucial service delivery statistics that will help in monitoring service uptake**

### **(HIV testing and ART uptake and follow-up)**

In general, from the IDU TIs, data related to HIV testing referrals (and the number of persons who have undergone testing) of IDU clients are more readily available compared with data about HIV-positive IDUs in relation to registration, ART eligibility, initiation of ART, and follow-up of ART. Lack of proper mechanisms for documenting these details, especially in sites that have relatively new TIs, could explain this observation. No perceptible differences could be found between HIV and low HIV prevalence sites in terms of issues related to access and use of HIV testing and ART services – except for the qualitative information that TIs with long experience in high HIV prevalence sites are more likely to have built good rapport with government service providers (ICTCs and ART centres). This rapport could account for the marginally better uptake of services by IDUs in the HIV high prevalence sites.

Certain types of data which were not easily available are mentioned below – centre-wise.

### **In IDU TIs**

Not in all TIs, the following data were available (In some sites, data were found to be discrepant and incomplete):

- Number of unique persons (unknown HIV status) who have been tested at least once
- Number of unique HIV-negative persons who have been tested twice last year (Note: Bi-annual voluntary HIV testing is recommended by NACO)
- Number of HIV-positive IDUs referred by TI who were registered at ART centres
- Number of HIV-positive individuals who were found to be eligible for ART (last year) and among those, the number of persons who were initiated on ART (last year)
- Number of HIV-positive IDUs on NSP and whether TI meets those persons' daily needs of clean needles/syringes



## In ICTCs

Not all required data about registration and testing of IDUs were available from ICTCs. For example, data on the number of IDUs registered (in the last year) were not available in two ICTCs; and data on the number of IDUs referred from TIs working with IDUs were not readily available in four ICTCs.

Possible key reasons for this apparent discrepancy in the number of referrals made and the number of tests done include:

- Accompanied referrals (by peer educators or ORWs) are often necessary and hence persons who are given referral slips often do not visit ICTCs. Travel costs are often high
- As already mentioned, while they wait in ICTCs, active IDUs lose patience since they develop drug withdrawal symptoms and hence some decide to leave without getting tested.

## In ART centres

Data related to number of IDUs who are eligible for ART and the time period within which they are initiated on ART; and number of IDUs who are in 'pre-ART' phase and who are regularly followed-up – were not readily available in ART centres.

(Note: It is possible that ICTC and ART centre staff were concerned about providing some of the requested data as they would not want their centre to be seen in a bad light<sup>e</sup>. Also, the research consultants who collected the data from ICTCs and ART centres mostly relied on the self-report of the staff they interviewed rather than directly double-checking the data from the records)

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<sup>e</sup> This was in spite of the assurance that the data collection from ICTCs and ART centres were part of formative research and not for evaluating their performance.



## 5. Recommendations

### A. Common recommendations for HIV testing and treatment services (ICTCs, ART centres and CCCs)

#### Sensitisation and training of health care providers

Anticipated and actual discrimination by IDUs (former or current) from health care providers prevent people from accessing HIV testing or ART. Even if IDUs had used that service previously, negative experiences prevent them from coming back to collect test results and to come for repeat testing, or to be regular in follow-up when they are on ART. Hence it is crucial that health care providers need to be sensitised on the issues faced by injecting drug users (males and females, including those who engage in sex work) and trained to provide competent clinical and counselling services for these populations.

#### Financial support for travel costs to visit ICTCs and ART centres

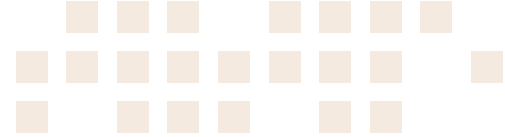
Majority of the IDUs reached through TIs are from lower socioeconomic class, and a considerable proportion are unemployed and are reluctant to go to hospitals on their own even if referral slips are given to them. Accompanied referrals have been known to increase HIV testing uptake or registration in ART centres and follow-up visits. Thus, support for the travel costs of IDUs and the accompanying TI staff (outreach worker or peer educator) to visit/accompany ICTCs or ART centres is needed in the TI budget or through other means (e.g., through ICTCs or ART centres).

#### Provide training to health care providers to address psychological and other individual level barriers to HIV testing or ART initiation

Psychological barriers such as lack of self-efficacy in drug adherence, fear of side-effects and fatalism prevent some IDUs from initiating ART. Similarly, factors such as fear of being tested HIV positive, and fear of adverse consequences such as family or partner rejection prevent some IDUs from getting tested for HIV. Hence outreach workers, counsellors and doctors need be trained to be competent in eliciting and providing tailored counselling to address various psychological barriers to initiating ART or getting tested for HIV.

#### Strengthen linkages and referral mechanisms across various service providers

Some broad guidelines for IDU TIs on referrals exist but often there are no reverse referrals from government centres (ICTC or ART centres) to IDU TIs as it is unclear when and where to refer. Detailed guidelines need to be developed for IDU TI, ICTC, and ART centres – on when and how to refer IDUs from one service to another service e.g. when to enrol an HIV-positive IDU in OST; or when to refer an HIV-positive IDU to CCC rather than to a government



hospital. Also, to ensure continuum of care for negative and HIV-positive IDUs across the HIV-related service pathways, mechanisms (e.g., meetings, cross-referral slips) need to be strengthened for better coordination among the various service providers (HIV testing; OST; ART registration, initiation and follow-up; linking with PLHIV networks).

### **Strengthen routine service delivery data collection and documentation systems at IDU TI, ICTCs and ART centres to help monitoring and improving service performance**

Even though, in general, adequate and reliable data on service uptake were available from most study sites, not all necessary data are available in some sites to assess optimal use of referrals, gap between referrals and registration, and follow-up of ‘pre-ART’ and ‘on ART’ IDUs and from the IDU TIs. Hence, it is crucial to strengthen routine service delivery data collection and documentation at IDU TIs, ICTCs and ART centres – to help in monitoring whether recommended processes (e.g., 100% of HIV-positive IDUs identified in ICTCs are referred to ART centres) are followed and to help in improving service performance.

## **B. Recommendations to remove barriers to accessing and using HIV testing (first time and repeat testing)**

### **Creating a positive and welcoming image of government ICTC centres, and ensuring privacy and confidentiality**

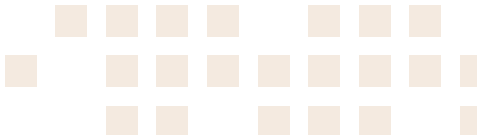
Ensuring privacy and confidentiality during counselling (e.g., in private rooms where counselling process is not interrupted by others) would greatly help in improving the effectiveness of the risk reduction counselling and in increasing the chances of uptake of first-time or repeat HIV testing among IDUs.

### **Expediting HIV testing process for core populations including IDUs**

To avoid problems due to withdrawal symptoms experienced by active IDUs when they wait for HIV testing and counselling, fixing a particular day and/or time for IDUs alone can be considered. One can consider giving priority to key populations being brought by TI staff to ICTCs, so that the waiting time is reduced. The possibility of providing results on the same day – as practiced in some centres – needs to be strongly considered.

### **Introducing rapid, non-invasive (non-blood) or dried blood spot tests at the field or drop-in centre level**

Having a rapid, non-invasive HIV test (such as saliva or urine) needs to be considered as it can then be done at the field level without the need to worry about the distance, time, and travel costs. However, adequate pre- and post-test counselling should then be ensured. The



national working group for IDU TIs of NACP-IV too have suggested rapid tests such as dried blood spot (DBS), which can be considered as it does not require any special specimen-transport requirement.

## Introducing mobile HIV testing and counselling units

Some sites have successful experiences of having mobile ICTC units. Where there are high concentrations of core populations including IDUs, a mobile unit can visit the field or drop-in centres at regular intervals to collect blood and provide proper pre- and post-test counselling.

## C. Recommendations to remove barriers to ART access and adherence

### Relax stringent requirements for address proof that prevent or delay initiation of ART

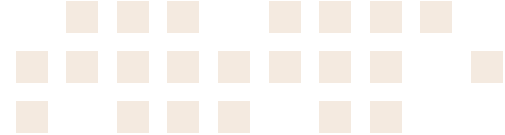
In some sites, many IDUs living with HIV are homeless or do not want to reveal their real address for fear of disclosure. While an address proof is required for follow-up, lack of appropriate address proof should not pose barrier to needy persons from receiving ART. If NGOs working with IDUs or PLHIV networks are willing to take responsibility of follow-up of those persons then as an interim measure, addresses of those agencies can be used to follow-up IDUs living with HIV.

### Consider using mobile phone text messages to remind people about follow-up appointments for HIV testing or follow-up in ART centres

Not all IDUs may have mobile phones. However, after getting the permission of IDUs to send health-related messages to their (or their friend's) mobile phones, reminders can be sent to them regarding next appointment for HIV testing or follow-up visits to ART centres. Mobile phone reminder calls have already been in vogue in several sites – both in IDU TIs and in ART centres. Considering an outreach team from ART centre for follow-up of people living with HIV (including IDUs) can also be pilot-tested.

### Address active drug and alcohol use among IDUs living with HIV

Active drug use and alcohol use poses direct and indirect risks for HIV transmission and acquisition. IDUs living with HIV and who are currently drug dependent need to be linked with needle/syringe programs or drug dependence treatment such as OST. Even though ideally all HIV-positive IDUs be enrolled in OST program to help them in 'stabilising' and ensuring proper follow-up and adherence, not all active IDUs living with HIV can be immediately enrolled in OST and thus require access to clean needles/syringes until then. As heavy alcohol consumption damages liver, current alcohol use among IDUs living with HIV (former or current) should be actively screened and linked with alcohol dependence treatment.



## Provide comprehensive ART education to IDUs living with HIV to facilitate ART uptake and adherence

Provide and reinforce HIV treatment messages to HIV-positive IDUs in different forms and avenues (pamphlets and posters in local languages in drop-in centres and ART centres); and through different providers (peers, outreach workers, doctors, and counsellors).

## Educate all IDUs about ART (irrespective of HIV status and CD4 count)

Treatment messages should not be restricted only to those who are known to be HIV-positive. Giving ART-related treatment messages to all (irrespective of their HIV status) helps diffusion of this information among the IDU community and avoids labelling people who receive treatment messages from outreach workers as being HIV infected.

# Appendices

## Appendix 1: Data Extraction Forms to Calculate the Need/Use Gap (Service Delivery Statistics)

### Appendix 1.1: Service use data collection from the 'Study IDU TI'

	Name of the TI: _____		
	Address: _____		
	Males	Females	Total
<b>A. Target and Registration</b>			
A1. Total number of IDUs to be registered in the TI (Target)			
A2. Total (cumulative) number of IDUs registered in the TI in the past year (April 1, 2011 – March 31, 2012)			
<b>1. Referrals to ICTCs in the past year (April 1, 2011 – March 31, 2012)</b>			
1a. Total no. of referrals made by the TI to ICTCs (any ICTC)			
1b. Total No. of tests done at ICTCs (any ICTC)			
1c. No. of unique persons who have been tested at least once			
1d. No. of unique individuals found to be HIV-positive			
<b>2. Referrals to ART centre in the past year (April 1, 2011 – March 31, 2012)</b>			
2a. No. of referrals made from the TI to ART centres			
2b. No. of people registered at ART centres			
2c. No. of HIV-positive IDUs who were found to be eligible for initiation of ART (CD4 count, presence of particular OIs, etc.)			
2c. No. of unique individuals initiated on ART			
2d. No. of registered persons (not initiated on ART yet) who were “regularly followed-up” at ART centres (e.g., visits ART centre every 3 or 6 months as the case maybe)			
<b>3. OST</b>			
3a. Total No. of persons registered for OST in the past year			
3b. No. of persons who were on OST in the last month of the fiscal year			
3c. No. of HIV-positive persons on OST			

3d. No. of HIV-positive persons on ART and OST			
<b>4. NSEP</b>			
4a. No. of unique persons reached through NSEP in the past month			
4b. No. of unique HIV-positive IDUs reached through NSEP in the past month			
<b>5. CCC</b>			
5a. No. of persons referred to CCC			
5b. No. of persons registered at CCC			
<b>6. PLHIV networks</b>			
6a. No. of persons referred to PLHIV networks			
5b. No. of persons registered at PLHIV networks			

**Appendix 1.2: Data collection from the ICTC  
(to where the 'study TI site' mostly refer clients)**

(Number of unique persons) Timeframe: Past year (April 1, 2011- March 31, 2012)	Name of the Study Site: _____		
	Address: _____		
	<b>Males</b>	<b>Females</b>	<b>Total</b>
1. No. of IDUs (any history of injecting drug use) registered at ICTCs <sup>1</sup>			
2. No. of IDUs referred from the Local 'Study TI'			
3. No. of IDUs referred from other IDU TIs			
4. No. of IDUs who have undergone HIV testing			
5. No. of IDUs who tested HIV-positive			
6. No. of IDUs who collected their test results <sup>2</sup>			
7. No. of HIV-positive IDUs who were referred to ART centre			
8. No. of IDUs (positive or not) who were referred to IDU TIs			

<sup>1</sup>Assumption is all of these persons might have received pre-test counseling.

<sup>2</sup>Assumption is all of these persons might have received post-test counseling when test result was given.

### Appendix 1.3: Data collection from the ART centre (to where the 'study TI site' mostly refer clients)

(Number of unique persons) Timeframe: Past year (April 1, 2011- March 31, 2012)	Name of the Study Site: _____		
	Address: _____		
	Males	Females	Total
1. No. of IDUs (any history of injecting drug use) registered at ART centre			
2. No. of IDUs referred from the 'Study ICTC'			
3. No. of IDUs referred from other ICTCs			
4. Among registered IDUs, no. of IDUs who were found to be eligible for ART (CD4 count, presence of particular OIs, etc.)			
5. No. of IDUs who were initiated on ART			
6. No. of IDUs who are currently on ART (i.e., adherent to ART)			
7. No. of HIV-positive IDUs who were lost to follow-up			
8. How many of those IDUs who were lost to follow-up were referred from IDU TIs (any IDU TI) <sup>3</sup>			
9. No. of referrals of HIV-positive IDUs to IDU TIs			

<sup>3</sup>Assumption is mainly IDU TIs take care of the follow-up of HIV-positive IDUs and not the mainstream PLHIV networks.



## **Appendix 2: Qualitative Topic Guides for Data Collection**

### **Appendix 2.1: Focus Group Discussion (FGD) topic guides**

2.1.1: For HIV-positive IDUs

2.1.2: For IDUs of any HIV status

### **Appendix 2.2: Stakeholder in-depth interview (IDI) guides**

2.2.1. For Project Coordinator and/or Director of IDU TI (for male and/or female IDUs)

2.2.2. For counsellor of IDU TI

2.2.3. For Outreach Workers (ORWs)

2.2.4. For ART doctor or counsellor

2.2.5. For ICTC counsellor

2.2.6. For CCC counsellor

2.2.7. For OST doctor or counsellor



## Appendix 2.1: Focus Group Discussion Topic Guides for IDUs

### 2.1.1. FGD Topic Guide for HIV-positive IDUs

#### **Note:**

- This FGD guide does not contain the actual wordings of the questions that will be asked. Before starting the FGD, please provide adequate information about the study and obtain written or verbal consent for participation from the participants. Also, collect background sociodemographic information from the FGD participants.

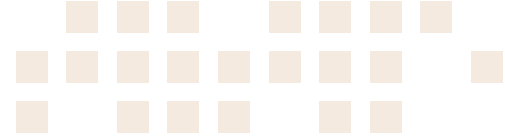
#### **Introductory questions**

- Briefly recap the purpose of the FGD.
- Can you briefly tell about the various services available for HIV-positive IDUs here [in that particular city/site]?

#### **ART Centre:**

- After an IDU is diagnosed as HIV-positive at ICTC (or another centre), what usually happens [next step]? [Note: Trace the referral pathways from ICTC or IDU TI – to ART centre].
- What issues, if any, you (or others) have faced in getting registered in ART centre or in initiation of ART? Can you elaborate on those issues? Do you have any suggestions on how to deal with those issues?
- In general, what do you think are the issues that prevent HIV-positive IDUs in accessing and using ART centres? You can tell about your own experiences or that of your friends.
- In general, what do you think are the factors that help (facilitate) HIV-positive IDUs in accessing and using ART centres?
- What are your suggestions to remove existing barriers and improve ART uptake among eligible HIV-positive IDUs?
- Based on your experiences or that of other IDUs known to you, how easy it is for a HIV-positive active IDU to get enrolled in OST? What kind of challenges, if any, they face? How does being on OST help HIV-positive IDUs (in terms of initiation of ART and adherence)?
- Once on ART, what factors facilitate or hinder ART adherence among IDUs? Do you have any suggestions to improve ART adherence level among IDUs?
- After registration in ART centre, what makes it difficult for IDUs (who do not require ART yet) to come for regular follow-up until they are initiated on ART?
- What do you think about the quality of services (clinical, counselling, etc.) in the ART centres? What are your suggestions, if any, to improve the quality of services?

If not articulated without prompts, PROBE for the following barriers.



Probe for the following factors that influence ART uptake and document specific examples to illustrate those factors:

### ***Individual-level Barriers***

1. Fear of adverse consequences of disclosure of HIV status (if accessing or using ART centre)
2. Unmet basic needs (shelter, food, etc.)
3. Insufficient and incorrect knowledge about ART (and OST)
4. Alcohol and active drug use
5. Psychological barriers (self-esteem, fatalism, etc.)

### ***Healthcare System and Programmatic Barriers***

1. Negative experiences with healthcare providers, in general, or ART healthcare providers, in particular (actual or perceived discrimination)
2. Lack of comprehensive and adequate ART counselling (actual or perceived)
3. Unfriendly administrative procedures (in registration at ART centre)
4. Inadequate education in targeted interventions (on ART)
5. Unmet service needs for HIV-positive IDUs (HCV/HBV screening and treatment)
6. Other: Distance, Time, Infrastructure, etc.

### ***Family and Social/Legal Barriers***

1. Lack of family support
2. Societal and community discrimination (for being drug user or HIV-positive)
3. Other: Legal, Police/Army harassment, etc.

### **CCC:**

- Can you tell about experiences of yours or other HIV-positive IDUs in using CCC? When and why IDUs are referred to CCC? (Explore: process of referral of HIV-positive IDUs to CCC, and registration issues)
- What issues, if any, do IDUs face in CCCs? How have you or other IDUs dealt with those issues?
- What do you think about the quality of CCCs – especially in terms of providing clinical and counselling services sensitively to HIV-positive IDUs? What are your suggestions, if any, to improve the quality of services in CCCs?



### **2.1.2: FGD Guide for IDUs** **(among IDUs of any HIV status – unknown, positive or negative)**

#### **Note:**

- This FGD guide does not contain the actual wordings of the questions that will be asked. Before starting the FGD, please provide adequate information about the study and obtain written or verbal consent for participation from the participants. Also, collect background sociodemographic information from the FGD participants.

#### **Introductory questions**

- Briefly recap the purpose of the FGD.
- Can you briefly tell about the various services available for IDUs here [in that particular city/site]?

#### **HIV testing (ICTC):**

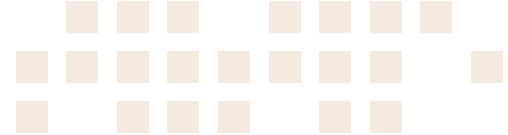
- Can you tell us how an IDU usually comes to know his or her HIV status? (Explore: on their own visiting ICTCs; referrals from NGOs/CBOs; referrals from private doctors; etc.)
- Can you tell us about in detail your experiences of HIV testing (ICTC) referral from the NGO? (who suggested, who accompanied, etc.)
- What challenges, if any, did you or others face in attending govt. ICTCs? Can you elaborate on those challenges? Do you have any suggestions how to deal with these challenges? (Explore whether the challenges are similar or different for first-time testers and repeat testers. If different, in what ways)
- What do you think about the quality of govt. ICTCs – especially in terms of dealing sensitively with IDUs? What are your suggestions, if any, to improve the quality of services in govt. ICTC? (counselling, privacy, test turnaround time, etc.)

#### **Needle and syringe program (NSEP):**

- From where all IDUs (especially HIV-positive IDUs) get clean needles and syringes?
- In general, how do IDUs (including HIV-positive IDUs) make use of the needles/syringes provided through NGOs? What kind of issues, if any, IDUs face in accessing needles/syringes provided by NGOs? Can you elaborate on those issues?
- In general, what do you think are the factors that help IDUs (including HIV-positive IDUs) to access needles/syringes?
- What are your suggestions to make more IDUs (including HIV-positive IDUs) to make use of the needles/syringes provided by NGOs?

[Note: Access to ART can also be explored with this group, if time permits]

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If not articulated without prompts, PROBE for the following barriers.

Probe for the following factors that influence HIV testing uptake (and NSEP), and document specific examples to illustrate those factors:

### ***Individual-level Barriers***

1. Fear of adverse consequences of disclosure of being an injecting drug user (if accessing or using HIV testing and NSEP)
2. Unmet basic needs (shelter, food, etc.)
4. Alcohol and active drug use
5. Psychological barriers (self-esteem, fatalism, etc.)

### ***Healthcare System and Programmatic Barriers***

1. Negative experiences with healthcare providers (actual or perceived discrimination)
2. Lack of comprehensive and adequate HIV testing counselling
3. Unfriendly administrative procedures (in registration at ICTCs)
4. Other: Distance, Time, Infrastructure, etc.

### ***Family and Social/Legal Barriers***

1. Lack of family support
2. Societal and community discrimination (for being drug user)
3. Other: Legal, Police/Army harassment, etc.



## Appendix 2.2: Topic Guides for Stakeholder In-Depth Interviews

### *Appendix 2.2.1. IDI guide for Project Coordinator and/or Director of IDU TI (for male and/or female IDUs)*

#### **Note:**

- This guide does not contain the actual wordings of the questions that will be asked.
- Not all of these questions will need to be explored. The focus of the interview will vary based on the experience and expertise of the stakeholder.

Provide the information note and informed consent form well in advance of the interview. If not done already, before starting the interview, provide the background information and administer the informed consent form (and get written or verbal consent).

#### **Introductory questions**

- Briefly recap the purpose of the interview.
- Briefly capture the experience/expertise of the stakeholder and his/her organisation. (E.g., Can you briefly tell me about the kind of work your agency does among IDUs and what has been your role?)

Only ask relevant questions from the following domains.

#### **HIV testing (ICTC):**

- Explain your process of referral to HIV testing (govt. ICTC) for IDUs.
- How would you describe the relation of your agency with govt. ICTC? (e.g., good, bad, okay, etc.) What made you to say so?
- What issues, if any, are faced by your agency or your IDU clients, from govt. ICTCs in referring IDUs for HIV testing (both for first-time testing and repeat testing in case of risk behaviour)?
- How have you dealt with those issues?
- What do you think about the quality of govt. ICTCs – especially in terms of dealing sensitively with IDUs? What are your suggestions, if any, to improve the quality of services in govt. ICTC?
- What are your suggestions for improving HIV testing referrals from TIs to ICTCs?

#### **Needle and syringe program (NSEP):**

- What kind of issues, if any, IDUs (especially HIV-positive IDUs) face in accessing and using your (or other agency's) needle/syringe services? Can you elaborate on those issues?
- In general, what do you think are the factors that facilitate IDUs to access/use needle/syringe exchange services? What steps have you or your organisation have taken to improve uptake of needles/syringes? What worked and what did not?

- What are your suggestions to remove existing barriers and improve access to and use of needle/syringe uptake? (Probing for various types of barriers – as listed in the FGD guide – can be done)
- What do you think about the coverage of your agency's NSP? What made you to say the coverage of NSP is (good or bad)?
- If coverage of services can be increased, what are your suggestions for the same?

### ART Centre:

- Explain your process of referral of HIV-positive IDUs for registration in ART centre and initiation of ART
- How would you describe the relation of your agency with ART centre? (e.g., good, bad, okay, etc.) What made you to say so?
- What issues, if any, are faced by your agency or your IDU clients, from ART centres? How have you dealt with those issues?
- What do you think about the quality of ART centres – especially in terms of dealing sensitively with HIV-positive IDUs (former or current)? What are your suggestions, if any, to improve the quality of services in ART centres?
- After registration in ART centre, what makes it difficult for IDUs (who do not require ART yet) to come for regular follow-up until they are initiated on ART?
- What are your suggestions, if any, for improving referrals of HIV-positive IDUs from TIs to ART centres?
- What do you think about the coverage of ART among eligible HIV-positive IDUs? What made you to say the coverage of these services is (good or bad)?
- If coverage of ART can be increased, what are your suggestions for the same?

### CCC:

- Explain your process of referral of HIV-positive IDUs to CCC
- How would you describe the relation of your agency with CCC? (e.g., good, bad, okay, etc.) What made you to say so?
- What issues, if any, are faced by your agency or your clients in CCCs? How have you dealt with those issues?
- What do you think about the quality of CCCs – especially in terms of dealing sensitively with HIV-positive IDUs (former or current)? What are your suggestions, if any, to improve the quality of services in CCCs?

## Opioid Substitution Treatment (OST):

- What kind of issues, if any, IDUs (especially HIV-positive IDUs) face in accessing and using your (or other agency's) OST services? Can you elaborate on those issues?
- In general, what do you think are the factors that facilitate IDUs to access/use OST services? What steps have you or your organisation have taken to improve uptake of OST? What worked and what did not?
- What are your suggestions to remove existing barriers and improve access to and use of OST uptake for eligible IDUs? (Probing for various types of barriers – as listed in the FGD guide – can be done)
- What do you think about the coverage of your agency's OST service? What made you to say the coverage of OST is (good or bad)?
- If coverage of services can be increased, what are your suggestions for the same?

### ***Appendix 2.2.2: IDI guide for counsellor of IDU TI***

#### ***Note:***

- This guide does not contain the actual wordings of the questions that will be asked.
- Not all of these questions will need to be explored. The focus of the interview will vary based on the experience and expertise of the stakeholder.

Provide the information note and informed consent form well in advance of the interview. If not done already, before starting the interview, provide the background information and administer the informed consent form (and get written or verbal consent).

#### ***Introductory questions***

- Briefly recap the purpose of the interview.
- Briefly capture the experience/expertise of the stakeholder and his/her organisation. (E.g., Can you briefly tell me about how long you have been working as a counsellor and in general, your experiences in working with IDUs?)

Only ***ask relevant questions*** from the following domains.

## HIV testing (ICTC):

- Explain your process of referral of IDUs for HIV testing (govt. ICTC).
- What are the challenges you face in terms of making the IDUs to attend govt. ICTCs? Can you elaborate on those challenges? Do you have any suggestions how to deal with these challenges?

- What issues, if any, are faced by your IDU clients from govt. ICTCs, when you refer them for HIV testing (both for first-time testing and repeat testing in case of risk behaviour)?
- What do you think about the quality of govt. ICTCs – especially in terms of dealing sensitively with IDUs? What are your suggestions, if any, to improve the quality of services in govt. ICTC?

### Needle and syringe program (NSEP):

- What kind of issues, if any, IDUs (especially HIV-positive IDUs) face in accessing and using your (or other agency's) needle/syringe services? Can you elaborate on those issues?
- In general, what do you think are the factors that facilitate IDUs (especially HIV-positive IDUs) to access/use needle/syringe exchange services? What steps have you or your organisation have taken to improve uptake of needles/syringes? What worked and what did not?
- What are your suggestions to remove existing barriers and improve access to and use of needle/syringe uptake? (Probing for various types of barriers – as listed in the FGD guide – can be done)

### ART Centre:

- Explain your process of referral of HIV-positive IDUs for registration in ART centre and initiation of ART
- What are the challenges you face in terms of making the HIV-positive IDUs to attend ART centres? Can you elaborate on those challenges? Do you have any suggestions on how to deal with those challenges?
- What issues, if any, are faced by your agency or your IDU clients, from ART centres? How have you dealt with those issues?
- After registration in ART centre, what makes it difficult for IDUs (who do not require ART yet) to come for regular follow-up until they are initiated on ART?
- What do you think about the quality of ART centres – especially in terms of dealing sensitively with HIV-positive IDUs (former or current)? What are your suggestions, if any, to improve the quality of services in ART centres?

### CCC:

- Explain your process of referral of HIV-positive IDUs to CCC
- What issues, if any, are faced by your clients in CCCs? How have you or your IDU clients dealt with those issues?

- What do you think about the quality of CCCs – especially in terms of dealing sensitively with HIV-positive IDUs (former or current)? What are your suggestions, if any, to improve the quality of services in CCCs?

### ***Appendix 2.2.3: IDI guide for Outreach Workers (ORWs)***

#### ***Note:***

- This guide does not contain the actual wordings of the questions that will be asked.
- Not all of these questions will need to be explored. The focus of the interview will vary based on the experience and expertise of the stakeholder.

Provide the information note and informed consent form well in advance of the interview. If not done already, before starting the interview, provide the background information and administer the informed consent form (and get written or verbal consent).

#### ***Introductory questions***

- Briefly recap the purpose of the interview.
- Briefly capture the experience/expertise of the stakeholder and his/her organisation. (E.g., Can you briefly tell me about how long you have been working as an outreach worker? Tell me briefly about what your routine)

Only ask relevant questions from the following domains.

#### **HIV testing (ICTC):**

- Explain your process of referral of IDUs for HIV testing (govt. ICTC).
- What are the challenges you face in terms of making the IDUs to attend govt. ICTCs? Can you elaborate on those challenges? Do you have any suggestions how to deal with these challenges?
- What issues, if any, are faced by your IDU clients from govt. ICTCs, when you refer them for HIV testing (both for first-time testing and repeat testing in case of risk behaviour)?
- What do you think about the quality of govt. ICTCs – especially in terms of dealing sensitively with IDUs? What are your suggestions, if any, to improve the quality of services in govt. ICTC?

#### **Needle and syringe program (NSEP):**

- What kind of issues, if any, IDUs (especially HIV-positive IDUs) face in accessing and using your (or other agency's) needle/syringe services? Can you elaborate on those issues?
- In general, what do you think are the factors that facilitate IDUs to access/use needle/syringe exchange services? What steps have you or your organisation have taken to improve uptake of needles/syringes? What worked and what did not?

- What are your suggestions to remove existing barriers and improve access to and use of needle/syringe uptake? (Probing for various types of barriers – as listed in the FGD guide – can be done)

### ART Centre:

- Explain your process of referral of HIV-positive IDUs for registration in ART centre and initiation of ART
- What are the challenges you face in terms of making the HIV-positive IDUs to attend ART centres? Can you elaborate on those challenges? Do you have any suggestions how to deal with these challenges?
- After registration in ART centre, what makes it difficult for IDUs (who do not require ART yet) to come for regular follow-up until they are initiated on ART?
- What issues, if any, are faced by your agency or your IDU clients, from ART centres? How have you dealt with those issues?
- What do you think about the quality of ART centres – especially in terms of dealing sensitively with HIV-positive IDUs (former or current)? What are your suggestions, if any, to improve the quality of services in ART centres?

### CCC:

- Explain your process of referral of HIV-positive IDUs to CCC
- What issues, if any, are faced by your clients in CCCs? How have you or your IDU clients dealt with those issues?
- What do you think about the quality of CCCs – especially in terms of dealing sensitively with HIV-positive IDUs (former or current)? What are your suggestions, if any, to improve the quality of services in CCCs?

### ***Appendix 2.2.4: IDI guide for ART doctor or counsellor***

#### ***Note:***

- This guide does not contain the actual wordings of the questions that will be asked.
- Not all of these questions will need to be explored. The focus of the interview will vary based on the experience and expertise of the stakeholder.

Provide the information note and informed consent form well in advance of the interview. If not done already, before starting the interview, provide the background information and administer the informed consent form (and get written or verbal consent).



### ***Introductory questions***

- Briefly recap the purpose of the interview.
- Briefly capture the experience/expertise of the stakeholder and his/her organisation. (E.g., Can you briefly tell me about how long you have been working as a doctor/counsellor and your experiences in working with IDUs? )

Only ask relevant questions from the following domains.

### **ART Centre:**

- What kind of issues, do you think, IDUs face in accessing ART? Can you elaborate on those issues?
- Do you think issues faced by male IDUs and female IDUs are the same or different in terms on accessing and using ART? What made you to say so (i.e., same or different)? Can you elaborate on that?
- What challenges do you face in making IDUs to get registered in ART centre or initiate ART?
- What challenges do you face in making IDUs to adhere to ART?
- What do you think about the adherence level of ART among HIV-positive IDUs on OST and those who are active injecting users? Can you explain.
- [For ART doctor:] If an HIV-positive IDU is eligible for ART based on his/her CD4 count, would you start ART based on this medical criteria alone? What other factors, in any, you would consider before initiating ART for that person?
- In general, what do you think are the factors that facilitate IDUs to access/use ART?
- After registration in ART centre, what makes it difficult for IDUs (who do not require ART yet) to come for regular follow-up until they are initiated on ART?
- What steps have been taken to improve uptake of ART? What worked and what did not?
- What are your suggestions to remove existing barriers and improve access to and use of ART uptake among eligible HIV-positive IDUs? (Probing for various types of barriers – as listed in the FGD guide – can be done)
- What do you think about the quality of services provided in this ART centre? Do the services meet the expectations of IDUs and their family members? Do you have any suggestions for how to meet or exceed their reasonable expectations?



### ***Appendix 2.2.5: IDI guide for ICTC counsellor***

#### ***Note:***

- This guide does not contain the actual wordings of the questions that will be asked.
- Not all of these questions will need to be explored. The focus of the interview will vary based on the experience and expertise of the stakeholder.

Provide the information note and informed consent form well in advance of the interview. If not done already, before starting the interview, provide the background information and administer the informed consent form (and get written or verbal consent).

#### ***Introductory questions***

- Briefly recap the purpose of the interview.
- Briefly capture the experience/expertise of the stakeholder and his/her organisation. (E.g., Can you briefly tell me about how long you have been working as an ICTC counsellor and your experiences in dealing with IDUs?)

Only ask relevant questions from the following domains.

#### **HIV testing (ICTC):**

- What kind of issues, do you think, IDUs face in accessing ICTC? Can you elaborate on those issues?
- Do you think issues faced by male IDUs and female IDUs are the same or different in terms of accessing and using HIV testing? What made you to say so (i.e., same or different)? Can you elaborate on that?
- In general, what do you think are the factors that facilitate IDUs to access/use ICTC (or HIV testing elsewhere)? What steps, do you know of, that have been taken to improve uptake of HIV testing among IDUs in this city/place? What worked and what did not?
- What are your suggestions to remove existing barriers and improve HIV testing (first-time and repeat testing) among IDUs?
- What do you think the quality of services provided in this ICTC? Do the services meet the expectations of IDUs and their family members? Do you have any suggestions for how to meet or exceed their reasonable expectations?



### **Appendix 2.2.6: IDI guide for CCC counsellor**

#### **Note:**

- This guide does not contain the actual wordings of the questions that will be asked.
- Not all of these questions will need to be explored. The focus of the interview will vary based on the experience and expertise of the stakeholder.

Provide the information note and informed consent form well in advance of the interview. If not done already, before starting the interview, provide the background information and administer the informed consent form (and get written or verbal consent).

#### **Introductory questions**

- Briefly recap the purpose of the interview.
- Briefly capture the experience/expertise of the stakeholder and his/her organisation. (E.g., Can you briefly tell me about how long you have been working as a counsellor in this CCC and your experiences in working with IDUs?)

Only ask relevant questions from the following domains.

Barriers and facilitators to access/use services

#### **CCC:**

- Can you tell in detail about the process of admission of HIV-positive IDUs to CCC? Whether the process of admission to CCC for HIV-positive IDUs is any way different from that for other people living with HIV? If so, in what ways?
- What kind of issues, if any, IDUs face in accessing and using CCC? Can you elaborate on those issues?
- Do you think issues faced by male IDUs and female IDUs are the same or different in terms on accessing and using CCC? What made you to say so (i.e., same or different)? Can you elaborate on that?
- What challenges you face in dealing with the issues of IDUs using CCCs?
- In general, what do you think are the factors that facilitate IDUs to access/use CCC?
- What are your suggestions to remove existing barriers and improve access to and use of CCC among needy HIV-positive IDUs?
- What do you think about the quality of services provided in this CCC? Do those services meet the expectations of IDUs and their family members? Do you have any suggestions for how to meet or exceed their reasonable expectations?

### ***Appendix 2.2.7: IDI guide for OST doctor or counsellor***

#### ***Note:***

- This guide does not contain the actual wordings of the questions that will be asked.
- Not all of these questions will need to be explored. The focus of the interview will vary based on the experience and expertise of the stakeholder.

Provide the information note and informed consent form well in advance of the interview. If not done already, before starting the interview, provide the background information and administer the informed consent form (and get written or verbal consent).

#### ***Introductory questions***

- Briefly recap the purpose of the interview.
- Briefly capture the experience/expertise of the stakeholder and his/her organisation. (E.g., Can you briefly tell me about how long you have been working as a doctor/counsellor in this OST site and your experiences in working with IDUs, in general?)

Only ask relevant questions from the following domains.

Barriers and facilitators to access/use services

#### **Opioid Substitution Treatment (OST):**

- What kind of issues, do you think, IDUs (especially HIV-positive IDUs) face in accessing OST services? Can you elaborate on those issues?
- Do you think issues faced by male IDUs and female IDUs are the same or different in terms on accessing and using OST service? What made you to say so (i.e., same or different)? Can you elaborate on that?
- What challenges do you face in making IDUs to initiate OST?
- What challenges do you face in making IDUs to adhere to OST?
- What do you think about the adherence level of ART among HIV-positive IDUs on OST? Can you explain?
- In general, what do you think are the factors that facilitate IDUs to access/use OST services? What steps have you or your organisation have taken to improve uptake of OST? What worked and what did not?
- What are your suggestions to remove existing barriers and improve access to and use of OST uptake among eligible IDUs? (Probing for various types of barriers – as listed in the FGD guide – can be done)
- Do you think your (OST) service's quality meet the expectations of IDUs and their family members? Do you have any suggestions for how to meet or exceed their reasonable expectations?



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