

# Sexual and Reproductive Health of People Living with HIV in India: A Mixed Methods Study

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## Acronyms and Abbreviations

**AIDS** – Acquired immunodeficiency syndrome  
**ARV** – Antiretrovirals  
**ART** – Antiretroviral therapy or treatment  
**BNP** – Bengal Network for People living with HIV and AIDS  
**CBO** – Community based organization  
**CD4** – Cluster of Differentiation  
**DFID** – Department for International Development (United Kingdom)  
**FGD** – Focus Group Discussion  
**FSW** – Female Sex Workers  
**HBC** – Hepatitis-C Virus  
**HBV** – Hepatitis-B Virus  
**HIV** – Human Immunodeficiency Virus  
**ICTC** – Integrated Counseling and Testing Centres  
**IDU** – Injecting Drug User  
**IDI** – In-depth Interview  
**INP** – Indian Network for People living with HIV  
**KII** – Key informant In-depth Interview  
**MNP** – Manipur Network of Positive People  
**MSM** – Men who have sex with men  
**NACO** – National AIDS Control Organization  
**NACP** – National AIDS Control Programme  
**NCP** – Network for Chennai People living with HIV  
**NGO** – Nongovernmental organization  
**NMP** – Network of Maharashtra by People living with HIV  
**PLHA** – People living with HIV and AIDS  
**SACS** - State AIDS Control Society  
**SPSS** – Statistical Package for Social Sciences  
**SWAM** - Social Welfare Association for Men  
**TNP** – Telugu Network for People living with HIV  
**UPNP** – Uttar Pradesh Welfare for People living with HIV  
**VCTC** – Voluntary Counseling and Testing Centre

## EXECUTIVE SUMMARY

### 1. BACKGROUND

In India, an ever-increasing number of persons are now becoming aware of their HIV-positive status. A significant proportion of these people living with HIV and AIDS (PLHA) can be reached out to assist them in adopting and maintaining safer sex and safer injecting drug use. Despite the logic that behind every HIV infection there is another HIV-positive person, there has been a neglect of prevention programs focusing on PLHA who know their HIV status. Similarly, reproductive health needs and rights of PLHA are largely misunderstood and have not yet received proper attention of the policymakers and service providers. Indian Network for People living with HIV (INP+) with support from the Department for International Development (DFID), has conducted this mixed methods study to create appropriate and evidence-informed policies and programmes to meet the specific sexual and reproductive health needs of various subgroups of PLHA.

### 2. STUDY OBJECTIVES

- To document the extent of risky and protective sexual and injecting drug use behaviors among various subgroups of PLHA
- To explore the various contexts of safer and unsafe sexual and injecting drug use behaviors among various subgroups of PLHA
- To explore the sexual and reproductive health needs of HIV-positive men and women – especially their family planning needs, and reproductive intentions and experiences

### 3. STUDY METHODOLOGY

Mixed methods (qualitative & quantitative) study design with concurrent triangulation strategy was used.

*Quantitative component:* A survey (n=430) was conducted using a face-to-face structured questionnaire among various subgroups of PLHA – heterosexual men and women, men who have sex with men (MSM), Hijras or Aravanis (Transgender women), Injecting Drug Users (IDUs); and female sex workers (FSW). SPSS version-14 was used for statistical analysis.

*Qualitative component:* Sixteen focus group discussions (n=112 participants), 55 in-depth interviews, and 7 key informant interviews were conducted. Interview and FGD data were explored using narrative thematic analysis and techniques adopted from grounded theory.

### 4. KEY FINDINGS

#### **a. Quantitative component (n=430)**

##### ***Characteristics of the participants***

A majority of the participants across the subgroups were poorly educated and from lower economic background. Among women, alcohol use was high among female IDUs (88%) and FSWs (51%). Heroin was the most commonly used injecting drug, with all the participants in IDU subgroups having had used it in the past 3 months.

##### ***Sex with casual partners was reported across the subgroups***

The proportion of those who had casual female partners in the past three months among heterosexual men, male IDUs and MSM was 17%, 28% and 13% respectively. And the proportion of those who had casual male partners among female IDUs, FSWs, MSM, and Hijras was 68%, 100%, 82% and 63% respectively.

##### ***Condom use was moderately high and most subgroups did not differ in the level of consistency of condom use according to partner type (regular versus casual)***

The proportion of participants who reported always using condoms with regular compared to casual partners for heterosexual men (vaginal sex) was 69% versus 59%, for male IDUs (vaginal sex) was 70% versus 71%), for MSM (receptive anal sex) was 78% versus 77%, for Hijras (receptive anal sex) was 66% versus 58%, and for FSWs (vaginal sex) was 69% versus 77%. Only female IDUs reported always using condoms appreciably less for vaginal sex with regular partners (50%) than with casual partners (82%). For insertive anal sex, both MSM and Hijras reported always using

condoms less with regular partners (50% for both groups) than with casual partners (about 70% for both groups).

***A notable proportion of male (but not female) PLHA on ARVs reported inconsistent condom use with regular partners***

About one-fourth of heterosexual men (n=14/45) who were currently on ARVs did not always use a condom when they had vaginal sex with their regular female partner. In heterosexual women, all of those who were currently on ARVs (n=20) reported consistent condom use in vaginal sex with their male regular partners.

***Across all subgroups, knowledge about the CD4 test, viral load test, Hepatitis-B and Hepatitis-C was inadequate***

While a majority of heterosexual men (57%), male IDUs (66%), and MSM (63%) had correct knowledge about the CD4 test, the majority of heterosexual women (62%), female IDUs (80%), FSWs (97%), and Hijras (57%) did not. Knowledge about the viral load test, Hepatitis B, and Hepatitis C was much worse.

***The prevalence of STI-related symptoms in the past 12 months was high, and a substantial proportion of persons did not receive treatment for their last STI-related symptom***

Half of heterosexual men, 56% of heterosexual women, 36% of male IDU, 72% of female IDU, 97% of FSW, 53% of MSM, and 33% of Hijras reported having had STI-related symptoms in the past 12 months.

***Induced abortion after HIV infection was not uncommon and may reflect inadequate counseling to prevent unintended pregnancies***

Induced abortion after knowing of HIV infection was reported in all subgroups of women - heterosexual women (16%); female IDUs (24%) and FSW (11%).

***Condoms were topmost in the list of contraceptives used followed by tubal ligation***

Among the PLHA who reported currently using contraception, all female IDUs, 98% of heterosexual women, 97% of heterosexual men, 93% of male IDUs, 92% of MSM, and 71% of FSWs reported using condoms. The next most common method reported across the subgroups was tubal ligation, which was particularly high among FSWs (n=17/35). Using oral contraceptive pills was reported by a small proportion (ranging from 3 to 17%) of the participants.

**b. Qualitative Component** (Totally 174 participants)

***Contextual factors regarding unprotected sex among PLHA***

Though many PLHA have adopted practicing safer sex, not all could consistently practice safer sex with different types of partners. Some of the interpersonal and structural factors that led to unprotected sex were: non-disclosure of HIV status due to fear of rejection by wife, heat of the moment and intimacy, forced sex by husband when under the influence of alcohol or injecting drugs, unplanned sex, when more money is offered to sex workers by clients, and forced sex (of FSW, MSM and ruffians) by police and ruffians.

***Reasons for sharing needles/syringes among HIV-positive IDUs (in Manipur)***

The reasons for sharing needles/syringes were: severity of withdrawal period prevented rational thinking; barriers in carrying sterile syringes; limited access to pharmacy-sold syringes; no money to buy sterile syringes; and non-availability of syringes in prisons. Barriers to obtaining clean syringes included: hilly terrain and high-conflict in Manipur; lack of awareness about availability of clean syringes from non-governmental organizations; and fear of arrest for possession of syringes. Nevertheless, HIV-positive IDUs adopted various strategies in an attempt to reduce the risk of HIV transmission to other IDUs: being a "receiver" of syringes and not a "giver"; being the "last receiver" of the shared syringe; asking others to wash used syringes with bleach; and through 'serosorting' (sharing syringes only with HIV-positive IDUs). These strategies, however, place HIV-positive IDUs at risk of contracting Hepatitis-B/Hepatitis-C and other HIV strains.

### ***Reasons for giving birth to a baby after HIV diagnosis and intentions to have a baby***

The common reasons for giving birth to a baby after HIV diagnosis and intentions to have a baby were: wish to sustain the family genes; need to experience motherhood; social influences such as not wanting to be labeled as 'barren' (women) and not to be questioned about their virility (men); trust on the recent medical advances to help them in having a negative baby; and the fear of impending death of the first baby. The reasons for not wanting to have a baby were: fear of passing on HIV infection to baby; not wanting to take risk (risk aversion/avoidance); fear of being judged by others; already has enough number of children; and concerns about the financial challenges in raising a baby.

### ***Family planning: Availability of information and services***

PLHA are given only limited options with the counseling limited to discussion on condoms only – emphasizing prevention of HIV transmission to others. Thus, providers often do not discuss about any other contraceptives (non-barrier methods); dual protection of condoms; dual methods of contraception; and emergency contraception.

## **5. RECOMMENDATIONS**

### ***a. Promoting Safer Sex Behaviors among PLHA***

- Adopt multiple strategies to promote and sustain safer sex among PLHA in a variety of settings: one-to-one risk-reduction counseling (peer and professional); group training programs on sexual health issues for PLHA; couple counseling (serodiscordant and seroconcordant); and mass media campaigns.
- Safer sex messages for PLHA need to focus on the benefits of consistent condom use with both infected and un-infected partners – which include prevention of re-infections and HIV superinfections; and avoid getting infected with drug-resistant strains and STIs.

### ***b. Promoting Safer Injecting Drug Use Behaviors among HIV-Positive IDUs***

- *Individual level:* Emphasize health consequences of needle/syringe sharing; Refer to drug substitution and drug dependence treatment programs; and Messages for HIV-positive IDUs should include both benefits to self and also to needle-sharing partners.
- *Structural level:* Scale-up syringe supply programs; Work with drug-peddlers to ensure clean syringe availability; and Advocate with law enforcement agencies and anti-drug agencies on importance of harm reduction activities.

### ***c. Sexual and Reproductive Health and Rights of PLHA***

#### **Policies and Action plans**

- Develop a national policy on sexual and reproductive health and rights of PLHA and implement that plan in NACP-III phase.
- Ensure greater involvement of people living with HIV and AIDS (GIPA) in sexual and reproductive health policy and programs for PLHA.
- Take steps to improve linkages and referrals between treatment/care centers and prevention and sexual/reproductive health services.
- Involve HIV-positive men in family planning counseling to provide support to their wife's decisions on family planning and to offer information about permanent contraception for men.

#### **Sexual and Reproductive Health Programs: Service delivery**

- Provide essential information to PLHA on: Dual use (prevention of infection and pregnancy) of condoms; Use of dual methods (condoms and another contraceptive); Safety of conception and childbirth; Unwanted/unintended pregnancy; Contraceptive options including emergency contraception; Dangers of unsafe abortion; and Access to legal, safe abortion.
- Provide risk reduction counseling and reproductive health services for HIV sero-discordant couples who wish to have their own baby.
- Train health care providers on sexual and reproductive health needs and rights of PLHA and emphasize the need to offer counseling in a non-judgemental, and unbiased manner.



## I. INTRODUCTION

In India, an ever-increasing number of persons are now becoming aware of their HIV-positive status. A significant proportion of these people living with HIV and AIDS (PLHA) can be reached out to assist them in adopting and maintaining safer sex and safer injecting drug use. Despite the logic that behind every HIV infection there is another HIV-positive person, there has been a neglect of prevention programs focusing on PLHA who know their HIV status. Similarly, reproductive health needs and rights of HIV-positive men and women are largely misunderstood and have not yet received proper attention of the policymakers and service providers. There is a need for comprehensive programs addressing the sexual and reproductive needs of PLHA, both to decrease the risk of HIV transmission to other people and to allow PLHA to responsibly exercise their sexual and reproductive rights. Recently the National AIDS Control Organization (NACO), India, has articulated the need to focus on positive prevention in its draft strategic plan for the third phase of the National AIDS Control Programme (NACP-III) – "...PLHA need to have access to prevention services to avoid infection being passed on to their partners".

Studies from other countries have shown that after knowing their HIV status, many PLHA adopt safer sex practices to avoid HIV transmission to their sexual partners (Schiltz & Sandfort, 2000; Crepaz & Marks, 2002). However, under various situations, PLHA may engage in high-risk sexual and injecting drug use behavior. Several studies from developed countries have shown that as many as one in three HIV-infected persons continue to practice unprotected anal and vaginal sex after knowing that they are HIV positive, and unprotected sex often occurs with partners of unknown or known HIV negative serostatus (Rosa et al., 1998; Marks et al., 1999; Kalichman, 2000). Through qualitative methods, the challenges associated with consistent condom use and other preventive behaviors among PLHA have also been documented primarily among HIV-positive gay men (Belcher et al., 2005; Bunnell et al., 2005) in developed countries.

In general, there is very limited information available from India on the sexual behavior of PLHA of any subgroup. Some studies among injection drug users (IDUs) (Panda S et al., 2005 and 1998) and prisoners (Sundar M et al., 1995) have documented high-risk sexual behaviour among those who were HIV-positive. These studies, however, were conducted among persons who were not aware of their HIV status prior to being enrolled in these studies, when they were tested for their serostatus. Being quantitative cross-sectional survey studies, they could not explain the reasons behind high-risk behaviours among PLHA who already know they are HIV-positive. Also, an increasing number of PLHA in India are being enrolled in the national ART program. At the end of October 2006, according to NACO, a total of 43,897 PLWHA were receiving ARVs in NACO-supported ART centers (Abraham et al., 2006). While studies from developed countries had shown mixed findings in relation to ART and condom use (Scheer et al., 2001; Miller et al., 2000), some studies from developing countries including India did not show any increase in sexual risk behavior of those PLHA who were on ART (Sarna et al., 2005 & 2006).

Through interactions with the various members of the state and district level PLHA networks, INP+ is aware that PLHA from various marginalized populations like IDUs, men who have sex with men (MSM), Hijras (Transgender women), and female sex workers (FSWs) face unique challenges and barriers in consistently practicing safer sex or safer injecting drug use behaviours. A qualitative study commissioned by INP+ documented the various contextual factors behind unprotected sex among HIV-positive MSM in Chennai, some of whom were heterosexually married (Chakrapani et al., 2005). But the contexts under which unprotected sex occurs between a known HIV-positive person and a partner of known or unknown HIV status might differ among the various subgroups of PLHA. Thus it is very important to understand these contextual factors in order to develop appropriate secondary prevention intervention

programs for different subgroups of PLHA. Despite this significance, in India till now there is very little empirical research in this area.

The sexual and reproductive health of PLHA is fundamental to their well-being and that of their partners and children (WHO, 2006). Most of the women come to know of their HIV status when they become pregnant and access antenatal care services, from which they are referred to voluntary counseling and testing centres. In the third phase of the National AIDS Control Programme (NACP-III), NACO is planning to rapidly scale up the Prevention of Parent-to-Child Transmission (PPTCT) services in India along with the Integrated (HIV) Counseling and Testing Centers (ICTC). Thus, more number of HIV-positive women would be identified. However, since the focus of PPTCT program is to prevent transmission to the baby (as the name also suggests), the sexual and reproductive health and rights of HIV-positive women and men are often sidelined, misunderstood, or even not recognized. Also, there are various barriers in accessing the antenatal and family planning services among HIV-positive women as shown in studies from other developing countries (Baek et al., 2005). In addition, as the health and well being of HIV-positive men and women improve due to ART and management of opportunistic infections, PLHA may consider or reconsider decisions regarding their sexual activity and reproduction. Hence, this study explores the sexual and reproductive health needs of HIV-positive women and men; barriers to accessing sexual and reproductive health services; and whether PLHA are able to exercise their sexual and reproductive rights in relation to abortion services, fertility, and family planning - deciding freely and responsibly the number, spacing and timing of their children.

The **objectives** of this mixed methods study include the following:

- To document the extent of risky and protective sexual and injecting drug use behaviors among various subgroups of PLHA
- To explore the various contextual factors related to safer and unsafe sexual and injecting drug use behaviors among various subgroups of PLHA
- To explore the sexual and reproductive health needs of HIV-positive men and women – especially their family planning needs, and reproductive intentions and experiences

The **key research questions** include:

*Quantitative component (Survey)*

- How prevalent are the various risky or protective sexual and injecting drug use behaviors among various subgroups of PLHA?
- What are the various factors that are associated with unsafe or protective behaviors?
- What is the level of knowledge and service use among PLHA in relation to their sexual and reproductive health?

*Qualitative component*

- What are the various contextual factors behind unprotected sex or unsafe injecting drug use behaviors among the diverse subgroups of PLHA?
- What are the risk reduction strategies and protection strategies adopted by PLHA to protect their sexual or needle-sharing partners and also to protect themselves?
- What are the various expressed and unarticulated sexual and reproductive health needs of PLHA?
- What are the barriers faced by PLHA in accessing and using the existing sexual and reproductive health services?

Consistent with the methodology of evidence-informed decision making, this mixed methods study findings will help policymakers and program managers to create appropriate and evidence-informed policies and programmes to meet the specific sexual and reproductive health needs of various subgroups of PLHA.

## II. RESEARCH METHODOLOGY

### 1. Study design

This was a mixed methods investigation using a triangulation design. A triangulation design is a type of mixed methods research wherein both qualitative and quantitative data collection are conducted concurrently and findings from both are integrated and conclusions drawn.

#### **Methods used in this mixed methods study**

##### **a. Quantitative component**

A survey (n=430) was conducted using a face-to-face structured questionnaire among various subgroups of people living with HIV – heterosexual men and women, MSM, Hijras or Aravanis (Transgender women), IDUs (men and women); and FSW.

##### **b. Qualitative component**

Sixteen focus group discussions (n=112 participants) and 55 in-depth interviews with various subgroups of PLHA, as well as 7 key informant interviews with health care providers and community leaders were conducted.

### 2. Participatory approach

Indian Network for People living with HIV (INP+) is the largest national network for PLHA in India. INP+ consists of 22 State level PLHA networks (SLN) and 106 District level PLHA networks (DLN). This research study was implemented through 6 positive people networks of INP+ (See Table 1) and 2 community-based organisations working with MSM and Hijras - Social Welfare Association for Men (SWAM), Chennai, and the Humsafar Trust, Mumbai. PLHA from various subgroups were involved in all stages of this research study - design, implementation, and analysis.

After community publicity, e-forum postings, application review, and in some cases face-to-face interviews, suitable field research team members were hired from the local communities. Selection of the interviewers was based on their communication skills, experience in working with the specific subgroup of people living with HIV, and ability to respect full confidentiality regarding personal information. The field research staff were given intensive three-day training on research techniques and research ethics. Pre- and post-training technical support and guidance were provided for the field research team members. The field research team in each research site typically included a field research coordinator, 2 interviewers & 2 peer recruiters. These team members were responsible for organizing, recruiting, and conducting most of the in-depth interviews and focus groups though some of them were conducted or facilitated by some of the research investigators. Almost all the survey interviews were conducted by the field research interviewers or field research coordinators.

### 3. Selection of states and research sites

The study was conducted in 6 states - Tamil Nadu, Andhra Pradesh, Maharashtra, Manipur, West Bengal and Uttar Pradesh. Selection of these states was based on regional representation (North, South, East and West) and HIV prevalence among different subgroups. The selection of research sites was based on the predominant subgroup of PLHA the sites provide services to and also on the capacity of those sites to implement the research project. Most of the positive people networks of INP+ serve heterosexual men and women living with HIV. Manipur network predominantly serves male and female IDUs living with HIV, and none predominantly serve MSM or Hijras. Thus, to recruit HIV-positive MSM and Hijras, partnerships were developed with two community based organizations working with MSM and Hijras (Transgender women) in Chennai and Mumbai. The list of study sites/organizations is given in Table 1.

**Figure 1: Locations of Recruitment Sites**



(Note: This pictorial representation does not claim to be the political map of India.)

#### **4. Study populations**

Participants were recruited through the positive people networks affiliated with INP+ and through two community organizations. A majority of the participants were service users of these agencies. In both the quantitative and qualitative components, the following subgroups of PLHA were recruited: HIV-positive heterosexual men and women; HIV-positive MSM; HIV-positive male and female IDUs, and HIV-positive Hijras; and HIV-positive FSWs.

#### **5. Eligibility criteria**

Common eligibility criteria across subgroups of PLHA were: HIV-positive for at least the past one year before the study; over 18 years of age; sexually active in the 3 months preceding the study; and ability to understand and give consent to the study.

For some of the subgroups there were additional eligibility criteria as follows.

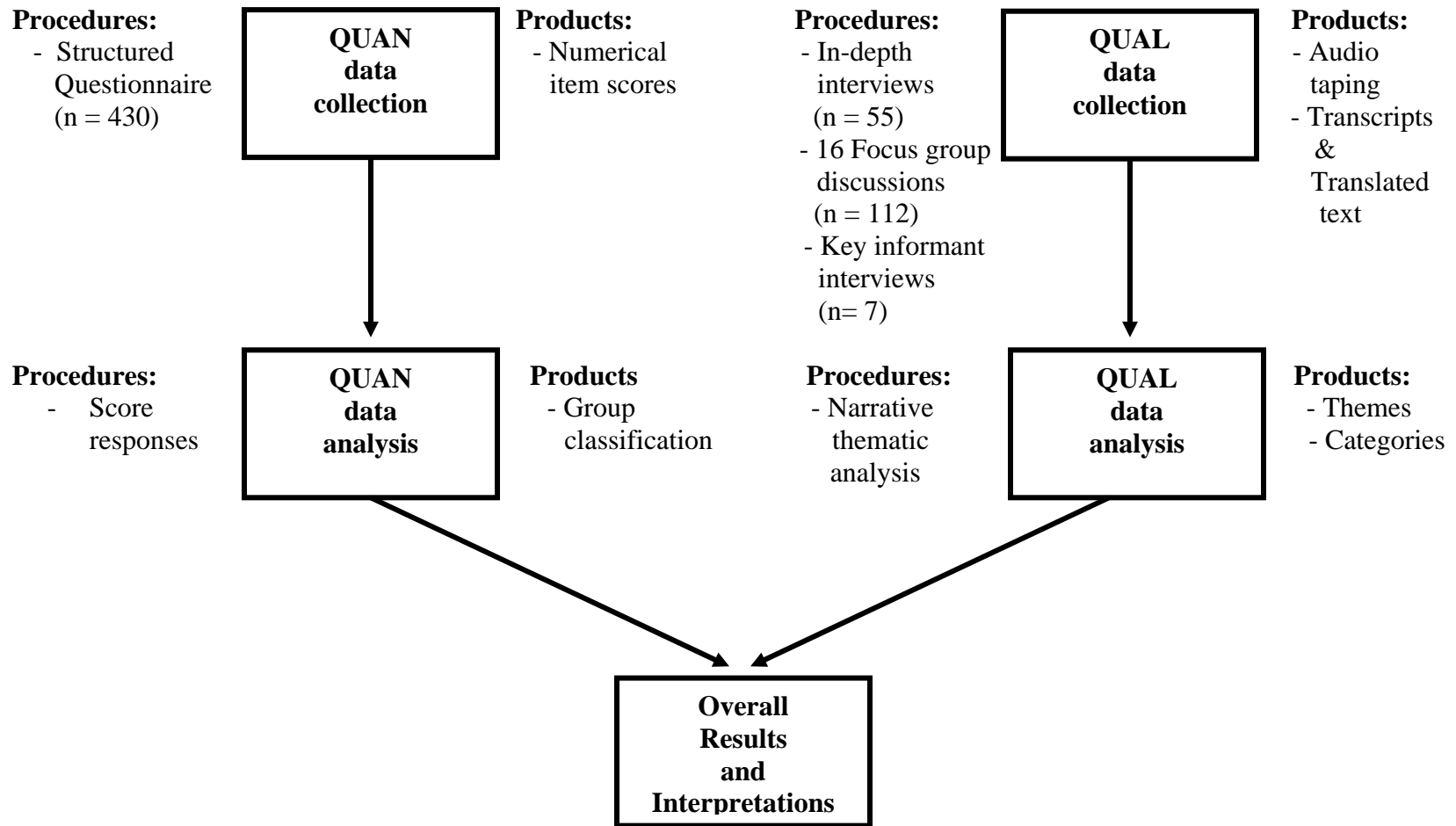
**Female sex workers:** Exchanged sex for money in the past one month.

**Men who have sex with men and Hijras:** Had sex with a man (any kind of sex – manual, oral, anal) in the past 3 months.

**Injecting drug users (men and women):** Had injected drugs in the past 3 months.

**DIAGRAM 1: VISUAL DIAGRAM OF THE PROCEDURE IN THIS MIXED METHODS STUDY**

(Based on the suggestions for visual presentation of the mixed methods study in the book: Creswell JW & Plano Clark VL. Designing and Conducting mixed methods research. Sage publications. 2007.)



## **6. Protection of participants: Informed consent, Confidentiality, and Ethics**

The study protocol was reviewed and approved by a community advisory board constituted by INP+. The community advisory board consisted of PLHA from various subgroups of PLHA. Also, PLHA participated in study development, implementation, and analysis especially to identify and address any ethical concerns. The ethical guidelines of Social Research Association have been followed (<http://www.the-sra.org.uk/documents/pdfs/ethics03.pdf>).

Informed consent was taken from all participants. Participants in in-depth interviews and focus group discussions were paid Indian rupees 250 each (about US \$ 6) to compensate for their time. Key informants were not paid.

At the beginning of each interview or focus group, the interviewees were provided with information about the purpose of the study, and the established conditions for anonymity and confidentiality. The participants were asked whether they had understood the information and if they were still willing to participate. To preserve the anonymity of the participants, they were asked to only make an 'X' mark to denote their consent on the informed consent form so there was no written record of their names. Additional measures taken were: replacing the participant's name with a code number on the tapes and in the transcripts; removal of names, places, and other identifying characteristics from the transcripts; and having the interviewers take a pledge and sign an agreement to keep in strict confidence their discussions with the interviewees.

## **7. Methods**

### **A. Quantitative component (Survey)**

#### **i. Sample size**

A total of 430 PLHA (heterosexual men=100, heterosexual women=100, MSM=60, Hijras or Transgender women=60, FSWs=35, male IDUs=50, and female IDUs=25) were recruited across the sites (details shown in Table 1).

#### **ii. Sampling procedures**

A range of sampling techniques was used to recruit various subgroups of PLHA. While recruitment of heterosexual populations, IDUs, and most FSWs was based on probability sampling techniques, the other marginalized populations were recruited through non-probability techniques.

#### ***Selection of heterosexual populations, female sex workers, and injecting drug users through positive people networks of INP+:***

Using a systematic sampling technique (selection of every Kth eligible PLHA) stratified by PLHA sub-group, eligible PLHA who attended the support group meetings and drop-in centers in the selected positive people networks over a period of two months were recruited for the study. The field research team in each site estimated the potential number of support group attendees from each sub-group being recruited at that site over a period of two months based on which the values of K were chosen. PLHA attending the support groups were approached by the research staff and those who were eligible were recruited. While 25 FSWs were recruited by the systematic sampling technique in Andhra Pradesh sites, 10 FSWs were recruited by the West Bengal Network for PLHA through referrals by an agency working with FSWs (convenience sampling).

#### ***Selection of MSM and Hijras through community organizations***

HIV-positive MSM and Hijras were recruited through snowball and convenience sampling by the community organizations working with them in Chennai and Mumbai.

**Table 1: Details of Study Methods and Sampling**

SLN/DLN or CBO*	State	Number of Survey Participants		Number of In-depth Interviews (IDI)		Number of Focus Group Discussions (FGDs)		Number of Key-informant Interviews (KII)	
		n		n		n		n	
<b>NCP</b>	Tamil Nadu	n = 50	25 HIV-positive men; 25 HIV-positive women	n = 8	4 HIV-positive men; 4 HIV-positive women	n = 2	1 HIV-positive women; 1 HIV-positive men		
<b>SWAM</b>	Tamil Nadu	n = 60	30 HIV-positive MSM; 30 HIV-positive Hijras	n = 6	3 HIV-positive MSM; 3 HIV-positive Hijras	n = 1	HIV-positive MSM		
<b>Guntur</b>	Andhra Pradesh	n = 50	15 HIV-positive men; 15 HIV-positive women; 20 HIV-positive FSW	n = 4	2 HIV-positive men; 1 HIV-positive women; 1 HIV-positive FSW	n = 2	1 HIV-positive men; 1 HIV-positive FSW	n = 2	1 Health care provider; 1 Community leader
<b>West Godavari</b>	Andhra Pradesh	n = 25	10 HIV-positive men; 10 HIV-positive women; 5 HIV-positive FSW	n = 4	1 HIV-positive men; 2 HIV-positive women; 1 HIV-positive FSW	n = 1	HIV-positive women		
<b>The Humsafar Trust</b>	Maharashtra	n = 60	30 HIV-positive MSM; 30 HIV-positive Hijras	n = 7	4 HIV-positive MSM; 3 HIV-positive Hijras	n = 2	1 HIV-positive MSM; 1 HIV-positive Hijras		
<b>NMP</b>	Maharashtra	n = 40	20 HIV-positive men; 20 HIV-positive women	n = 6	3 HIV-positive men; 3 HIV-positive women	n = 2	1 HIV-positive men; 1 HIV-positive women	n = 1	Health care provider
<b>Allahabad</b>	Uttar Pradesh	n = 15	15 HIV-positive women	n = 6	3 HIV-positive men; 3 HIV-positive women	n = 2	HIV-positive women	n = 1	Health care provider
<b>Varanasi</b>	Uttar Pradesh	n = 15	15 HIV-positive men						
<b>Kolkatta</b>	West Bengal	n = 25	10 HIV-positive men; 10 HIV-positive women; 5 HIV-positive FSW	n = 4	2 HIV-positive men; 2 HIV-positive women	n = 1	HIV-positive FSW		
<b>South 24 - Parganas</b>	West Bengal	n = 25	10 HIV-positive men; 10 HIV-positive women; 5 HIV-positive FSW	n = 3	3 HIV-positive FSW	n = 1	HIV-positive FSW	n = 1	Health care provider
<b>MNP</b>	Manipur	n = 75	50 HIV-positive male IDUs; 25 HIV-positive female IDUs	n = 7	4 HIV-positive male IDUs; 3 HIV-positive female IDUs	n = 2	1 HIV-positive male IDUs; 1 HIV-positive female IDUs	n = 2	Health care provider

\*SLN = State Level positive people Network  
 DLN = District Level positive people Network  
 CBO = Community-based Organization

### **iii. Survey instrument**

Unique structured interview questionnaires designed specifically for various subgroups of PLHA were administered by the community interviewers. Information was collected about: sociodemographic characteristics, alcohol and substance use, health and treatment, sexual behaviour and condom use, fertility and pregnancy, contraceptives/family planning methods, reproductive health and knowledge, and sexually-transmitted infections. All questionnaires were originally drafted in English, translated into native languages, back-translated into English, and then finalized in native languages. Questionnaires were pilot tested in the respective native languages and questions were further refined to make the questionnaire comprehensible to the target participants. The participants were interviewed in private rooms in the offices of the implementing organizations or in other places (such as participant's home) agreeable to the participants and where privacy was ensured. No names or any other personal identifying information were collected. Average time to answer all questions was about 40 minutes.

### **iv. Measures**

#### ***Sociodemographic Characteristics***

The information collected included: age, education, employment status, income, marital status and living arrangements.

#### ***Alcohol and Substance use***

Participants were asked whether they had consumed alcohol in the past 3 months; those who drank were asked about days per week of alcohol use and drinks per day on the days they drank. Measures on substance use included: ever used recreational drugs or injecting drugs, type of drugs used in the past 3 months, sharing of needles or syringes, and exchange of sex for drugs or money.

#### ***Health and Treatment***

Measures on health and treatment included: year and place of HIV testing; pre-test and post-test HIV counseling; reasons for undergoing HIV test; knowledge on CD4, viral load, Hepatitis-B and Hepatitis-C; and treatment for HIV.

#### ***Sexual Behavior and Condom Use***

Participants were asked about the number and types of partners and sexual practices with different types of partners in the past 3 months. Two major categories of partners were examined. Regular partner(s) were defined as - "Your main or primary partner with whom you have an ongoing sexual relationship (you might call him/her your lover or husband/wife)." Casual partners were defined as - "Your sexual partner whom you have not met before having sex or with whom you have had only casual acquaintance. You may or may not pay or receive money for having sex with her/him. And she/he is not your regular partner (wife/husband or lover)." HIV status of current male and female regular partners and disclosure of HIV status to partners was collected separately for male and female partners. Frequency of condom use for vaginal, oral and anal sex with different types of partners in the past 3 months was obtained. Participants were also asked whether a condom was used in the last vaginal, oral or anal sex with different types of partners.

#### ***Fertility and Pregnancy***

Female participants were asked about their fertility and pregnancy history and intentions. The measures included: ever given birth, desire for children, number of live born children, reasons for not having children after HIV diagnosis, induced abortion, antenatal care, and information provided during antenatal care visits.



### ***Contraceptives/Family planning methods***

Measures included: type of contraceptives used in the past and currently, reasons for using family planning methods, and information sources.

### ***Reproductive Health and Knowledge***

Participants were assessed about their knowledge and attitudes about reproductive health. The assessment included: ideal number of children for a married couple; chances of a woman becoming pregnant during breastfeeding; whether a woman has the right to decide about her pregnancy; and abortion of unwanted pregnancy.

### ***Sexually Transmitted Infections (STI)***

STI measures included: Whether the participant had undergone any STI evaluation in the past 12 months; place of STI evaluation; experienced any STI-related symptoms in the past 12 months; type of STI-related symptoms; treatment for the last STI-related symptom; and place of treatment for STIs.

## **B. Qualitative component**

Sixteen focus group discussions (with 112 participants) and 55 in-depth interviews with various subgroups of PLHA, as well as 6 key informant interviews were conducted (Table 1).

### **i. In-depth interviews (IDIs)**

A total of 55 PLHA (See Table 1 for details) participated in the in-depth interviews, which lasted about 60 to 90 minutes.

Snowball sampling and stratified purposive sampling techniques were used to recruit these participants. The research staff informed PLHA who were coming to the offices of the positive people networks (or community based organizations) about the study and asked about their willingness to participate. Some participants referred other potential participants to this study (Snowball sampling). To identify the issues of selected categories of persons within the PLHA subgroups (for example, married women, widows), the research staff were asked to specifically recruit those categories of persons (Stratified purposive sampling) (Miles & Huberman, 1994). The topics discussed with the participants included: sociodemographics, HIV/AIDS knowledge, Sexual behaviour, Substance use, Disclosure, Sexually Transmitted Infections, Family planning, Antiretroviral drugs, Desire for having children, Marriage, and Sexual and reproductive health rights and Informational needs.

Informed consent was obtained from all participants, including specific consent for audiotaping of the interview. The interview consisted of open-ended questions to explore the contextual factors under which they had unprotected sex since the diagnosis of HIV infection and also to understand the contexts in which they could practice and sustain safer sex. As categories emerged, subsequent interviews were used to explore the emergent categories and conditions. Therefore, as the study progressed, the focus of the interviews was changed and tailored accordingly based on what was learned from previous interviewees ('progressive focusing').

### **ii. Key informant interviews (KII)**

In-depth interviews were conducted with 7 Key Informants using a semi-structured interview guide. These key informants included the heads of community organizations, PLHA activists, and health care providers. They were selected because of their extensive experiences in working at the grass-root or policy level and for their insights regarding the sexual and reproductive health/rights of PLHA. Topics discussed were: barriers and

facilitators of safer sex and safer injecting drug use among PLHA; accessibility and quality of sexual and reproductive health services (counseling and clinical) for PLHA; availability of family planning options; and opinions on the sexual and reproductive rights of PLHA.

### **iii. Focus group discussions (FGD)**

Sixteen focus groups (with 112 participants) were conducted using a semi-structured open-ended interview guide. Separate FGDs were held for various subgroups of PLHA. The main focus of the discussion was on identifying the various sexual and reproductive health needs of PLHA. The topics discussed with the participants were: HIV/AIDS Knowledge, Sexual behaviour, Substance use, Disclosure, Sexually Transmitted Infections, Family planning, Prevention of Parent-to-Child Transmission (PPTCT), Desire for having children, Marriage, Sexual and reproductive health/rights, and Informational needs. About 6 to 9 persons participated in each focus group and the duration of the discussion ranged from 60 to 120 minutes.

## **8. Data Analysis**

Analyses of quantitative and qualitative data were conducted separately (as explained below) and later compared and contrasted. The following questions were examined when comparing the quantitative and qualitative findings: To what extent do the quantitative and qualitative data converge? How and why? To what extent do the themes identified in the qualitative approach support the survey results? What similarities and differences exist across the levels of analysis? (Creswell, 2007). In the individual discussion sections on quantitative and qualitative findings, similarities and differences, if any, between quantitative and qualitative findings were presented.

### **A. Quantitative data analysis**

All participants were assigned a unique identification number to protect their confidentiality. SPSS version-14 was used for data entry and data analysis. Within each subgroup of PLHA, results for each variable were described using proportions. For each variable, proportions were qualitatively compared across the subgroups. Statistical tests were not performed for these comparisons.

### **B. Qualitative data analysis**

All the in-depth and focus group discussions were conducted in native languages. A few key informant interviews were conducted in English. In-depth interviews, key informant interviews and focus group discussions were audiotaped and then transcribed verbatim in native languages and then translated into English. During transcription, all personal identifiers were removed and a subject/interview code was assigned to protect confidentiality. Transcription and translation of most of the native transcripts were done by professional transcriptionists cum translators, mostly hired from within the respective states. Standard guidelines were given to these persons to ensure accurate transcription and translation. The field research coordinators checked the accuracy of the transcripts by randomly choosing 20% of the transcripts and comparing them with the respective audiotapes by listening to them. Also, they compared almost all the translated texts with the corresponding native language transcripts to find whether the translation had been done accurately with no substantial differences in the meaning. .

Three investigators individually analyzed the cleaned translated texts, followed by team analysis at regular intervals throughout the analytic phase of the project. Interview and FGD data were explored narrative thematic analysis and using framework analysis – the former using the analytic techniques from grounded theory (Strauss & Corbin, 1990). Initial themes were identified using line-by-line coding. Themes were then listed, compared and contrasted

by three independent researchers using a method of constant comparison. Constant comparison is a process through which each piece of data is compared and contrasted with other data to build a conceptual understanding of the categories within the phenomenon of interest. Themes were subdivided in an inductive process according to the data that emerged, and were then applied across all interviews and focus groups. The results correspond to the emergent categories and all representative quotes were drawn from the interviews and focus groups. Findings were arrived at by triangulation of the key informant interviews, focus group discussions and in-depth interviews. We discussed the findings/interpretation at a meeting with the field research team members and selected community representatives from different subgroups of PLHA. The inputs and suggestions were also included as 'feedback data'.

## **9. Validity**

### ***a. External validity (generalizability) of the quantitative component***

Selection of study sites was purposive. Selection of states was based on regional representation and HIV prevalence among different subgroups. Selection of research sites was based on the predominant subgroup of PLHA to which the sites provide services and on the capacity of the sites to implement the research project. While recruitment of heterosexual populations, IDUs, and most FSWs was based on probability sampling, the other marginalized populations were recruited through non-probability snowball and convenience techniques. Most study participants were receiving services from the study site agencies. Thus, no attempt was made to select nationally representative samples of the various subgroups of PLHA, and our findings may not be nationally generalizable, particularly to PLHA who do not receive agency services. However, by using several sampling techniques which are supplementary to each other, an attempt has been made to minimize the possible bias arising from convenience sample (Ritchie, Lewis, & Elam, 2003).

### ***b. Validity of the qualitative component***

#### ***Internal validity/trustworthiness:***

In ensuring internal validity, the following strategies were employed.

*Triangulation of data:* Data was collected through multiple sources – interviews with key informants; interviews with PLHA; and focus group discussions with PLHA.

*Community members checking:* The community advisory board set up by the INP+ provided inputs throughout the analysis process. Community members were involved in most phases of this study, from the study instruments development to checking interpretations and conclusions.

*Transferability:* Rich, thick, and detailed descriptions are provided so that anyone interested in transferability will have a solid framework for comparison. Data collection and analysis strategies have been reported in detail in order to provide a clear and accurate picture of the methods used.

### ***c. Validity (Inference quality) of the concurrent triangulation design***

The threats to validity of this concurrent design have been minimized by using large qualitative samples, using unobtrusive data collection procedures, and addressing similar questions in both quantitative and qualitative approaches (Creswell, 2007).

## **10. Role of the funding source**

The sponsor of the study had no role in study design, data collection, data analysis, data interpretation, or writing the report.

### III. QUANTITATIVE COMPONENT - KEY FINDINGS & DISCUSSION

This study has focused on the sexual and injecting drug use behaviors, and reproductive health of various subgroups of PLHA. We have found many commonalities as well as differences among these subgroups in relation to their sexual behavior and condom use; sharing of needles/syringes; condom use with different types of partners; disclosure of HIV status to sexual and needle-sharing partners; knowledge about CD4, viral load, Hepatitis-B, and Hepatitis-C; knowledge and attitudes about reproductive health issues; and current use of family planning methods. (Though this discussion is primarily about the quantitative findings across the subgroups of PLHA, we have also included relevant information from the qualitative data to point out commonalities and any apparent discrepancies.)

#### 1. Characteristics of the participants

(Please refer to Table 2)

##### ***Study participants were predominantly from lower economic background with limited education***

With the exception of male IDUs, a majority of the participants across the subgroups were poorly educated and from lower economic background. But noticeably, though almost three-fifths of male IDUs completed higher secondary education or college, more than one-third were unemployed. Hijras and MSM were in the higher range of the monthly income compared to other male subgroups. Twenty-seven out of 37 Hijras (73%) who reported sex work as their main occupation also reported a monthly income of more than Rs. 3000. But a similar association could not be found for MSM. Female sex workers were less educated than other subgroups, with 97% not completing high school. Also, the proportion of illiterate persons among female IDUs (32%) and female sex workers (14%) was relatively high.

##### ***Many were living with their regular partner of any HIV status***

Almost all heterosexual men and women were married and lived with their spouse. However, appreciably fewer IDUs, FSWs, MSM, and Hijras lived with a spouse or other regular sex partner. Fifteen percent of MSM and 20% of Hijras lived with their male partner, and 45% of Hijras lived with their 'Guru' (Master or Teacher) or 'Chelas' (Disciples). About one-quarter of married heterosexual men reported their spouses to be HIV-negative (serodiscordant), compared to more than three-fifths of male IDUs. However, more than 90% of married heterosexual women reported their spouse to be HIV-positive; this was expected because almost all reported being monogamous and presumably acquired HIV infection from their husband.

**Table 2: Sociodemographic characteristics of the study participants**

	Men	Women	IDU		FSW	MSM	Hijras
	(n=100)	(n=100)	(n=75)		(n=35)	(n=60)	(n=60)
	(%)	(%)	Men (n=50)	Women (n=25)	(%)	(%)	(%)
			n (%)	n (%)			
<b>Education</b>							
Haven't Completed Primary Education	16	24	1 (2%)		13 (37%)	2 (3%)	5 (8%)
Completed Primary Education (5 <sup>th</sup> STD)	20	21	1 (2%)	3 (12%)	12 (34%)	9 (15%)	19 (32%)
Completed Elementary Education (8 <sup>th</sup> STD)	24	19	10 (20%)	5 (20%)	3 (9%)	20 (33%)	12 (20%)
Completed High School (10 <sup>th</sup> STD)	22	20	9 (18%)	2 (8%)	1 (3%)	16 (28%)	12 (20%)
Completed Higher Secondary Education (12 <sup>th</sup> STD)	12	6	17 (34%)	6 (24%)		9 (15%)	6 (10%)
Completed College Degree	4	2	12 (24%)	1 (4%)		2 (3%)	4 (7%)
Completed Diploma Course	1					2 (3%)	1 (2%)
Illiterate	1	8		8 (32%)	5 (14%)		1 (2%)
No response					1 (3%)		
<b>Current occupation</b>							
House wife		34		3 (12%)			
Unemployed	10	15	18 (36%)	1 (4%)		3 (5%)	
Daily Wage Laborer	41	27	6 (12%)	2 (8%)		10 (17%)	
Government Staff			3 (6%)			1 (2%)	
Private Company Staff	12	7	5 (10%)			22 (37%)	1 (2%)
Voluntary Organization Staff	13	10	1 (2%)			8 (13%)	4 (7%)
Sex worker				16 (64%)	35 (100%)	7 (12%)	37 (62%)
Self-employed	21	3	14 (28%)	1 (4%)		5 (8%)	1 (2%)
Other	3	3	3 (6%)	2 (8%)		4 (7%)	17 (28%)
<b>Monthly income</b>							
No Income	10		18 (36%)			3 (5%)	
< Rs. 1000	10	16	2 (4%)	4 (16%)	3 (9%)		1 (2%)
Rs. 1001 - 2000	36	36	14 (28%)	7 (28%)	12 (34%)	4 (7%)	5 (8%)
Rs. 2001 - 3000	26	20	5 (10%)	4 (16%)	16 (46%)	20 (33%)	21 (35%)
Rs. 3001 - 4000	5	5	3 (6%)	1 (4%)	3 (9%)	20 (33%)	21 (35%)
Rs. 4001 - 5000	5	3	3 (6%)	1 (4%)		10 (17%)	10 (17%)
Rs. 5001 +	5	2	4 (8%)	4 (16%)	1 (3%)	3 (5%)	2 (3%)
<b>Current marital status</b>							
Unmarried	4		15 (30%)	4 (16%)	3 (9%)	46 (77%)	53 (88%)
Married	93	97	29 (58%)	8 (32%)	13 (37%)	14 (23%)	7 (12%)
Separated	2	3		3 (12%)	14 (40%)		
Divorced	1		2 (4%)	7 (28%)	1 (3%)		
Widowed			4 (8%)	3 (12%)	4 (11%)		
<b>HIV status of spouse</b>							
	(n = 93)	(n = 97)	(n=29)	(n=8)	(n=13)	(n=14)	(n=7)
HIV Positive	65 (70%)	89 (92%)	11 (38%)	8 (100%)	3 (23%)	4 (29%)	
HIV Negative	24 (26%)	1 (1%)	18 (62%)		2 (15%)	6 (43%)	4 (57%)
Not willing to answer	1 (1%)	2 (2%)			1 (8%)		
Do not Know	3 (3%)	5 (5%)			6 (46%)	4 (29%)	3 (43%)
No Response					1 (8%)		
<b>Living arrangements</b>							
	(n=100)	(n=100)	(n=50)	(n=25)	(n=35)	(n=60)	(n=60)
Living with spouse	93	97	29 (58%)	8 (32%)	13 (37.1%)	9 (15%)	
Living with other sexual partner	2	2			9 (26%)	9 (15%)	12 (20%)
Living alone	4			5 (20%)	10 (29%)	14 (23%)	21 (35%)
Other	1	1 (1%)	21 (42%)	12 (48%)	3 (9%)	28 (47%)	27 (45%)
<i>Mean Age in Years</i>	34.02	28.28	35.60	31.04	29.69	27.92	31.63

## 2. Alcohol and injecting drug use

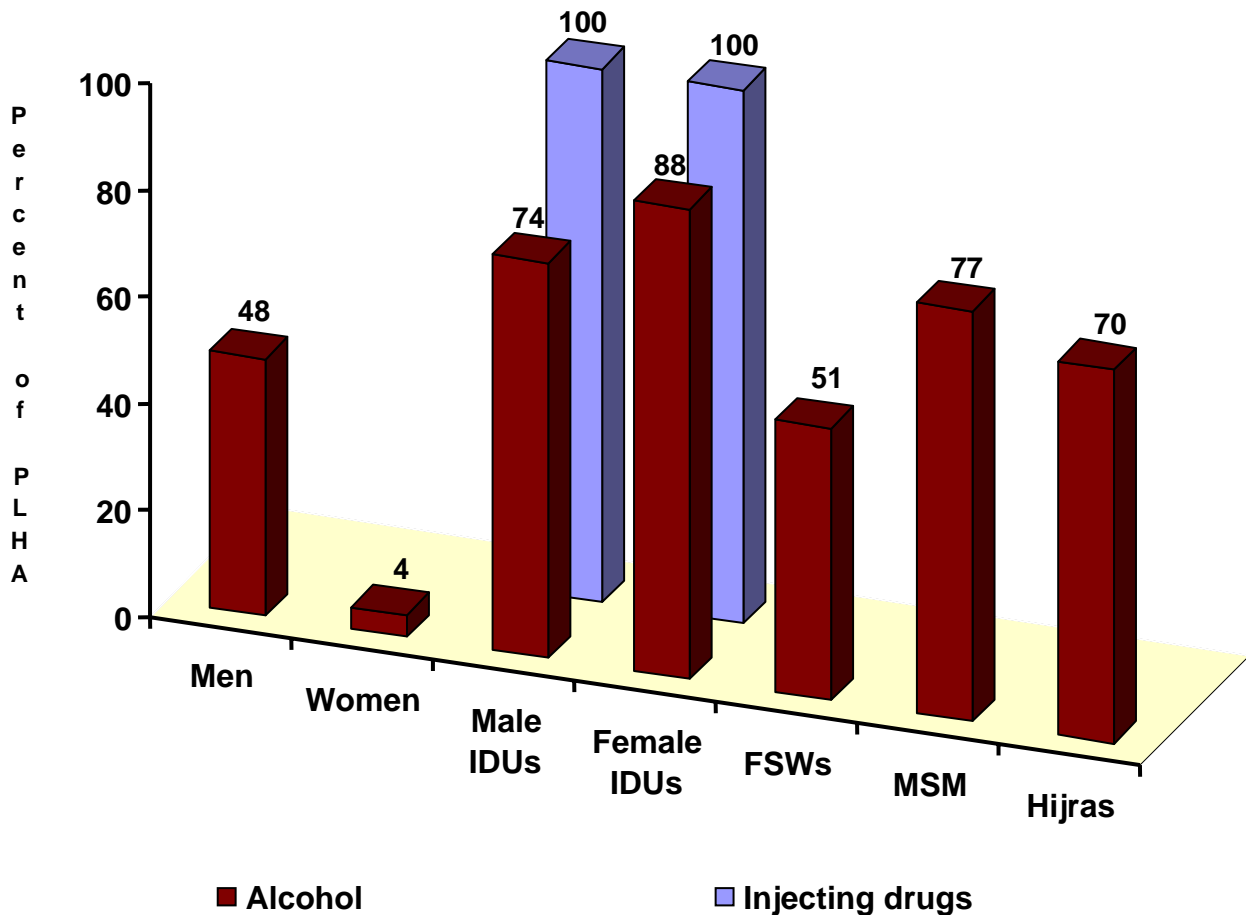
### **Alcohol use was greater among IDUs, FSW, MSM and Hijras**

Alcohol use was found across all subgroups. More than two-third of male IDUs, MSM and Hijras were using alcohol. Among women, alcohol use was high among female IDUs (88%) and FSWs (51%). Alcohol use was strikingly low among heterosexual women (4%), which reflects the commonly observed scenario that a majority of the Indian women do not drink alcohol.

### **None of the participants (other than IDU subgroups) injected recreational drugs**

Apart from the IDU subgroups (male and female), none of the participants from other subgroups had ever injected recreational drugs. Heroin was the most commonly used injecting drug, with all the participants in IDU subgroups having had used it in the past 3 months. The next most common injecting drug was methamphetamine. As mentioned earlier, all IDUs (male and females) were recruited from Manipur, where the predominant mode of HIV transmission is through injecting drug use. In other states of India, the predominant mode of transmission is sexual and hence the absence of injecting drug use in other groups reflects this scenario.

**Figure 2: Alcohol and Injecting drug use in the past 3 months**



### ***A significant proportion of IDUs shared needles with persons of unknown HIV status***

About one-third of male and female IDUs reported having shared a syringe or needle in the past 30 days. All the male IDUs who had shared needles (n=17) did so with persons of unknown HIV status while only about one-third of female IDUs (n=3/8) who had shared with other persons did so with persons of unknown HIV status. Though 'sero-sorting' (sharing needles with other HIV-positive IDUs) was mentioned as one of the HIV transmission risk reduction strategies in the qualitative interviews, the quantitative data from the male IDUs differ from that finding. But, more than half of the female IDUs had shared needles with IDUs of known HIV status (positive). The small number of those who had shared needles precludes arriving at any conclusion but one can note the trend that female IDUs tend to share with other HIV-positive IDUs.

### ***Many female IDUs engaged in sex work for earning money to buy drugs***

None of the male IDUs, but about two-thirds of the female IDUs reported having exchanged sex for drugs or money in the past 3 months. All the female IDUs (n=11) who participated in the qualitative in-depth interviews and focus group reported engaging in sex work to get money for buying injecting drugs but denied having ever exchanged sex for drugs. In the survey, since the question asked was, "In the past 3 months, how many times did you have sex in exchange for drugs or money?" it was not possible to differentiate between those female IDUs who had exchanged sex for money only and those who had exchanged sex for drugs. .

## **3. Sexual practices and condom use**

(Note: All the study participants were sexually active in the past 3 months – since that formed the eligibility criteria.)

### ***Sex with casual partners was reported across the subgroups***

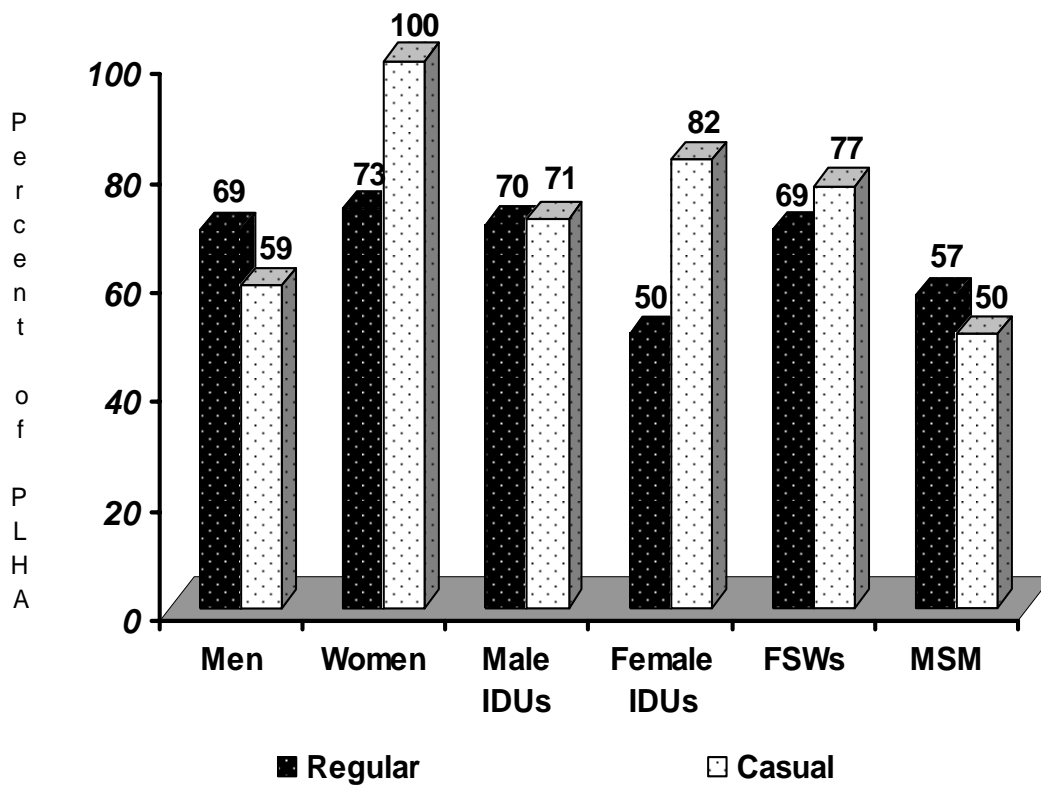
The proportion of those who had casual female partners in the past three months among heterosexual men, male IDUs and MSM was 17%, 28% and 13% respectively. And the proportion of those who had casual male partners among female IDUs, FSWs, MSM, and Hijras was 68%, 100%, 82% and 63% respectively. However, only 3% of married heterosexual women reported having had sex with casual partners in the past 3 months. This is not surprising since most of the heterosexual women, although monogamous, were likely to have been infected by their husbands and to continue to remain monogamous. The three heterosexual women who reported having had casual partners were separated from their husband. Thus, apart from the heterosexual women subgroup, there was evidence for substantial concurrent sexual partnerships even among those who had regular partners.

### ***Condom use was moderately high and most subgroups did not differ in the level of consistency of condom use according to partner type (regular versus casual)***

The proportion of respondents who reported always using condoms with regular compared to casual partners for heterosexual men (vaginal sex) was 69% versus 59%, for male IDUs (vaginal sex) was 70% versus 71%), for MSM (receptive anal sex) was 78% versus 77%), for Hijras (receptive anal sex) was 66% versus 58%, and for FSWs (vaginal sex) was 69% versus 77%. Only female IDUs reported always using condoms appreciably less for vaginal sex with regular partners (50%) than with casual partners (82%). Furthermore, for insertive anal sex, both MSM and Hijras reported always using condoms less with regular partners (50% for both groups) than with casual partners (about 70% for both groups). Participants in the in-depth interviews and focus groups reported that condom use in insertive anal sex was seen to decrease the stiffness and hence make it difficult for Kothi-identified MSM and Hijras to insert. However, this would not explain the difference in condom use with regular versus

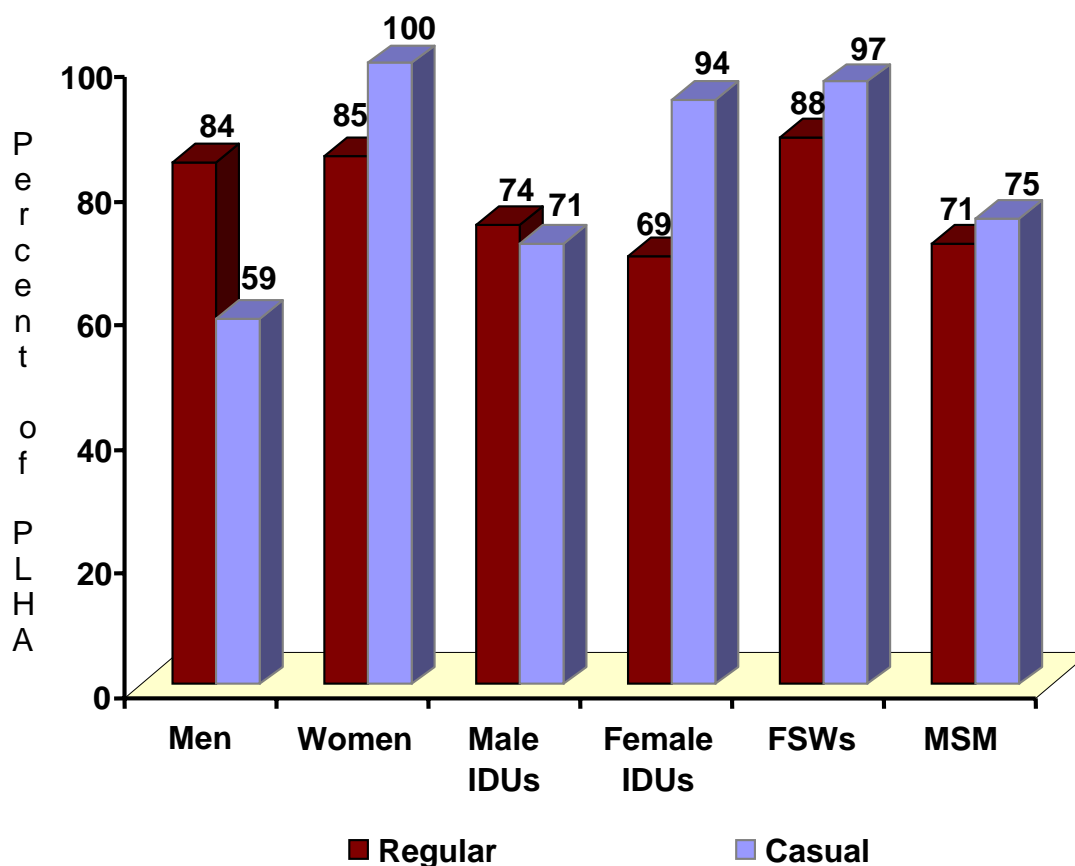
casual partners. Finally, about three-fourths of the heterosexual women subgroup reported always using condoms for vaginal sex with their male regular partners (most of whom were known HIV-positive).

**Figure 3: Consistent condom use for vaginal sex in the past 3 months by partner type**





**Figure 4: Condom use in the last vaginal sex by partner type**



***Condom use in heterosexual anal sex was low***

In general, the frequency of heterosexual anal sex was low (except FSW), and condom use was low among those who engaged in this practice. The numbers were too small to make comparisons across subgroups.

***MSM engaged in insertive anal sex more frequently than did Hijras***

Thirty percent of MSM reported engaging in insertive anal sex with a regular partner in the past 3 months, and 53% reported engaging in insertive anal sex with a casual partner. In contrast, only 7% of Hijras reported engaging in insertive anal sex with a regular partner, and only 12% reported engaging in insertive anal sex with a casual partner. Though the Hijra community frowns upon insertive behavior among Hijras, that some Hijras engage in insertive anal sex is consistent with some qualitative findings reported earlier (Chakrapani V et al., 2002) which documented the practice of insertive anal sex (in addition to receptive anal sex) in a small proportion of Hijras.

***Condom use was high during last vaginal sex in all subgroups and during anal sex among MSM and Hijras***

Condom use during last vaginal sex was around 70% or higher with both regular and casual partners for all subgroups except heterosexual men (84% with regular partners, but only

59% with casual partners). Among MSM and Hijras, condom use during last anal sex (insertive or receptive) with both regular and casual male partners was in the 80% to 95% range, except for insertive anal sex with regular partners, which was around 70%. Although, asking about condom use during last sex may minimize recall error, it may not adequately represent the predominant condom use pattern.

***In all subgroups, condom use with casual partners was moderately high to high despite non-disclosure of HIV status***

Though most of the participants in any subgroup did not disclose their HIV status to their casual partners, condom use was high in the male and female IDU, FSW and MSM subgroups and was moderately high in the heterosexual men and Hijras subgroups. One of the reasons told by the participants in the qualitative interviews for non-disclosure of HIV status to casual partners was consistent use of condoms with them. Since the risk of HIV transmission to the casual partners was reduced or abolished because of condom use, the respondents might not have felt the need to disclose their HIV status. However, a significant proportion of PLHA did not use condoms in sex with casual partners and they also did not disclose their HIV status to them. Disclosure of one's HIV status to sexual partners - even defined as a form of safe sex by some researchers (Marks et al., 1992) – however, may or may not lead to safer sex as noted in some studies (Chakrapani et al., 2006) and also the qualitative findings of this study.

***Condom use with HIV-positive regular partners was lower than condom use with regular partners whose HIV status was negative or unknown***

The proportion of participants who reported always using condoms with HIV-positive regular partners was lower than the proportion who reported always using condoms with regular partners whose HIV status was negative or unknown in heterosexual men (62% Vs 87%), male IDU (50% Vs 79%) and female IDUs (40% Vs 67%). In FSW group, the proportion was almost the same (75% versus 68%) This comparison could not be done for MSM or Hijras because the HIV status of all but one of the regular male partners of MSM and Hijras, respectively, was either HIV-negative or unknown.) Thus, PLHA could have different reasons for having protected sex with partners of different HIV status. Using condoms even with known HIV-positive regular partner means that at least some PLHA might be aware of the health risks posed by unprotected sex to themselves and to their HIV-positive partners. Using condoms with HIV-negative or unknown HIV status partners could be to prevent HIV transmission to those partners. The reasons given for having unprotected sex with partners of different HIV status are summarized in the qualitative findings section.

To sum up, although the frequency of unprotected sex was generally not high, there was room for improvement. Unprotected sex by PLHA poses health risks to themselves (HIV re-infections with new drug resistant strains of virus and STIs) and also poses the risk of transmission to their sexual partners. The various contextual factors behind unprotected sex are discussed in the section on qualitative findings.

**4. A notable proportion of male (but not female) PLHA on ARVs reported inconsistent condom use with regular partners**

About one-fourth of heterosexual men (n=14/45) who were currently on ARVs did not always use a condom when they had vaginal sex with their regular female partner. This unprotected sex places partners (both un-infected and infected) at risk of acquiring drug-resistant strains. In heterosexual women, all of those who were currently on ARVs (n=20) reported consistent condom use in vaginal sex with their male regular partners. Such a comparison was not

possible in the other subgroups (FSW, male and female IDUs, MSM and Hijras groups) due to small number of participants who were on ARVs.

#### **5. PLHA did not receive adequate post-test HIV counseling**

Though about three-fourths of the participants from male and female IDUs, MSM and Hijras (80%, 88%, 73% and 85% respectively) received post-test HIV counseling, only about two-third in heterosexual men and women, and FSW groups (60%, 63% and 69% respectively) received post-test HIV counseling. Since it is important that all PLHA receive counseling about safer sex practices, safer injecting drug use and disclosing their HIV status to their sexual and needle-sharing partners, this is a low figure. Obviously, communicating the HIV test result alone is not sufficient and it is important to provide appropriate post-test counseling to all PLHA that also addresses safer sex and safer injecting drug use. Qualitative findings also showed that information or counseling about safer sex and safer injecting drug use was not provided by all providers and even if provided, was often judgmental, with limited counseling provided.

#### **6. Across all subgroups, knowledge about the CD4 test, viral load test, Hepatitis-B and Hepatitis-C was inadequate.**

While a majority of heterosexual men (57%), male IDUs (66%), and MSM (63%) had correct knowledge about the CD4 test, the majority of heterosexual women (62%), female IDUs (80%), FSWs (97%), and Hijras (57%) did not. Knowledge about the viral load test, Hepatitis B, and Hepatitis C was much worse. Though more than half of male IDUs did have correct knowledge about Hepatitis B and Hepatitis C, lack of correct knowledge among a substantial minority of male IDUs and among most female IDUs means that they are not aware of the risks of acquiring or transmitting these viruses when they share needles. Also, the lack of information prevents many from getting vaccinated against Hepatitis-B, one of the vaccine-preventable diseases. In heterosexual women and Hijras, none had been vaccinated against Hepatitis-B. And in other subgroups, only a very small proportion of participants had been vaccinated against Hepatitis-B: heterosexual men – 4%; male IDUs – 10%; female IDUs – 16%; FSW – 3%; and MSM – 3%). Given the extent of HBV and HCV co-infections with HIV and the related complications in relation to antiretroviral treatment, coupled with lack of free treatment for HCV in public hospitals, correct knowledge about these viruses is urgently needed.

#### **7. The prevalence of STI-related symptoms in the past 12 months was high, and a substantial proportion of persons did not receive treatment for their last STI-related symptom**

Half of heterosexual men, 56% of heterosexual women, 36% of male IDU, 72% of female IDU, 97% of FSW, 53% of MSM, and 33% of Hijras reported having had STI-related symptoms in the past 12 months. The major STI-related symptoms experienced across the subgroups were genital discharges (penile and vaginal), burning pain during urination, itching or burning in the genital area (females), pain during intercourse (females), sores, ulcers or warts in the genital area, anal sores (MSM and Hijras), and growths in the ano-genital area (MSM and Hijras). While at least three-fourth of the MSM, Hijras, heterosexual men, female IDUs, and FSWs had taken treatment for their last STI-related symptom, only 55% of the heterosexual women and 44% of male IDUs had taken treatment. Most of the participants had taken treatment for the last STI-related symptom in government or private hospitals or in the clinics of voluntary organizations.

### **8. Most HIV-infected women, across all subgroups, did not want to have children in the future, whether or not they had ever given birth**

Eight-nine percent of heterosexual women, 91% of FSWs, and 72% of female IDUs had ever given birth. Most women in each of these subgroups did not want to have children in the future, whether or not they had ever given birth. However, of those heterosexual women who had ever given birth, 9% (n=8/89) did so after knowing their HIV status. This means, even after knowing the HIV status some women would still continue their pregnancy for a variety of reasons. Hence, appropriate information and counseling need to be available to women living with HIV so they can make informed decisions about continuing pregnancy and preventing transmission of HIV to the child.

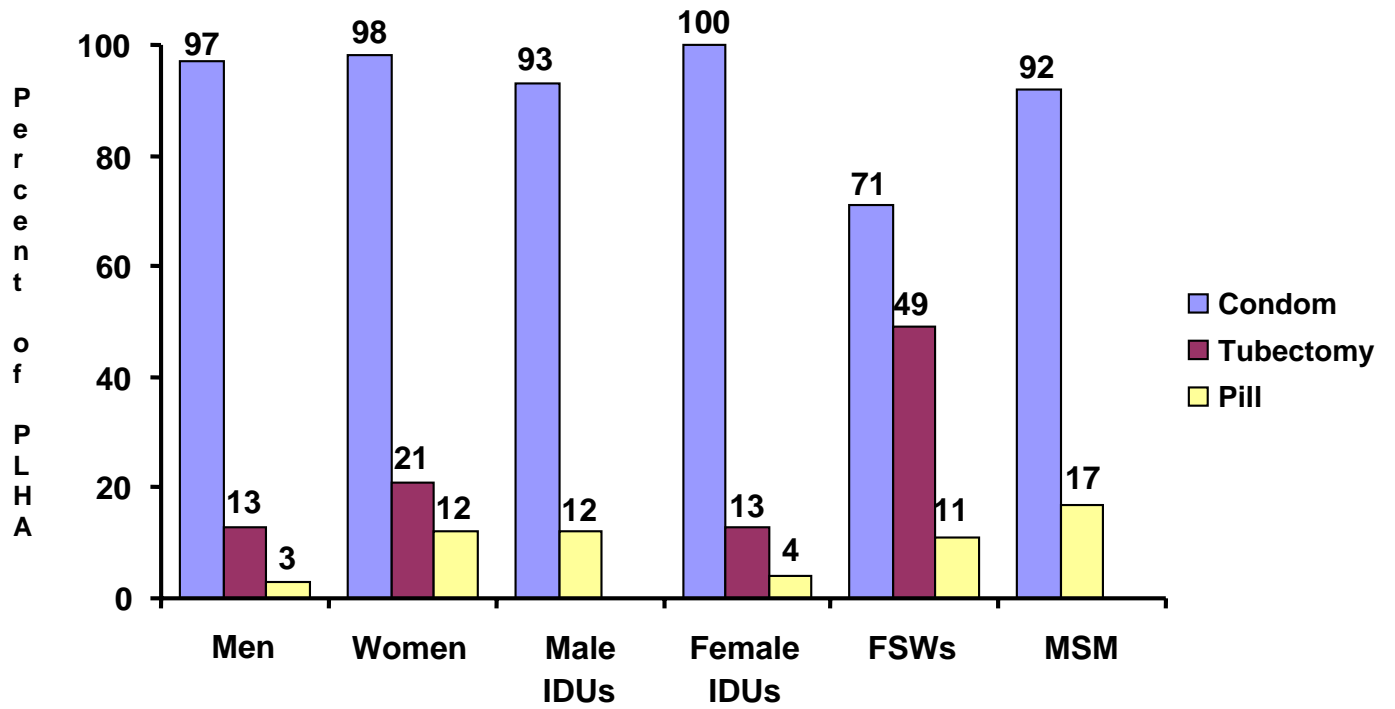
### **9. Induced abortion after HIV infection was not uncommon and may reflect inadequate counseling to prevent unintended pregnancies**

Induced abortion after knowing of HIV infection was reported in all subgroups of women - heterosexual women (16%); female IDUs (24%) and FSW (11%). The main reason given for induced abortion was fear of giving birth to an infected child, although some women reported that they or their partner did not want more children or that the pregnancy was life-threatening. The women who underwent induced abortion might not have received adequate information about contraceptives and family planning methods which might have led to unintended pregnancy. Also, it is possible that some of women might have been coerced by the health care providers to undergo abortion as expressed by some of the participants in the in-depth interviews and focus groups. Dual contraceptive methods (condoms along with another contraceptive) should be promoted to women who do not want to become pregnant.

### **10. Condoms were topmost in the list of contraceptives used followed by tubal ligation**

Among the PLHA who reported currently using contraception, all female IDUs, 98% of heterosexual women, 97% of heterosexual men, 93% of male IDUs, 92% of MSM, and 71% of FSWs reported using condoms. This was because it is more likely to be seen as a dual protection method (protection against infections and pregnancy). The next most common method reported across the subgroups was tubal ligation, which was particularly high among FSWs (n=17/35). In the qualitative interviews, participants mentioned that they were often coerced by health care providers to undergo tubal ligation. Using oral contraceptive pills was reported by a small proportion (ranging from 3 to 17%) of the participants across the subgroups. Qualitative interviews revealed that the low use of contraceptives other than condoms could be due to overestimation of the risks posed by using oral pills, intrauterine devices and tubal ligation. However, a small proportion used dual methods (condom along with another method like pills or tubal ligation) possibly to prevent re-infections as expressed in qualitative interviews. Qualitative findings also revealed lack of male involvement in family planning counseling that has led to the greater burden posed on women on using family planning methods (other than condoms) especially permanent contraception methods like tubal ligation. Only 4 men were reported to have undergone vasectomy (male permanent sterilization).

**Figure 5: Type of contraceptives used by different subgroups of PLHA**



## IV. QUALITATIVE COMPONENT - KEY FINDINGS & DISCUSSION

### ***Characteristics of the participants***

Qualitative component included sixteen focus group discussions (with totally 112 participants), 55 in-depth interviews with various subgroups of PLHA, and 6 key informant interviews (Table 1). The characteristics of the participants who participated in these interviews and focus group discussions are summarized below.

### ***Characteristics of the In-depth interview participants***

A total of 55 in-depth interviews were conducted among different subgroups of PLHA (see Table 1 for details). The mean age of the participants was 30.6 years. Among these 55 PLHA, 49% were currently married, 38% were unmarried, and 7 were widowed. Twenty-seven percent of the participants had completed high school. Of those who were employed, 48% were staff of voluntary organizations.

### ***Characteristics of the participants of FGDs***

In the 16 FGDs, a total of 112 PLHA participated. The age of the participants ranged from 20 to 48 years (Mean age = 30.5). Thirty-seven percent of participants had completed high school. Eighty-two percent of the FGD participants were employed at the time of interview. Of those who were employed, 39% were sex workers, and 33% were staff of voluntary organizations. Two-third (63%) of the participants were currently married and lived with their spouse.

## **A. CONTEXTUAL FACTORS REGARDING UNPROTECTED SEX AMONG PLHA**

While many PLHA have adopted safer sex practices, as seen in the quantitative findings, some PLHA were unable to consistently practice safer sex. This section focuses on the various contextual factors reported by different subgroups of PLHA regarding unprotected sex with their regular, casual, paying and paid partners. While some of the factors appear common to all participants (such as decreased pleasure with condom use) others are more specific or unique to a particular subgroup. As such, reported contextual factors are summarized by subgroup.

### **1. CONTEXTS IN WHICH CONDOMS WERE NOT USED BY HETEROSEXUAL COUPLES (including IDUs)**

#### **a. Non-disclosure of HIV status associated with unprotected sex**

Many men expressed fear of rejection and possible separation from their wife if they were to reveal their HIV status. They discussed their sense of helplessness in continuing to have unprotected sex with their wives since they felt using condoms or decreasing the frequency of sex could raise suspicion.

#### ***Wife unaware of his HIV status – She does not want to use condoms***

“Once I tried [using condom]. She did not like to use condom. She often told me why we should use condoms since we are husband and wife...”

#### ***Fear that wife can discover he is HIV-positive if he insists on condom use***

“...No...never [used condoms with wife]...once when I used condom she raised questions so from then onwards I never used condoms...”

*Need to satisfy girl friend for fear of losing her*

“In another words, there is a fear of flirtation [means she might go to other men] ... so even though I practice safer sex eight times out of ten times with my girl friend, the remaining two times I do without condoms”. This HIV-positive IDU, in absence of disclosure, tried his best to always use condoms when he had sex with his girl friend. But since she liked to have sex without condoms, occasionally he did not use condoms.

**b. Assumption that wife must be positive by this time**

Some men believed it likely that their wives had already contracted HIV from them. As such, they felt no need to use condoms or disclose their status. Further, they did not suggest their wife to get tested for HIV.

“In 2005 I knew my status. During my long course on drugs I never had sex with women other than my wife. My children looked healthy. I think my wife might be positive as our sexual relation is a bit much longer.....yet I have not tested her. Now my wife has come out with some symptoms like skin infections on her body so I plan to test her soon.”

**c. ‘Both of us are positive – So why condoms?’**

If both husband and wife are HIV-positive, they believe it is acceptable to have unprotected sex occasionally. Some noted diminished sexual pleasure if a condom was used.

*No sexual satisfaction*

“...When I do it [have sex] without condom I get full satisfaction. My wife knows that I am positive. My wife also felt that as both of us are positive she also agreed to have sex without condom...”

*To use or not to use?*

“Some times I feel like using it, some time not...Main reason is, there is no satisfaction....Yes, ‘Both of us are infected so what is the necessity in using condoms’ – thinking in this manner we won’t use condoms.” (An HIV-positive man)

*Once in a while it is okay to have sex without condoms*

“...one or two times it was done without condom...thinking that I am doing it to my own wife. Like this, I did it [sex without condoms] once or twice but not frequently.”

**d. ‘Heat of the moment’ and Intimacy**

Some individuals – both men and women – indicated condoms were a barrier to achieving passion and intimacy. As a married woman explains: ““We use regularly. But whenever we were in ‘excessive emotion’, they [condoms] are not used. Some times, it is not properly worn.” (Both husband and wife are positive). A HIV-positive man explained why he did not use condoms with his positive wife. ““Now my wife has already got it. We have so much love for each other that whenever we have sex she would say ‘Oh Ji! Why are you using condom? Let us do [have sex] without it [condom].””

**e. Forced sex without condoms by husbands (under influence of alcohol or drugs)**

In instances where men were under the influence of alcohol or drugs, individuals noted a higher likelihood of unprotected sex. As explained by a woman and a man – below.

*Husband under alcohol influence*

“Yes, one or two times it [forced sex by husband] happened...Only when he is drunk such things happen...he troubles me by asking to do so [forcing to have sex]...no condom in such situations.”

*Drugs prevent from using condoms with wife*

“I know my [HIV] status but sometimes we feel we do not want to use condom... In such situation [under drug influence], we forcefully do it [sex with wife] without condom but repent later.”

**f. Wife wants a child**

Some men indicated their wife insisted on unprotected sex in order to conceive. Even in cases where HIV-positive men were practicing safer sex, they felt compelled to have unprotected sex even at the risk of infecting their wives. This was found among both men who had disclosed their HIV status to their wife as well as men who had not disclosed their HIV status.

*Wife wants one more child – Wife is unaware of husband’s status*

While discussing an HIV-positive friend, a participant said: “As they have only one child, his wife wanted another child. In order to hide his secret, he again started not using condoms...thus he has three children...told his wife when his condition became critical. His wife and two children were found to be positive.”

*Wife wants a male child – Wife is aware of husband’s status*

“I have two daughters and they were found to be [HIV] negative. Consulting with my wife, we are planning to have a boy child...we tried twice [means had unprotected sex twice]. Earlier we always used condoms. After we came to know she had become pregnant we consulted doctor and after that as per doctor’s advice we always use condoms.”

**2. CONTEXTS IN WHICH CONDOMS WERE NOT USED WITH FEMALE CASUAL PARTNERS**

**a. Safer sex is the partner’s responsibility: Wants ‘full’ sexual pleasure from casual partners**

Men, especially IDUs, reported that they expected “full” sexual pleasure during casual sex, and thus were disinclined towards condom use with their casual female partners or FSWs. Further, men tended to shift responsibility for safer sex negotiation to their female partners, and presumed their partners accepted unprotected sex unless they demanded otherwise.

*With casual female partners*

“I do have sex with women other than my wife. The women with whom I have sex will ask me whether I want to use condom or not. That means, she has no objection whether I use condom or not. I want full pleasure I did not use [condom]...”

*With female sex workers*

“...I again had vaginal sex...I did not use condom. As she was also a drug addict she did not refuse...she wants only the money...I wanted pleasure.”

**b. Unplanned sex – No condoms used**

Male participants reported that they were unable to engage in safer sex because many of their sexual encounters were not planned in advance and they did not always carry



condoms. Further, they were not inclined to leave to purchase condoms 'in the heat of the moment'.

*With casual female partner - "Sex by accident"*

"...I was having that sex without any plan, [not] carrying condoms in my pocket, it was just like an accident. I have not had any idea that the girl whom I know there in the party...we were enjoying the party...we forgot to take condom...if we had the condom by chance, we would have used it".

*With female sex worker – 'Heat of the moment'*

"When my sexual feelings become stronger I go to pharmacy or to DIC [drop-in centre] and take some condoms...but if I meet them [sex workers] suddenly from where I can take condoms? On such situations, I did not use condoms."

### **c. Assumption that female sex workers are positive – hence no condoms**

A participant mentioned that since he believed most sex workers to be HIV-positive he did not use condoms with them. He argued that since he contracted HIV from sex workers, they were likely to be HIV-positive and there was no need to use condoms. As he said, "...when I had sex with sex worker, since I am positive they may also be positive...[hence] I sometimes did it [had sex] without condoms."

### **d. Alcohol use prevents condom use or increases condom breakage**

In a FGD, a male participant discussed why IDUs have problems using condoms when they are under the influence of alcohol: "When we are high on alcohol, we are unable to use condoms in a proper way or we become careless about it [means not use condoms]. Sometimes they do it without condoms or sometimes they did not realize that the condom is torn".

## **3. CONTEXTS IN WHICH CONDOMS WERE NOT USED BY HIV-POSITIVE FEMALE SEX WORKERS**

**(Note:** This section includes findings among HIV-positive female IDUs who engage in sex work)

### **a. More money offered: No Condoms**

Many FSWs indicated they were unable to negotiate condom use with their clients. In fact, many clients persuaded them not to use condoms by offering more money.

*Clients insisted and FSW could not convince them to use condoms*

"We have to perform sex with all the clients. We need money. Some client give 50 Rupees, some give 100 rupees. They do not want to use condom. Those clients give more money we have to obey them. Some clients are drunk. The clients who pay less money, we use condoms after making them understand."

*FSW needed additional money provided by accepting to have unprotected sex*

"One day her [friend of a FSW] son was sick and doctor advised for blood test. She had no money and requested her elder daughter but she declined. On that day, a customer came to her. He was fully drunk and compelled my friend to have sex without condom. She did it because she needed money for her son...several times she protested but he was fully drunken and paid no attention to her."

*FSW does not want to lose client*

“...I asked them (clients) to use condom. Some will agree. But some *Kamine* [mean fellows] tear the condom with their fingernail at the time of sex. If I compel them to use, they say that they do not get pleasure using a condom. Will say [other wise] I will see other place.”

#### **b. Alcohol use (by self or clients) decreases condom use**

If clients are under the influence of alcohol, then often they do not want to use condoms. It is difficult to negotiate with them to use condoms. Even if a FSW is able to put a condom on her client, the client generally tears off the condom or removes it. Occasionally, FSWs are able to put a condom on without the client's knowledge.. Sometimes, the customers also intoxicate the FSWs with alcohol so they are less able to be aware of and express concern regarding condom use..

“Most customers used to come drunken and used to have sex without condoms. They want to give more money for not using condoms, if again we request for condom, want to give more money. Some customers ask us to have drinks. Since they are paying more so we have to give company [drink with them]. What to do – because we need money for treatment and for children and family.” (A female IDU who engage in sex work)

“He was drunk and forced me to drink...[I] drank without my wish. What can I do? He gave me 200 rupees...I was unconscious. He did it [had sex] in my back without condom. Next day I was not able to walk straight.” (A FSW who is not an IDU)

#### **c. Partner did not believe in the disclosure of HIV status**

Though a FSW revealed her HIV status to her regular partner he did not believe her because she looked healthy. As a result, no condoms were used.

“I disclosed my status to one of my temporary (regular sexual partner) husband. But he was not prepared to use condom. He said ‘Oh! Do not tell lies. You look so healthy.’... Then I said do not tell like this [without condom]. It [HIV] may attack you. He replied ‘Let it come. [If] it comes I will be the loser. Let us enjoy.’”

#### **d. Forced sex by ruffians**

Many FSW talked about forced sex by ruffians and they could not report them to police. “They [ruffians] came to us. They force us to do (sex), even if when I am sick. They beat me. ..Put burning cigarette on my hand. [They] removed my clothes...bite my whole body scratched my body with their nail. [They] did (sex) without condom. I could not do any thing.”

#### **e. ‘Not my responsibility’**

Though some FSWs did insist that their clients use condoms, some FSW may discuss condoms but not insist upon them. As such, some of them have unprotected sex with those clients. “I ask my clients to use condom... also give hints about the disease. If they are not using then why should I bother? Anyway I am going to die.”

#### **f. Non-availability of condoms**

Sometimes lack of availability of condoms can lead to unprotected sex with clients. A FSW told: “...once we went to a hotel. I did not have condom. My client also did not have condom...It was late night. The medical [shop] was closed. Where do I get condom? I had to do without condom.”

**Box 1: CONTEXTUAL FACTORS REGARDING UNPROTECTED SEX AMONG PLHA**

**1. Contexts in Which Condoms Were Not Used By Heterosexual Couples (Including IDUs)**

- a. Non-disclosure of HIV status since fear of rejection by wife
- b. Assumption that wife must be positive by this time
- c. Felt there was no need to use condoms since both were positive
- d. "Heat of the moment" and Intimacy
- e. Forced sex by husband under alcohol or drug influence
- f. Desire to have a child

**2. Contexts in Which Condoms Were Not Used With Female Casual Partners**

- a. Wants 'full' sexual pleasure from casual partners and thus no condoms
  - b. Unplanned sex – No condoms used
- c. Assumption that FSWs are positive – hence no condoms
- d. Alcohol use prevents condom use or increases condom breakage

**3. Contexts in Which Condoms Were Not Used By Female Sex Workers**

- a. More money was offered by male clients
- b. Alcohol use (by self or clients) decreases condom use
- c. Partner did not believe in the disclosure of HIV status
- d. Forced sex by ruffians without condoms
- e. Not seen as their responsibility to always use condoms
- f. Non-availability of condoms

**4. Contexts in Which Condoms Were Not Used By MSM and Hijras**

- a. No sexual satisfaction when condoms are used
- b. Love and Intimacy with male lover
- c. More money offered by male clients for having unprotected sex
- d. Alcohol use, Forced sex, and Condom use
- e. Regular partner does not like using condoms

**4. CONTEXTS IN WHICH CONDOMS WERE NOT USED BY HIV-POSITIVE MSM and HIJRAS**

**a. No sexual satisfaction when condoms are used**

Some participants reported that condom use reduced sexual pleasure for both themselves and their partners.

"Some say 'We are not getting fun...[when] we use condom'...they do it [have sex] without condom." (A Hijra)

"I know about condom use...but sometimes the pleasure is not there if we use a condom. That is why I do not prefer to use condom." (A Kothi-identified MSM)

**b. Love and Intimacy with male lover**

In spite of disclosure of HIV-positive status, the regular partner of a Hijra insisted on not using condoms. As this Hijra explained "Sometimes I tell him to use condom - 'I have no one and you may get my disease' - then he says "If we die, we'll die together, why we [need to] use condom?" I tried to make him understand but he won't listen... Now for the past two months we have started doing it with condom. He is [now] using condom and I'm also feeling good because of this."

Fear of rejection and separation from their male lover prevented some Hijras and MSM from revealing their HIV status and using condoms. A Hijra said, "With my "husband" [male lover] I never use condom...he knows that I used to go [for sex work] and he knows I won't work without condom. Hence he is not using condom and all with me...No I didn't tell him about all these things [HIV status]... I thought it won't be good to tell him and he loves me and I'm afraid he will leave me if I tell him about these all."

A Kothi-identified MSM conveyed similar reasons for not using condoms with his regular male partner. "Once I asked him to wear condom. He asked 'Why? You have disease?' If I tell about me [HIV status] to him, he will not come to me. He will not have sex with me. [Hence] I do sex without condom. He must not even be thinking that I have this type of disease."

### **c. More money is offered for unprotected sex**

Some MSM and Hijras who engage in sex work reported that they would sometimes not insist on condom use if additional money was offered for unprotected sex.

"Yes, now it is five-six years since he left my house, now I have no one to care about and if I get someone, who is ready to pay me 1000 to 2000 rupees, I'm ready to do it happily without condoms." (A Hijra)

Yes, when I go for [sex work] very good and wealthy people come there, in ...good cars, there will be officers and normally our rate is 200 Rupees but they will offer 1000 Rupees for doing it [having sex] without condom and when I will be in need of money...some times it happen without condom because of our helplessness." (A Hijra)

" I told him that I may have disease. But I did not tell I already have. So he told me 'I will not use condom. Can you come or not?' Then I told I will come. He did it [had sex] without condom and paid me 200 Rupees." (A Kothi-identified MSM who engage in sex work)

### **d. Alcohol use, Forced sex, and Condom use**

Under the influence of alcohol, participants and their partners were not as able to use condoms. Participants also reported forced sex with clients who were under the influence of alcohol.

"One day it happened like this. We were sleeping in our room. There are two lads in our area - they are very cheap people. And they were thinking about doing sex with me for many days but I opposed doing sex with them. They had forced sex with me and that time it happened without condom. They were drunk ...one held my hands and the other was doing wrong [sex] that too without condom." (A Hijra)

"Once what had happened you know? One of my customers offered me alcohol. Then I went with him to drink alcohol. I found there two more. They were drunk and I was also fully drunk. Then they forced me [to have sex]. All three did [had sex] without condom." (A Kothi-identified MSM who engage in sex work)

"Once I met 3 policemen from [place]. It was one o' clock at night. I was returning home after watching a movie. They came on my way. They told 'Hey! Come here. Where are you going? Are you a [derogatory term].' They were drunk. One of them caught me tightly. One was inserting on my back. Another was giving in my mouth. They had also beaten me. In

that situation I was not even able to tell them my status... They did it without condom.” (A Kothi-identified MSM)

#### **e. Regular partner does not like using condoms**

Some participants reported that their regular partner’s behaviors are beyond their control. Even if they convince them to put on the condom, their partner might throw it away or tear it. They felt helpless in such a situation as they did not want to jeopardize or break the relationship with their male regular partner. As a Kothi-identified MSM explains: “ He (regular partner ) asked me for (sex). I thought he would put on condom. He started to do... I could not know whether he used or not since I did not see. Later when I turned he removed the condom and threw it. What could I do? I can not scold him.”

### **B. CONTEXTUAL FACTORS REGARDING NEEDLE SHARING OR UNSAFE INJECTING DRUG USE BEHAVIORS AMONG HIV-POSITIVE IDUs**

These findings are based on two focus groups (n=16 participants) and 7 (4 males, 3 females) in-depth, semi-structured interviews conducted with HIV-positive IDUs in Manipur, India.

#### **Box 2: CONTEXTUAL FACTORS REGARDING NEEDLE SHARING AMONG HIV-POSITIVE IDUs**

1. Withdrawal symptoms supersede rational behaviour
2. Barriers to carrying sterile syringes
3. Limited access to pharmacy-sold syringes
4. No money to buy syringes
5. Non-availability of syringes in prison

#### **1. Withdrawal symptoms supersede rational behaviour**

Many HIV-positive IDUs attributed sharing of needles or using unclean syringes to the severity of their withdrawal symptoms. When their withdrawal symptoms begin, their need for the drug supersedes all other concerns, even as they may have knowledge of infection risks.

“There are so many obstacles in carrying syringes in our pocket since in this present society. There are many organizations that ban [against] drugs – though syringes are abundantly available at the drug peddlers’ place...I know that one syringe costs only five rupees. Even I can take them free of cost from DIC (drop-in center) but during my withdrawal I go directly to the [drug peddler’s] spot and whatever syringes are available – they are mostly already used ones – [I use it]. Everyone wash it with water we did not wash it properly [even]. It does not mean we did not realize what we have done but the realization comes only after we had drugs...”

“It is mainly due to our withdrawal syndrome ...at that very moment we forget about disease [HIV]. As a result, we are not afraid of taking the risk.”

“The number-one reason why IDUs share needles and syringes is the fear of public; number-two reason is drug craving and number-three reason is we are not giving importance to new needles and syringes – we give importance – more focus on drugs. That is the matter”.

## **2. Barriers to carrying sterile syringes**

Barriers to carrying clean syringes, including fear of arrest, force IDUs to choose unclean syringes available in a drug peddler's spot. Since drug peddlers may not allow IDUs to take the drugs out of the spot because of fear of police, IDUs have to inject with whatever syringes are available in the spot.

### ***a. Lack of sterile syringes in the drug peddler's place***

"In my locality drugs are easily available, very near to this drug peddlers' house....there was also a police station. For me, it is not only that the police will catch me but also my negligence. As a result I did it [with used syringe] on the [drug peddler's] spot. Due to my withdrawal symptoms even there was a time when I injected it with someone's blood inside that syringe. And there was a time when my syringe fell inside the latrine and I took it out and inject with it. All these things are due to my negligence....my first priority is always given to drugs..."

*Peddler does not allow IDUs to take drugs outside the spot*

"I went to the spot but the peddlers were not allowing me to take drugs away [fear of police] instead they insisted that it had to be done on the spot...I did it with the syringe available there [used one]."

### ***b. Lack of new syringes makes heroin users inject first and then share with spasmoproxyvan (SP) users***

Though some HIV-positive IDUs mentioned risk reduction strategies like being the 'last receiver', they also mentioned why they are occasionally forced to share their syringe. When they are with SP injection users at a drug peddler's spot and there are only one or two sterile syringes available, they prefer to inject first since they can not wait until SP users (whose HIV status they may not know) finish.

"Yes, sometimes [we use first]. Those people who use SP tablets block all their veins – unlike us who use heroin. So they take much longer time but for us it takes only five or six seconds. ...we sometimes help them...sometimes we inject in their neck vein. So they take long time to do it ...we do first and with the same syringe they do after me...yes, I tell them I am positive. So I ask them to wash it properly. We did the same thing earlier – some people told us and some did not."

### ***c. Fear of arrest if syringes are carried***

"While when I was carrying a syringe in my pocket, on the way, I run into some policemen frisking on the road [since Manipur is a high conflict area]. They found me with the syringe. As a result...they knew me I was a drug user. They detained me and trying to get me to police station. Luckily...I was let free. Then afterwards, whenever I go for drugs I never carry syringes...whatever is available at the spot of drug-peddler's I use it. ...that is how I started using needles and syringes with other people. "

"...sometimes when we go to buy drugs we face tight security. In such situation if we do not carry any syringes...we do it with whatever syringes that were available in the [drug peddler's] place.

### ***d. Fear of harassment by anti-drug pressure groups if syringes are carried***

In addition to the police force, IDUs also face problems from self-professed 'anti-drug' agencies whose actions, in spite of their possible good intentions, are described by IDUs as a kind of harassment. This also deters many IDUs from carrying syringes with them.

“I am also one of the dug users who share needles and syringes. Due to fear of organizations like [...], I do not want to take the risk of carrying syringe on my own. So it is better to go to the spot and whatever syringes available at the spot I use them”.

### **3. Limited access to pharmacy-sold syringes**

Though some IDUs reported they are able to buy syringes from pharmacies, others reported that they still have a hard time convincing the pharmacists to give them syringes. Also, since the pharmacies are often very far from the shooting galleries (Manipur also being a hilly area) they do not find any pharmacies nearby to buy syringes from. Sometimes, the fear of being identified as an injecting drug user by the pharmacist prevents some from buying syringes from pharmacies.

“...most of the time pharmacists are very strict so we hardly buy syringes from the pharmacy. So [we] buy one syringe and we use it several times.”

“We, sometimes, inject in top [of the hills]...to avoid others [police]. To get a clean syringe there is not possible.”

“We are worried about buying syringes...might expose to other people that we are drug users. For this reason, we use the old syringes”.

### **4. No money to buy syringes**

#### ***a. No money left after buying drugs***

Though the cost of a sterile syringe is very low, IDUs may be left without any money after buying drugs and thus may not bother getting clean syringes – especially if they are not economically independent.

“After buying drugs, there would not be even one paisa [penny] left in our hands. In that case we have to use the old syringes...”

“...one shot costs 50 rupees [US \$ 1.25]... if there is no source of income than naturally for a woman this [sex work] is the easiest way to earn money...in such case she may not be interested in buying clean syringe every time”. (A female HIV-positive IDU talking about why some women do not use clean syringes).

#### ***b. High injection frequency - Need for more syringes***

Sometimes, the supplies by NGOs or outreach workers do not match the demand of injecting drug users. High frequency of injections also discourages IDUs from spending money on syringes.

“I use number-4 [heroin injection] everyday ...for me it takes...around 40 syringes in a month...sometimes I had to share ...or use old [unclean] syringes”

“I take [inject] almost daily...I could not spend money for new syringes also daily...Yes, I pick up some [syringes] at NGOs”.

### **5. Non-availability of syringes in prison**

The lack of availability of sterile syringes, in spite of the availability of injecting drugs, inside prison means sharing of syringes among the inmates is common.

"Inside the jail I met many of my friends. I somehow get money from my family and I started using it [drugs] inside the jail. Outside the jail I never shared syringes with others...inside the jail we do not have syringes; the police sold it for Rs.100 (about 2.5 US \$) per syringe. So if I buy a syringe then I can get drugs free of cost [from friends who buy drugs]. In this way, we started sharing syringe...some times we share it after cleaning with bleach water...when police asked we told them that we used it for washing clothes".

**Box 3: Risk-Reduction Strategies Adopted By HIV-positive IDUs To Prevent Transmission To Other Needle-Sharing Partners**

HIV-positive IDUs adopted various strategies in an attempt to reduce the risk of HIV transmission to other IDUs as summarized below. These strategies, however, place HIV-positive IDUs at risk of contracting Hepatitis-B/Hepatitis-C and other HIV strains.

**1. Being a "receiver" of syringes and not a "giver"**

"I always get from others...I don't share [means give to others]...No, They do not know [HIV status]."

**2. Being the "last receiver" of the shared syringe**

"I did not know their [needle-sharing partners'] status...[But] I have always told them about my status. I let them do it first – after that, I do it."

"I always tell my status to my friends. So I prefer to be the last one to inject drugs in the slot."

**3. Asking others to wash used syringes with bleach**

"I tell them [other IDUs] to wash with bleach or water...They may not want to do it but insist...I got this [HIV] because someone did not ask me to do so [wash syringes]. Now, I have to do it."

**4. Through 'sero-sorting' (Sharing syringes only with HIV-positive IDUs).**

"I give my used syringe to friends who are already positive".

Interviewer: Did you ever give anyone your syringe – that you had already used once?

Participant: Yes...because they are also positive.



## **C. REPRODUCTIVE HEALTH NEEDS OF PEOPLE LIVING WITH HIV**

Though exploring the factors behind pregnancy decision-making of HIV-positive women is necessary from the perspective of prevention of transmission of HIV to the baby and to prevent unintended pregnancies, there is also a need to focus on it from the rights perspective. PLHA have the reproductive right to responsibly decide when and whether to have a child, and how many children to have. Also, PLHA have the right to adequate information to make informed choices about conception and continuing pregnancy and also the right to have the information and tools to prevent unintended pregnancies. These rights have been confirmed and endorsed by international guidelines on HIV/AIDS and human rights issued by UNAIDS and the Office of the United Nations High Commissioner for Human Rights, 1998 (UN, 1998). Inductive analyses of the qualitative data gathered from in-depth interviews and focus groups with HIV-positive men and women, and from key informant interviews, informed by grounded theory, suggested a reproductive rights perspective was central to understanding reproductive issues.

### **REPRODUCTIVE INTENTIONS AND DECISION-MAKING IN HAVING A BABY**

#### **1. Reasons for giving birth to a baby after HIV diagnosis and intentions to have a baby**

Various reasons were cited by the participants for wanting to have a baby. These include reasons for deciding to continue the pregnancy after they were diagnosed with HIV and reasons they chose to conceive after they knew their HIV-positive status. The decision by an HIV-positive couple to have a baby of their own depends on a variety of factors and may follow careful consideration of the pros and cons from their own points of view and value systems. Overall, many participants articulated that PLHA have the right to have their own baby, as clearly stated by an HIV-positive woman who wanted to have a baby (husband HIV-positive): “Whether it is positive or negative [couple] they need a baby...it is a doctor’s duty to give medicine to them [to prevent HIV transmission to baby]...they have to consult with doctor **but they have to decide...**” [emphasis added].

#### **Box 4: REPRODUCTIVE INTENTIONS AND DECISION-MAKING IN HAVING A BABY**

##### **A. Reasons for giving birth to a baby after HIV diagnosis & intentions to have a baby**

1. Sustaining the family genes
2. Need to experience motherhood
3. Social influences
4. Treatment advances
5. Fear of impending death of the first baby

##### **B. Reasons for Not Wanting To Have a Baby**

1. Fear of passing on HIV infection and feelings of responsibility
2. Do not want to take risk (Risk aversion)
3. Fear of being judged by others (especially health care providers)
4. Already has children
5. Economic constraints

#### ***a. Sustaining family lineage***

Several participants – almost all men – talked about the need to have a baby from the perspective of sustaining their family. An HIV-positive married man said, “My parents always wanted me to sustain our generation. I would follow that.” Similar views were expressed by other men in the focus groups: “Being born here [in the world] we need to leave certain things for others to remember us”; “Some couples want to leave an heir behind them...It is natural. Isn’t it?” A peer counselor in a focus group discussion (FGD) narrated a story of an

HIV-positive couple's desire to have their own baby. "...He is the first male child of his family. They [couple] wished to have an heir. So even if you are going to strongly say not to have a baby, they wouldn't listen. Those in their home do not know about them [HIV status]; but they have the right to have a baby, can give birth...." Thus, many participants indicated a strong desire to have a child of their own.

#### ***b. Need to experience motherhood***

Some HIV-positive couples were concerned about possible negative reactions from their health care providers or their family members if they were to tell them that they were thinking about having a baby. However, some HIV-positive couples indeed had decided to have a baby since they wanted to experience motherhood or parenthood. While these couples understood the risk of HIV transmission to their baby, they were willing to take that risk.

A woman asked, "What is there in a life in which there is no baby." Another woman said: "Whether negative or positive, the desire to have a baby is present in all women." This perspective may reflect societal norms that portray childbearing and motherhood as one of the essential roles for a woman.

#### ***c. Social influences***

##### *Not wanting to be labeled as 'barren'*

The fear of being labeled as 'barren' influenced decision-making to have a baby—even if a woman's personal choice might be not to have a baby. As a woman explained: "It has been since two years we got married...found to be positive in the first year itself. My mother-in-law keeps asking me when I am going to give her a grandson. If there is no baby, I have to face the blame. I am also afraid that they might consider getting my husband to marry some other women." Thus, in absence of disclosure of HIV status to their family members and in not wanting to be labeled as 'barren', some HIV positive couples feel compelled to fulfill the expectations of their family members.

##### *Manliness will be questioned*

Concerns about having their manhood or virility questioned if they did not have children emerged as a concern among some male FGD participants. For example, a man reported, "One cannot walk with pride on the road. They might talk behind you if there is no child after 2 or 3 years [of marriage]. 'There might be a problem' [with him]."

##### *Family members are asking for the 'good news' (conception)*

An HIV-positive married man narrated how he was periodically questioned by family members and relatives about the "good news" (conception): "My family [parents] does not know about us [HIV status]. We cannot explain to them why we do not want to have a baby. My wife has also joined them [in asking for a baby]. I do not know what will happen...we are thinking about having...."

##### *Need to have a boy child*

Some participants, even among couples that already have children, expressed a desire to have another child, hoping that it would be a boy. A peer counselor explained: "...They already have a child. His CD4 is low. His wife is also very weak. 'We need a boy child. I need another baby'. We counseled him to have the baby once their health gets better. But they walked out of the counseling room as though they did not get proper counseling. What can we do?...They could not understand."

Another HIV-positive man with an HIV-negative wife expressed his dilemma regarding having a baby: “We have a girl child...It has been three years now [after first child’s birth]. My mother is asking for a grandson...also she [wife] complained she could not answer the questions of neighbors and relatives; ‘when you are going to give a brother baby to your elder child?’ I do not know what to do...”

#### ***d. Treatment advances – Antiretroviral Treatment (ART) and Prevention of Parent-to-Child Transmission (PPTCT)***

##### ***Better health because of ART***

A peer counselor who has been counseling PLHA in a government hospital reported her experiences that some HIV-positive couples decide to have a baby after their CD4 count improves. She reported that HIV-positive couples say, “Now in our body, CD4 count is high. Hence we can...have a baby. [HIV] will not come to baby.” Thus, couples who may have previously not tried to have a child may reconsider their decision once they feel their health is improved.

##### ***Wants to have an HIV-negative baby; confidence in medical advances***

A woman who already has an HIV-positive child reported that since now there is a PPTCT program and HIV transmission to the baby can be prevented, she was confident in having a “negative baby” now. “If we take treatment as advised and take safety measure...then our baby will also be negative. I have three children, two [female] babies. For both babies, by giving nevirapine, both babies are negative.” Thus, previous experiences of having HIV-negative babies have encouraged this woman to have another one.

#### ***e. Fear of impending death of the first baby***

An HIV-positive man in a seroconcordant relationship expressed his wife’s desire to have a baby because of fear of impending death of the first baby. “If something happens to our baby, there is another baby. For that, she wants to have another baby.” An HIV-positive married woman, currently pregnant, explained why she decided to become pregnant even after having had an HIV-positive baby previously. She explained that they could console themselves with the second baby while they are alive and they would view the second baby as a companion. “At least the second baby would be of help to us by being with us.”

## **2. Reasons For Not Wanting To Have A Baby**

In spite of expressed desires among some participants to have a baby, many other participants reported reasons that after HIV diagnosis they decided not to have a baby or any additional children.

#### ***a. Fear of passing on HIV infection and feelings of responsibility***

Men and women both mentioned that they should not be passing on the infection to their baby. A woman in a FGD explained, “What has come to me [HIV] should not come to my child. It would not be 100% correct [foolproof]. Isn’t it? Thus I think it would be better not to have a baby.” Another woman who works as a peer counselor in a government hospital, in spite of having seen the effects of PPTCT programs, decided not to have a baby. “After I have joined [as a peer counselor], I have seen three children born in a good manner, found to be good [HIV-negative]. But I do not...have confidence. That’s all.”

Some were worried about leaving their child infected in the world and with no one to take care of it. “My child will then be worried why parents gave birth,” was the response from one man.

Another man wanted to avoid being blamed by his child in the future: “If the baby is affected [infected] and become like us then it will think, ‘my father and mother is responsible for this.’ That is why I refuse...” A married woman shared a similar concern: “Why should we torture our baby for our small desire. Consider all babies as our baby and we will live...I take care of my younger brother’s children. I raise one baby personally and other children are also seen as my children.”

***b. Do not want to take risk (Risk aversion)***

*Do not want to take even a small risk*

Some women did not want to take any risk of having a child with HIV infection. “In giving birth to a baby, not everyone will have a negative baby. Then why we have to give trouble to it [baby]. Hence it is better without it [having a baby].”

*No ‘100% assurance’ from doctors*

A woman complained that doctors do not give 100% assurance for having a negative baby, which made her to decide not to take a chance. “HIV-affected persons if ask for a baby, 100% assurance is not given [by doctors]. That is a big problem.”

***c. Fear of being judged by others (especially health care providers)***

PLHA in many focus groups expressed concerns that if they expressed desire to have a baby they would be looked down upon by the health care provider (HCP) as selfish and unconcerned about passing HIV to their babies. But some other PLHA in a focus group spoke against these perceptions. According to them, “doctors and counselors tell these things only for the benefit of PLHA and they have good intentions...[decisions] are not imposed on us...”. However, one person still not convinced by the counter-arguments wondered even if the HCP were successful in imposing their decisions on their patients. He questioned, “How long it will work?” – meaning that PLHA might still go ahead and decide to have a baby if they want to and may not come back to the center if they are afraid of negative reactions from HCP.

A woman mentioned that they might be blamed by the society for being selfish: “Tomorrow what will the society say? ‘She has given birth to fulfill her desire. Why she has to bother about her baby? [they have fulfilled] their wish...she gave birth’. I do not want to hear that...”

***d. Already has children***

Some people felt they already have an adequate number of children and hence there is no need to have further children. Though a woman wanted another child after HIV diagnosis, her husband (HIV-positive) reasoned that they already have two children. “...my husband will say ‘we already have two children. If we raise them properly that is sufficient’...”

Another person has adopted two children since did not want to pass on the infection to his HIV-negative wife. “Yes, has two children. But I have adopted them [sister’s daughters]...No, it is not her [wife’s] decision [to adopt].”

***e. Economic constraints***

A male participant from a FGD mentioned the economic constraints in raising the baby: “If both the husband and wife are weak, they cannot give birth to a baby and raise it. It will become very difficult. We have to buy the necessary things. To educate it. Hence, when we cannot even meet the needs of one baby...that is why one baby is enough”. Another participant was concerned about the additional costs if the second baby also turns out to be

HIV-positive. “If that [second] baby also is positive then we can not manage. We are already spending a lot [of money] on treatment and other stuff...it would only be an additional burden.”

### **3. Within the couple, who decides about having a baby?**

Most of the participants in different focus groups mentioned that the decision-making lay with the couple and “no one else” should decide for them. As a peer counselor expressed, “we cannot compel them [PLHA] not to have baby.”

As two HIV-positive men explained, the decision to have a baby was their HIV-positive wife’s wish and they are just fulfilling it. “My wife is pregnant now. In the hospital she was asked to undergo family control [operation]. But she is refusing. I have told her too – to undergo family control - to stop with one child. But she wants to have two. I have to agree...[she] will not listen.” Another man simply mentioned, ““My wife has to decide. I leave it [decision] to her.”

Sometimes the decision seems to be a joint decision, as mentioned by an HIV-positive married man, “It [decision to have a second baby] was by both. When we die there is no one to tell our family name.”

A married HIV-positive man whose wife is negative had adopted a baby, one of his relative’s children. He is not having sex with his wife. When asked about whether the decision to adopt a baby was done by both, he answered: “It is a good opinion...they [wife] have the right. But some issues should be dealt with only by men.” Thus, some men might exert control over decisions around conception and adoption. One woman complained that her husband was forcing her to have a baby. She said, “I am his second wife. I was brought since the first wife did not have any child. After that elder sister [first wife] died, he started pressurizing me to have a baby [had forced sex]. He tells me ‘If you do not bring a baby I will bring another woman.’”

## **PREGNANCY-RELATED COUNSELING EXPERIENCES OF PLHA IN GOVERNMENT HOSPITALS)**

### **1. Directive or biased counseling prevents HIV-positive couples from making informed decisions**

After HIV diagnosis, women or couples who want to have a baby often do not disclose that to their HCP. A male FGD participant explained: “No one wants to talk about [desire to have a child].” Another male reported, “Only after becoming pregnant do they go [to doctors]. No discussion before that [about having a baby].” It is possible that PLHA already have indications from their interactions with HCP that they should not even be thinking about having a child. Some couples, who do disclose to a peer or professional counselor, often go back “unsatisfied” with the counseling. This especially happens when the couple wants to have a child but the counselor discourages them. A female FGD participant said: “...counselor was trying his best not to motivate us to have a baby...” Thus directive counseling may leave some couples unsatisfied with the counseling they had and some proceed to have a child without the benefits of sound medical advice.

Participants discussed some of the frequently asked questions by counselors or doctors to HIV-positive couples who are currently pregnant or who are thinking about having a baby:

- “Can you raise this baby without any problems?”
- “Who will take care of your baby after you[r death]?”

- “Your health might get spoiled if you are going to have a baby. Think about it. If you are not going to be well then who will look after your baby?”
- “Your baby will be a problem to you since it might also get HIV and you may not able to take care of it.”

Though all these questions and concerns of HCP may be part of guiding patients to make an informed decision, the majority of information is given to discourage having a child. Furthermore, the confrontational tone of the health care provider made many PLHA feel that counselors and doctors were against the idea of PLHA having a baby. PLHA reported that they were not provided with comprehensive and balanced information to make informed decisions and that, rather, the decision of health care providers was forced on them.

## **2. Some health care providers coerce PLHA to undergo abortion or tubectomy**

For those who already have a baby and who want to have another child, some doctors outright refused and ask them to undergo a tubectomy. A woman said: “She [doctor] told ‘No chance! Get operated [tubectomy].’” One woman was very assertive in expressing that she did not want to undergo tubectomy: “You can do whatever you want to. I am not going to do it’...I told the doctor.”

While some doctors and counselors give adequate information to PLHA that help them in making informed decisions on whether or not to continue a pregnancy, some do not seem to be doing so. A woman explained, “I was three months pregnant and that doctor said ‘You have to undergo abortion or your health will be spoiled.’ We went back to that [government] hospital only at the time of delivery.” Another woman said, “Doctor asked me ‘What will you do if the baby becomes positive? Do you still want to continue your pregnancy?’” While providers’ reasons for motivating PLHA to undergo abortions might be based on their moral values, in a FGD, two peer counselors working in PPTCT programs in government hospitals gave different perspectives based on their insider knowledge. A peer counselor said, “It was because they [doctors] know they have to take care of this woman if she comes for delivery to this [government] hospital. That [assisting delivery] poses a greater risk to them than now [conducting Medical Termination of Pregnancy].” Another peer counselor felt that it was probably because if the baby is born and later found to be positive the statistics of positive babies might increase in that hospital and thus health care providers did not want that to happen.

## **“ARE WE GIVEN ‘OPTIONS?’”: PERCEPTIONS AND EXPERIENCES OF PLHA IN USING FAMILY PLANNING METHODS**

### **1. “No options for us”: No discussion on any contraceptives other than condoms**

Most of the participants across different states mentioned that the focus of any HIV or pregnancy counseling is exclusively on condoms, with very little discussion of other contraceptive methods. As a man explains: “First they say ‘Use condoms and have safe sex’. They don’t go to next level [talk about other contraceptives]. For general people [HIV-negative] what will they say? ‘If you are not safe, a baby will be born. To avoid that, use Copper-T or [oral contraceptive] pills or undergo [family control] operation’ - ...but for us there is no choice. Isn’t it?. As soon as we go they will say [mimicking the counselor] ‘My Lord! Without putting on the cover [condom] don’t even take it out.’” [laughs]

A married woman who has previously visited government hospital for her first delivery (before she became HIV-positive) narrated how the content of counseling has changed now – focusing only on condom use. She said, “Four years back [before her HIV diagnosis] they

talked about Copper-T, oral contraceptive pills, this and that; now they ‘focus’ only on condoms – then operation [tubectomy].”

A woman offered a possible explanation for why the health care providers might be focusing on condoms alone: “They [health care providers] can tell...what they tell for others [HIV negative]. ‘No, they are HIV-positive. Even if I tell about other [contraceptives] it is a risk [HIV transmission to others].’ They might think like that and might decide. I don’t know.” Thus, it is possible that providers might think that talking about other contraceptives may decrease condom use by PLHA – posing risk of transmission to others. For many PLHA, the result is inability to explore other contraceptive options with health care providers.

## **2. Barriers to uptake of family planning methods other than condoms**

### *Misconceptions and overestimation of side-effects of oral pills (OCs)*

A married woman mentioned that she would not want to take pills because she has a hot body. This ‘folk knowledge’ or misbelief is common in many parts of India. “...I will tell [my husband] ‘Oh No! My body is usually hot. I will die. Don’t even mention me about those tablets.’ Some persons, though never having tried oral pills, feared side-effects, as a result of hearing the accounts of other women who have taken them. As a woman said, “I do not have any experience and I shall share what I know. Those who take Mala-D [oral contraceptive pill] get dizziness, body pain...I do not want to use.”

### *Others’ negative experiences and loss of daily wages deter some from undergoing tubectomy*

Though advised by her doctor to undergo tubectomy, a woman refused because she thought that meant loss of wages to the family. She said, “Friends complained of stomach ache [after tubectomy]...I have to work 24 hours. Only if I work there will be money. I said ‘I will not do.’ My husband also agreed with me.” Another woman was afraid of getting weak after tubectomy: “Once I get operated I will become weak...then I need to be at home for a minimum of 6 months. We need to have a good diet. We don’t have such a luxury.”

Negative experiences of friends who used Copper-T led a woman to avoid trying it. A woman explained why she does not want to use Copper-T: “Two of my neighbors got rid of Copper-T since it did not suit them... One can get pain or fever. There are many problems with it.”

### *Some PLHA felt using Copper-T and oral pills are cumbersome and inconvenient*

A peer counselor who have been counseling PLHA on family planning methods explained how difficult it is to “convince” some PLHA to use other contraceptives: “We say, ‘even if you are on oral pills you must use condoms when you have sex.’ We tell the same for Copper-T: ‘Whenever you have sex always use condoms’...but many would not agree to put on Copper-T since it has to be periodically changed. They will make a lot of trouble - even with doctors. Hence we do not want to talk about it [Copper-T]. Even when you talk about pills they would not agree. They will say we are already on ‘strength pills’ [vitamins] and how many more [pills] we can take?’...” Thus, dual method protection may not seem very attractive for some PLHA.

### *Condoms alone are seen as sufficient by some PLHA*

Some PLHA see condoms alone to be sufficient since even if they want to use Copper-T or oral pills they also need to use condoms. As a peer counselor told: ‘Since we emphasize on using condoms even with Copper-T, many then say ‘We don’t want Copper-T, we don’t want

pills. We will use Nirodh [condoms].” Thus, they are missing the opportunity to use dual methods and to have extra protection against any unwanted pregnancies.

### **3. Limited or no discussion on family planning methods leads to unintended pregnancies or unnecessary procedures**

Though some women did not make a deliberate decision to have a baby, they may have conceived because of inconsistent condom use or no condom use at all. Some women may find sensitive health care providers who perform a medical termination of pregnancy (MTP) if eligible. However, others might not find sensitive doctors and are even discouraged by some providers to undergo abortion. This may not be to save the life of the growing fetus but possibly because of fear of HIV transmission to providers if they perform MTP, as described by some participants. Some known HIV-positive women are brought to government hospitals only after 4 months of pregnancy because of ignorance. Thus, these women might not be able to undergo MTP and continue their pregnancy without any other options. An incident was narrated by a man who reported that he was scolded by the counselor for making his wife pregnant for the second time; but he defended himself by saying, “What shall I do? I was drunk at that time and did not use condoms. There is no point in scolding now.” This also demonstrates that a woman’s not wanting to get pregnant is not the only factor, but is also contingent on their partner’s behavior.

The absence of tailored counseling to suit the needs of a woman had led her to undergo procedures like abortion and menstrual regulation, which could have been avoided. Adequate information and tailored counseling should have prevented these unnecessary procedures. “Once I had doubt and underwent abortion [MTP] when my husband was not well. [I thought] Now I don’t need child – later we will. Saying so, I will take a tablet once in a month if my periods do not come. No, I do not use oral pills or Copper-T...”

Also, once conceived, many may choose to continue unintended pregnancies. A woman said, “Then what to do? Baby has stopped [meaning she has conceived]. We have to only continue like that.” Some may want to continue their pregnancy not necessarily because they want a baby but because otherwise other people would blame them for undergoing abortion. As a woman explains; “I conceived after a long time...I was tested positive at that time [during antenatal checkup]. I wanted to clean [abortion] but what will others say? They will not understand. They will say ‘She wanted [a baby], she had, and now she does not want. Is she has any defect [health problem]?’ I do not want to face that [situation]...We have not told anyone [about HIV status].” Thus, fear of others’ reactions and fears around disclosure of HIV-positive status may lead some women to have a child even if they might prefer not to continue the pregnancy.

### **4. Lack of male involvement in family planning counseling puts the burden on women**

In India, often women go to their parents’ home when they are pregnant and antenatal care visits to hospitals often take place from there. Thus, husbands often may not accompany their wife when she visits the hospital for antenatal care. This was seen as one of the reasons for lack of involvement of males in the family planning methods. A man explained, “When my wife goes for a visit they also talk about family control. And they try to convince her for operation. But since I am not going with her – they do not talk about family control with me.” In the quantitative component of this study, among the 100 heterosexual men and 50 male IDUs, only 2 men reported having undergone vasectomy before HIV diagnosis and 2 more men undergone vasectomy after being diagnosed HIV-positive. Thus, in general, there is a much less involvement or consideration of the roles of men in family planning especially in permanent contraceptive methods.



## **REPRODUCTIVE CHOICES FOR HIV SERODISCORDANT COUPLES: LACK OF APPROPRIATE COUNSELING AND FERTILITY SERVICES**

### **1. Apparent lack of demand is seen as lack of need for family planning counseling for HIV serodiscordant couples**

A PLHA who works as a peer counselor in a PPTCT center expressed that she had not seen any serodiscordant couple being given counseling about having a baby in the centre where she is working for the past five years. Some participants wondered whether serodiscordant couples would be thinking about having a baby at all. A male FGD participant explained: "I think she (HIV-negative partner) would be thinking of how to not get HIV from her husband. Having a baby would be the last thing on her mind." A similar opinion was expressed by a male participant in a FGD: "[doctors] tell the serodiscordant couples not to have sex at all. In such situation, how can anyone even think about having a baby. Among the two, one person will be only thinking of how they can escape [from infection]...no importance to having a child." In contrast, some participants in this study who were in serodiscordant relationships expressed their own or their partner's desire to have a child.

Some participants felt that serodiscordant couples often get separated once their serodiscordant status is known, so not many of these couples would remain to attend counseling on whether to have a baby or not. But some participants did acknowledge having seen serodiscordant couples who wanted to have their own baby even if they had to take some risk. For example, one serodiscordant couple's (husband positive, wife negative) desire to have a male child (since their parents and in-laws wanted this) was a strong motivating factor to "take risk" of possible infection of the negative partner, though they already have a female child. Some reported that negative women become pregnant and then come to the government hospital, not before becoming pregnant. Lack of discussion about family planning options with these couples was cited as the key reason behind this.

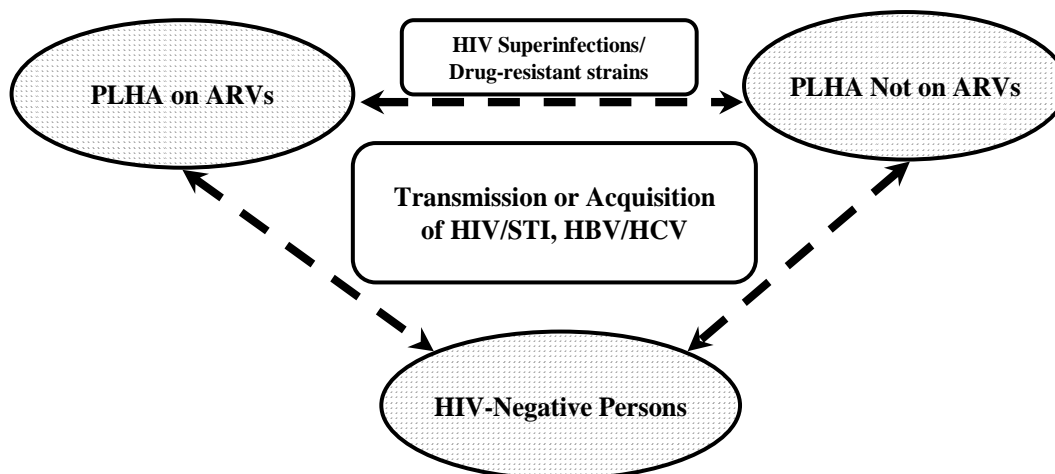
A key informant was of the opinion that fear of being judged by others and lack of information on how serodiscordant couples can have an HIV-negative baby often prevent serodiscordant couples from coming forward for counseling before they decide to conceive. "The main or...the only counseling message for any serodiscordant couple is 'Do not have sex without condoms.' There is no discussion about whether they are thinking about having a child and telling them what are the options available to them. They go back with such a guilty feeling that they do not even want to discuss with doctors or counselors about their intention to have a baby." Thus, there may be a concern among some health care providers that if they engage with the couple in discussion about conceiving a child, the HIV-negative partner may become infected. This silence on the part of providers may prevent serodiscordant couples from having open discussions with health care providers. Consequently, PLHA in serodiscordant relationships have a great deal of difficulty in getting necessary information to help them in making informed decisions about having a child.

### **2. Lack of information/services in government hospitals for HIV serodiscordant couples who want to have a baby**

Many PLHA reported they had never heard about a 'sperm washing' technique being offered or even mentioned as an option for serodiscordant couples. A few active positive people network members mentioned that there are some NGOs who at least provide information to serodiscordant couples about 'sperm washing,' but warn them that, "It will cost a lot of money. Are you ready [to pay] for it?" The lack of information and availability of 'sperm washing' in government hospitals coupled with the high cost of 'sperm washing' means many serodiscordant couples who want to have their own baby have to take the risk of possible HIV infection of the seronegative partner.

## V. CONCLUSIONS & RECOMMENDATIONS

Diagram 2: Unprotected sex or Needle-sharing: Health risks to PLHA & Others



### **Sexual behavior of PLHA**

The quantitative findings of this study have showed that though a large proportion of PLHA across subgroups consistently used condoms, at least some proportion of PLHA did not use condoms consistently. The qualitative findings summarized the various contextual factors – individual, interpersonal and structural – that need to be addressed when designing prevention interventions for PLHA. Thus, there is a need for a wide variety of approaches to prevent transmission of HIV from PLHA to others and also to protect the health of PLHA. Though it is evident from quantitative data that many PLHA are practicing safer sex, many PLHA may require support and skills-building in relation to the disclosure of HIV status to their partners and how to sustain safer sex even after disclosure.

There are various opportunities by which talking about safer sex can be incorporated into routine medical care of PLHA. In India, currently PLHA are seen and treated in a variety of treatment, care, and support centres such as government ART centers, community care centers, TB clinics, STI clinics, and PPTCT services. Mechanisms by which risk reduction counseling can be incorporated as part of the routine clinical care need to be explored. Risk-reduction counseling need to be tailored to the specific needs of the various subgroups of PLHA. The messages about the benefits of safer sex should focus not only on preventing HIV transmission to other persons but also the benefit to PLHA by protecting them from getting other infections – re-infections with new HIV types; superinfections with drug-resistant HIV strains or aggressive strains; and STIs, which may accelerate the disease.

Policymakers and health care providers should realize that it is crucial to acknowledge the sexual aspirations of PLHA to assist them in leading a fulfilling sexual life and also to provide them the necessary information, and support in sustaining safer sex.

### ***Injecting drug use behaviors of HIV-positive IDUs***

As the quantitative findings of this study show, many HIV-positive IDUs have adopted safer injecting drug use behaviors by not sharing their needles/syringes with other people. However, there are a variety of contextual factors under which some proportion of HIV-positive IDUs could not consistently practice safer injecting drug use behaviors. Also, it is important to recognize that most IDUs are also sexually active and require support to practice and sustain safer sex behaviors. By engaging in sex work for money to buy drugs, HIV-positive female IDUs face health risks by being forced by their clients to have unprotected sex with them. Since use of drugs and alcohol interfere with the ability to practice safer sex, we need to address these issues among HIV-positive IDUs.

Thus, as a harm reduction measure, the emphasis needs to be on avoiding needle sharing and providing clean syringes/needles to them. The most common theme behind unsafe injecting drug use behaviors mentioned by almost all the IDU study participants was withdrawal, which prevents them from taking any rational decision in relation to needle/syringe-sharing. Hence, it is also very crucial to focus on how to assist them in relation to their chemical dependency. Prevention messages and uninterrupted syringe supply need to happen along with linking HIV-positive IDUs to drug substitution therapy (oral buprenorphine or methadone) and to drug dependence treatment programs. Also, the structural barriers in carrying clean syringes in Manipur need to be removed by sensitizing and advocating with police force, army, and anti-drug agencies by emphasizing the importance of harm reduction measures so that the prevention efforts among IDUs are not undermined.

### ***Reproductive Choices and Health of PLHA***

A variety of contextual factors influence a HIV-positive individual regarding the decision to have a baby, and reproductive choice for PLHA cannot be seen only as an ethical or medial issue (Cooper et al., 2005; Guttmacher, 2006). Irrespective of whether it is a personal choice or not, for various reasons PLHA find it difficult to openly discuss with their health care providers about their intentions, and consequently, opportunities to provide them adequate information on reproductive choices and help them in taking informed decisions are missed. Even if PLHA disclose their reproductive intentions often they receive biased counseling reflecting the moral views of the health care providers. Some providers may even coerce HIV-positive women to undergo an abortion. Also, quality abortion services are not available to those PLHA who want to discontinue their pregnancy, forcing them to go to unqualified practitioners.

Often HIV diagnosis among women is made during their antenatal checkup and then they are referred to PPTCT programs. Outside the PPTCT setting, often there is limited discussion with PLHA about their intentions to have a baby. Consequently many PLHA may not be aware of the various family planning options available to them. Even if there are discussions with health care providers on these issues, PLHA are given only limited options with the counseling limited to discussion on condoms only – emphasizing prevention of HIV transmission to others. Thus, providers may not want to discuss about any other contraceptives (non-barrier methods). But they might also not have adequate knowledge about the various contraceptive options available for PLHA (WHO, 2006). Thus, it is essential that health care providers have adequate knowledge and provide nondirective counseling in relation to family planning options for PLHA to ensure prevention of unintended pregnancies and unsafe abortions, and to ensure safer pregnancy.

HIV serodiscordant couples also need unbiased counseling and support in relation to sustaining safer sex. If they choose to have their own baby, possible options including 'sperm washing' should be discussed with them and referred to facilities where it is provided. However, lack of such services in government hospitals pose additional financial burden to PLHA or compel them to take the risk of HIV transmission to their seronegative partner by having unprotected sexual encounters in an attempt to conceive. Specific guidelines on how to educate and provide counseling to HIV serodiscordant couples are needed and health care providers need to be trained on the same.

Thus, to conclude, appropriate prevention interventions for PLHA – focusing on both sexual and injecting drug use behaviors – need to be integrated into existing treatment, care and support services. Reproductive intentions of PLHA, including serodiscordant couples, need to be recognized and respected. Comprehensive information on reproductive and family planning options, and nonjudgemental counseling need to be available to PLHA to assist them in making informed decisions about when and whether to have a baby, and also to assist them in preventing unintended pregnancies.

## **BOX 5: SUMMARY OF RECOMMENDATIONS**

### **A. PROMOTING SAFER SEX BEHAVIORS AMONG PLHA**

1. Adopt multiple strategies to promote and sustain safer sex among PLHA in a variety of settings: one-to-one risk-reduction counseling (peer and professional); group training programs on sexual health issues for PLHA; couple counseling (sero-discordant and seroconcordant); and mass media campaigns.
2. Safer sex messages for PLHA need to focus on the benefits of consistent condom use with both infected and un-infected partners – which include prevention of re-infections and HIV superinfections; avoid getting infected with drug-resistant strains; and STIs.

### **B. PROMOTING SAFER INJECTING DRUG USE BEHAVIORS AMONG HIV-POSITIVE IDUs**

#### **1. Individual level**

- a. Emphasize health consequences of needle/syringe sharing
- b. Refer to drug substitution and drug dependence treatment programs
- c. Messages for HIV-positive IDUs should include both benefits to self and also to needle-sharing partners

#### **2. Structural level**

- a. Scale-up syringe supply programs
- b. Work with drug-peddlers to ensure clean syringe availability
- c. Advocate with law enforcement agencies and anti-drug agencies on importance of harm reduction activities

### **C. SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS**

#### **1. Policies and Action plans**

- a. Develop a national policy on sexual and reproductive health and rights of PLHA and implement that plan in NACP-III phase
- b. Ensure greater involvement of people living with HIV and AIDS (GIPA) in sexual and reproductive health policy and programs for PLHA
- c. Take steps to improve linkages and referrals between care centers and prevention and sexual/reproductive health services
- d. Involve HIV-positive men in family planning counseling to provide support their wife's decisions on family planning and to offer information about male-specific permanent sterilization methods

#### **2. Sexual and Reproductive Health Programs: Service delivery**

##### **a. Provide essential information to PLHA on:**

Dual use (prevention of infection and pregnancy) of condoms; Use of dual methods (condoms and another contraceptive); safety of conception and childbirth – sperm washing, artificial insemination, In vitro fertilization (IVF) as methods of assisted conception and ART and cesarean section for child birth; unwanted/unintended pregnancy, contraceptive options including emergency contraception, the dangers of unsafe abortion, and access to legal, safe abortion.

**b. Provide** risk reduction counseling and reproductive health services for HIV sero-discordant couples who wish to have their own baby.

**c. Training health care providers** on sexual and reproductive health needs and rights of PLHA and also offering counseling in a non-judgemental, and unbiased manner.

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## VII. GLOSSARY

<b>Abortion</b>	The termination of pregnancy from whatever cause before the fetus is capable of extrauterine life.
<b>Condom</b>	A latex or natural membrane sheath placed over an erect or partially erect penis for use during intercourse to reduce the risk of disease and unwanted pregnancy. The tip of the condom catches the semen. Condoms are readily available in most countries.
<b>Contraception</b>	Prevention of conception using techniques, devices or drugs.
<b>Dual method</b>	using a barrier method for protection against sexually transmitted infection and another method for contraception.
<b>Dual protection</b>	prevention of both STI/HIV infection and unwanted pregnancy. This can be achieved by the correct and consistent use of condoms alone or by the simultaneous use of two methods, one of which must be a condom.
<b>Family Planning</b>	implies the ability of individuals and couples to anticipate and attain their desired number of children and the spacing and timing of their births. It is achieved through use of contraceptive methods and the treatment of involuntary infertility. ( <i>Source: Working definition used by the WHO Department of Reproductive Health and Research</i> )
<b>Hepatitis B</b>	Hepatitis is a disease of the liver. It is usually caused by a virus, although it can also be caused by long-term overuse of alcohol or other toxins (poisons). Hepatitis B can move from one person to another through blood and other bodily fluids. It can be transmitted through sexual intercourse and through needles such as those shared by intravenous drug or steroid users who have the virus. A pregnant woman can also pass hepatitis B to her unborn baby.
<b>Hepatitis C</b>	Like hepatitis B, hepatitis C can lead to cirrhosis or liver cancer. Hepatitis C is transmitted from person to person through blood or other body fluids. Hepatitis C is the most serious type of hepatitis - it's now one of the most common reasons for liver transplants in adults. And there's no cure and no vaccine.
<b>Reproductive Health</b>	Reproductive health is defined by WHO as a state of physical, mental, and social well-being in all matters relating to the reproductive system at all stages of life. Reproductive health implies that people are able to have a satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when, and how often to do so. Implicit in this are the right of men and women to be informed and to have access to safe, effective, affordable, and acceptable methods of family planning of their choice, and the right to appropriate health-care



services that enable women to safely go through pregnancy and childbirth.

### **Reproductive rights**

“Reproductive rights embrace certain human rights that are already recognised in national laws, international human rights documents and other relevant consensus documents. These rights rest on the recognition of the basic right of all couples and individuals to decide freely and responsibly the number and spacing and timing of their children and to have the information and means to do so, and the right to attain the highest standard of sexual and reproductive health.” (*para. 95, Beijing Platform for Action, 1995*)

### **Sexual health**

Sexual health is a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled.

### **Sexual rights**

Sexual rights embrace human rights that are already recognized in national laws, international human rights documents and other consensus statements. They include the right of all persons, free of coercion, discrimination and violence, to:

- the highest attainable standard of sexual health, including access to sexual and reproductive health care services;
- seek, receive and impart information related to sexuality;
- sexuality education;
- respect for bodily integrity;
- choose their partner;
- decide to be sexually active or not;
- consensual sexual relations;
- consensual marriage;
- decide whether or not, and when, to have children; and
- pursue a satisfying, safe and pleasurable sexual life.

The responsible exercise of human rights requires that all persons respect the rights of others.

### **Sexually Transmitted Diseases (STD)**

Diseases that people get by having intimate sexual contact, including having sex (vaginal, oral, or anal intercourse) with someone who already has the disease. There are many different kinds of STDs including herpes, HIV, and syphilis. All STDs are preventable.

**Induced abortion** Intentional termination of pregnancy prior to fetus reaching the state of viability by mechanical (surgical) means or by drugs.

**Unintended Pregnancy** An unintended pregnancy is a pregnancy that is either mistimed or unwanted at the time of conception.

**Sero-discordant** A term used to describe a couple in which one partner is HIV positive and the other is HIV negative. Serodiscordant relationships are also referred to as "magnetic".

**Seroconcordant** A term used to describe a couple in which both partners are of the same HIV status (ie both are HIV positive or both are HIV negative).

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