



# A Report

From India





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# ACRONYMS

<b>AIDS</b>	Acquired Immune Deficiency Syndrome
<b>APAC</b>	AIDS Prevention and Control Project
<b>ART</b>	Anti Retroviral Treatment
<b>BPL</b>	Below Poverty Line
<b>BSS</b>	Behavioral Sentinel Surveillance
<b>DFID</b>	Department for International Development
<b>FPA India</b>	Family Planning Association of India
<b>FSW</b>	Female Sex Workers
<b>GIPA</b>	Greater Involvement of People Living with HIV/AIDS
<b>GNP</b>	Global Network of People Living with HIV
<b>HIV</b>	Human Immunodeficiency Virus
<b>ICW</b>	International Community of Women Living with HIV
<b>ICRW</b>	International Centre for Research on Women
<b>IPPF</b>	International Planned Parenthood Federation
<b>MARP</b>	Most At Risk Population
<b>MSM</b>	Men having Sex with Men
<b>NGO</b>	Non-Government Organization
<b>NACO</b>	National AIDS Control Organization
<b>NACP</b>	National AIDS Control Programme
<b>NRHM</b>	National Rural Health Mission
<b>PLHIV</b>	People Living with HIV
<b>PMTCT</b>	Prevention of Mother to Child Transmission
<b>PPTCT</b>	Prevention of Parent to Child Transmission
<b>PUD</b>	People who Use Drugs (sometimes referred to as Injecting Drug Users)
<b>STD</b>	Sexually Transmitted Diseases
<b>TG</b>	Transgender
<b>TNSACS</b>	Tamil Nadu State AIDS Control Society
<b>UNAIDS</b>	Joint United Nations Programme on HIV/AIDS

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# EXECUTIVE SUMMARY

Despite great strides being made in the area of prevention of HIV/AIDS and in the treatment and care of people living with HIV (PLHIV) through innovative programming and inclusive policies, large numbers of PLHIV in India still have to live with the reality of stigma and discrimination faced in multiple settings. Evidence from studies conducted in India point to the prevailing notions of morality and misperception of the transmissibility of the infection that triggers stigma and discrimination. However, the use and applicability of a single tool that measures the experiences of stigma faced by PLHIV has, so far, not been verified in India. The PLHIV Stigma Index, a joint initiative of organizations- GNP+, ICW, IPPF and UNAIDS, aims to not only documenting the extent and forms of stigma experienced by PLHIV but examine and measure changing trends in HIV related stigma and provide an evidence base for policies and programmes informed by real experiences of PLHIV.

The PLHIV Stigma Index study in Tamil Nadu is the first of its kind to quantify the stigma and discrimination experienced by people living with HIV in the state. The study was conducted between December 2010 to September 2011 and used a cross sectional design to survey a sample of 1594 people living with HIV. A uni-stage cluster sampling was used by dividing the total sample over the districts as proportional to the number of pre ART registrations. Samples were drawn from all PLHIV groups- general category, Men having sex with men (MSM), Transgender (TG) Female sex worker (FSW), and People who Use Drugs (PUD). Although sufficient sample sizes were estimated for the general category it was not possible to estimate statistically valid sample sizes for other sub-populations as sizes of the sub-populations were not known. It was decided to reach as many of them as possible within the study period through snowball sampling technique with not less than 50 for each group. Interviewees were then reached through the district level networks and their block level branches by using purposive sampling.

Study findings indicate that self stigma among the PLHIV respondents was incredibly high, with the marginalized groups expressing more self stigma reportedly based on their sexual identity or behaviors. Feelings of shame and guilt are often based upon actual experiences of social exclusion such as being forbidden to participate in religious and family activities, and verbal and physical assault. Alarmingly, violence is often perpetrated by close family members while in the case of PUD and TG, more public violence is reported. The impact of such social and self stigma is felt on decisions to isolate oneself from services and social relationships. This impact is however lessened for people belonging to support networks although the same is not seen among MSM and TG, perhaps indicating that interventions to address self stigma within these networks need to be enhanced. While reports of discrimination in the workplace, educational settings, and health care settings was not very high, yet the few instances that existed

indicated that such acts of discrimination have not been totally eliminated. Some pregnant women are coerced to terminate their pregnancies while knowledge and awareness of prevention of mother to child transmission (PMTCT) has not reached many women and female sex workers. In terms of redressing stigmatizing acts, most PLHIV in the study knew of and had approached networks and NGOs but when it comes to policies and laws that safeguard their rights, there was little knowledge about such safeguards.

There is still much to be done to address stigma and discrimination among PLHIV in India. The sample for this study was drawn from Tamil Nadu, a state which has witnessed a strong and effective response to the epidemic in terms of securing services, mounting large scale and innovative preventive approaches, and increasing coverage. Yet the persistence of stigma, both felt and enacted, is a pointer to existing gaps in the response. It is also a pointer to how much more prevalent stigma would be in those states that have not had such a wide coverage of response. We now have the evidence that stigma prevails in multiple settings and this calls for an integrated approach that addresses family, community, workplace, education and health care settings. Culturally sensitive community-level education is critical to diminishing the effects of social stigma, while approaches that raise consciousness about sexual identities and correspondingly that raise self esteem are necessary to address the profound feelings of shame that marginalized communities experience. Recommendations for programme, policy and research are thus based on the major findings.

The programmatic focus should be on empowerment of marginalized communities through mobilization and emphasis on topics and subjects hitherto not dwelt on at all or only cursorily- these include education sessions/campaigns on sexual orientation, sexual health rights and human rights, and expansion of communication strategy on stigma reduction through regular meetings with the media and scale up of NACP IV and NRHM programmes. Sensitization of health care providers on reproductive choices, ensuring pre test counseling during HIV testing, and community based stigma reduction campaigns are other recommendations. The policy framework should include mainstreaming issues of self stigma in NRHM trainings, introduction of stigma within a broader human rights perspective in medical curricula, evaluation of work place policies, relook at mechanisms of legal redress, and address integration and linkage of social welfare programmes and schemes for HIV positive people. Research recommendations include replication of stigma index study to study trends across populations and regions in India as well as evaluation of innovative stigma reduction intervention.



# BACKGROUND

## Study Background

Although HIV prevalence in India is relatively low, there were an estimated 2.4 million people living with HIV in India in 2008 while new infections have emerged from previously low prevalence states such as West Bengal, Orissa and Punjab. (NACO, 2010), The reason for this is partly due to widespread failure to respond adequately to stigma and discrimination. Indeed, as a consequence of felt and enacted stigma, people living with HIV are marginalised and driven from the reach of prevention, treatment, care, and support services. Their invisibility enables the denial of a problem, and leaves stigma reduction efforts low in the list of priorities.

The PLHIV Stigma Index study in Tamil Nadu is the first of its kind to quantify the stigma and discrimination experienced by people living with HIV in the state. The PLHIV Stigma Index is a joint initiative of organizations- GNP+, ICW, IPPF and UNAIDS who have worked together since 2004 to develop this survey. After an initial pilot study, the full-scale implementation of the HIV Stigma Index began in 2008, in various countries of the world. Since then, people living with HIV have been trained to strategically integrate the tool with their work, build partnerships to strengthen the research process and help shape future programmatic interventions and policies with the data gathered from the surveys.

The People Living with HIV Stigma Index aims to:

- Document the various experiences of people living with HIV regarding HIV-related stigma and discrimination
- Compare the situation of people living with HIV in other places where the Stigma Index is being rolled out
- Detect and measure changing trends in HIV and AIDS related stigma over time
- Broaden understanding of the extent and forms of stigma and discrimination faced by people living with HIV in different countries
- Provide an evidence base for policy change and programmatic interventions informed by real experiences of people living with HIV.
- Provide a local, national and global advocacy tool to fight for improved rights for people living with HIV
- Increase the empowerment, involvement and capacities of participating people living with HIV in responding to stigma

## BACKGROUND

International Planned Parenthood Federation (IPPF) was funded by UKaid from the Department for International Development to implement this project. In India, IPPF Member Association- Family Planning Association of India (FPA India) provided all the support to the consultant to carry out this project. This project was implemented from December 2010 to September 2011.

The current report is divided into four chapters. This chapter provides a summary of the available literature in India on stigma and discrimination towards PLHIV. The second chapter presents the details of the methodologies used in the study. The third chapter focuses on the key findings from the Stigma Index survey and the fourth chapter presents conclusions followed by programmatic and policy recommendations.

### Review of literature

Global literature on HIV prevention and treatment programmes indicates that stigmatizing attitudes and discriminatory practices may deter people from accessing health care for fear of testing, lead to concealing of HIV status from medical care workers, lead to low uptake of and poor adherence to prevention and treatment services, limit uptake of services as PMTCT and ART, destroy family and social lives, reduce likelihood of disclosure of HIV status to sexual partners, lead to social isolation, depression and other conditions that contribute to a decline in mental health status, and cause loss of income and support groups, adversely affecting economic status (Mahajan et al, 2008; Aggleton, 2000). Stigma plays out in a number of specific and damaging ways, including denial of health and other services, verbal abuse and harassment, social isolation and physical and sexual violence. These manifestations of stigma and discrimination are harshest among those groups most marginalized and most vulnerable to HIV – sex workers, men who have sex with men, and people who use drugs and their partners, making stigma and discrimination particularly difficult barriers to overcome in utilizing services (Lau et al. 2007; Cloete et al. 2008; Thi et al. 2008; Jha and Madison 2009; Chakrapani et al. 2009; MacQuarrie et al. 2009). Previous research (Nyblade et al, 2009, Ogden & Nyblade, 2005, Parker and Aggleton, 2003, Reidpath and Chan, 2005) as well as the latest update on stigma among people living with HIV (PLHIV) in the Asia and the Pacific region point to the still prevailing stigma in various environments: family and community life, employment and health care settings. The findings of the study point out to still existing stigma and discriminatory acts in many Asian countries: recent job loss due to HIV status, discrimination by teachers, loss of work opportunity (UNAIDS, 2011).

## **Stigma and HIV/AIDS in India**

Research studies conducted on HIV-related stigma in India have revealed a high number of cases of stigma and discrimination ranging from restrictive and coercive policies to cases of individual harassment. While lack of knowledge and understanding drives a lot of the stigmatization and fear, in India, local cultural beliefs add to perceptions of "sexual wrongdoing" which further reinforce stigmatizing stereotypes resulting in the isolation and exclusion of infected people (Aggleton, 2000). Especially in the context of women, stigma is reported to be further intensified based on notions of gendered bodies and economic motivation (Van Hollen, 2010). Consequently, women face higher stigma within the household after they are widowed as they are blamed for the infection and also for living longer which motivates their in-laws into depriving them of family property. Pre existing prejudices and social inequalities contribute to increased stigma and discrimination against marginalized groups as has been found in a recent study in which most non HIV infected people expressed blame, transmission misconceptions and negative attitude toward infected people, especially toward sex workers, who use drugs PUDs and Men having sex with men (MSM) (Eckstarnd et al, 2011). In other instances, fear of transmission resulting from lack of knowledge is found to lead to expressions of stigma in health care settings such as testing for HIV without consent, breaches of confidentiality (disclosure of test results to hospital staff and the patient's family members), labelling (hospital files and notices being left out in view of all), and withholding of treatment (Mahendra et al, 2007; Bharat et al, 1998). A study characterized HIV stigma in India by a framework based on people's experiences, and divided stigma into enacted, felt or perceived, vicarious and internalized stigma. While enacted stigma was reported to be infrequent in the study, perceived and internalized stigma was high based on hearing stories of discrimination or what is called vicarious stigma, leading to suppression of HIV status. Although this study found enacted stigma to be low, subsequent studies in India continue to find discriminatory behavior experienced by PLHIV. In one study, women participating in the Prevention of Parent To Child Transmission (PPTCT) programme reported refusal of treatment, moral judgment and abusive behavior by health care staff (Rahangdale et al, 2010) while in another study, half of the women respondents feared seeking care due to bad experiences at a maternity hospital such as breach of confidentiality, refusal to treat and humiliating statements made by health care staff (Thomas et al, 2009). Thus, fear

## BACKGROUND

of infection and moralizing attitude remain salient factors causing stigma in India. While most studies of experiences of stigma have been conducted among heterosexual men and women, very few studies are located within more marginalized populations like People who Use Drugs (PUD) and MSM. Only one study conducted among PUD examined and found positive association between perceived stigma and injecting risk behavior (Latkin et al, 2010) while another study conducted among kothi identified MSM reported stigma and discrimination across multiple social and institutional contexts (Chakrapani et al, 2007). Among FSW, stigma and discrimination was found to be a major barrier to ART access (Chakrapani, et al, 2009). Most of these studies have been qualitative investigations and those that used quantitative methodologies did not necessarily use stigma indices or rigorously validated measures of stigma. A problem related to the absence of scientifically measured stigma is the lack of universal applicability of tools that have been developed, a fact highlighted in most of these studies.

### Measurement of stigma and critical need of current study

Important steps have been taken globally in measuring stigma, yet a single tool that captures the multidimensionality of the concept and validated across diverse populations has been challenging to develop. Stigma measurements are beset by problems of capturing multiple domains, applying to diverse populations with multiple stigmas, and defining structural or institutional stigma. In India, measurement of stigma is still rudimentary. Only one study was found (Zelaya et al, 2008) that tested and validated a stigma tool (adapted from previous tools) in Chennai. This tool measured stigma across four dimensions but was tested only among general men, thus limiting its applicability to other population groups, namely marginalized communities. There is, thus, a lack of research on the forms of HIV/AIDS-related stigma, the different contexts in which they occur and their sources. In addition, problems have been encountered in defining and measuring the impact of stigma. Programme implementers and policy makers have also called for more data that accurately describes and quantifies stigma so as to build an understanding of the effect stigma may have on prevention and treatment programmes and to assess the success of stigma reduction interventions. Towards that end, the People Living with HIV Stigma Index is a standardised tool to collect information from people living with HIV around the world which has been developed to address these issues.



# METHODOLOGY

## Study Design

The stigma index study in Tamil Nadu was based on a mixed method approach. However, qualitative part of the study was much smaller than the quantitative part. Quantitative part of the study consisted of a cross-sectional sample survey among the people living with HIV with a sample size of around 1600. Our report is based on the quantitative study while the qualitative study report is presented separately. The study covered six segments of the HIV positive population separately, with the same questionnaire. These were general men and women, transgenders, People who Use Drugs, MSM, PUD and female sex workers (FSW). General men and women were those who did not belong to any of these key or most at risk populations.

## Sample Size

Since Tamil Nadu has a huge number of positive men and women in the general category; the required sample size was estimated at 600 for each category (men and women). This sample size was sufficiently large to estimate any dichotomous variable with a margin of error 5% absolute, confidence level 90% and design effect 2. It was not possible to estimate statistically valid sample sizes for other sub-populations as sizes of the sub-populations were not known. It was decided to reach as many of them as possible within the study period through snowball sampling technique with not less than 50 for each group. Due to time and resource constraints the number of general men and women fell short of the targets. Still it was large enough to make definite conclusions with sufficient accuracy. Final sample sizes for different sub-population were:

General Male	General Female	Trans-genders	MSM	FSW	PUD	TOTAL
489	593	162	196	98	56	1594

## Sampling Strategy

A uni-stage cluster sampling was used by dividing the total sample over the districts as proportional to the number of pre ART registrations. The sample for each district was then more or less uniformly distributed over the entire district in order to ensure maximum spread. Both urban and rural areas were covered. The interviewees were reached through the district level networks and their block level branches through purposive sampling.

### Inclusion Criteria

People aware of their confirmed positive status, above 18 years old, able to communicate in Tamil and agreeing to participate in the study were chosen for the interviews. People below 18 years old were excluded because it was difficult to obtain consent of their guardians.

### Selection and Training of Interviewers

Interviewers for the study were People living with HIV. They were selected from each sub-population category on the presumption that some people, belonging to special sub-populations, might not feel comfortable to share information with others. Accordingly, it was decided that positive women will be interviewed only by positive women, an MSM by another MSM, a transgender by another transgender and PUD by other PUD. Interviewers were trained on ethics, sampling strategy, interview technique, informed consent and maintenance of confidentiality.

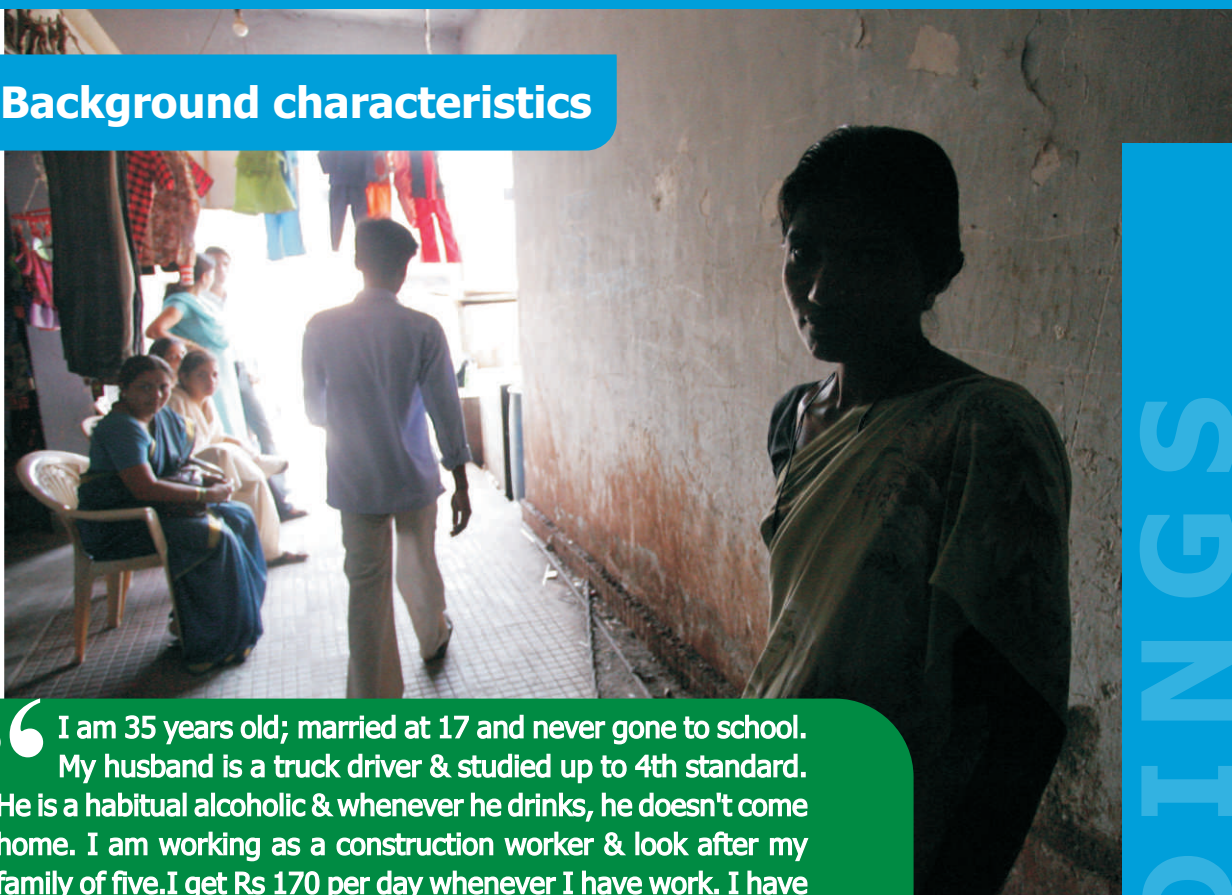
### Ethical Consideration

The study used internationally approved PLHIV stigma index questionnaire developed and pioneered by a partnership by the consortium of International Community of Women Living with HIV (ICW), International Planned Parenthood Federation (IPPF), Global Network of People living with HIV (GNP+) and UNAIDS. The same standard has already been used in the roll out of the PLHIV Stigma Index in other countries like Sri Lanka, Pakistan and Bangladesh in South Asia. However, given the sensitivity of the issue and as recommended in the user guide for the stigma index roll out, the questionnaire was translated in local language which is Tamil and back translated into English to maintain consistency and submitted for ethical review to the Ethics Committees of Family Planning Association of India (FPAI) and of National AIDS Control Organisation of India (NACO). The questionnaire was also shared with the Project Advisory Committee (PAC) of the project. The composition of the PAC members and their roles and responsibilities have been outlined in the process documentation as a separate report to guide future roll out in other states. All of them endorsed the final version of the questionnaire used in the study.

Each interviewee was asked to read an information sheet describing scope and purpose of the study at the beginning of the process. In case he/she was unable to read, the content of the information sheet was read out to him/her. Following this his/her consent was sought for the study. Participation in the study was totally voluntary. The interviewee was free not to answer any question he/she did not like or withdraw from the study at any point of time. However, no such case was registered where the interviewee withdrew himself/herself in the middle of the interview. Identities of the people were not written on the questionnaire; they were identified by codes only.

# KEY FINDINGS

## Background characteristics



“ I am 35 years old; married at 17 and never gone to school. My husband is a truck driver & studied up to 4th standard. He is a habitual alcoholic & whenever he drinks, he doesn't come home. I am working as a construction worker & look after my family of five. I get Rs 170 per day whenever I have work. I have three children -the first two are HIV positive. I have taken a loan to repair my house. Doctors have asked me to take nutritious food. My children will often ask me, “Mummy, doctor has asked us to eat eggs. Why don't you cook eggs for us?” I don't know the answer. I just smile at them. ”

**Overall, respondents were economically and socially vulnerable with women being the highest sufferers from poverty, unemployment, and low education.**

A sizeable majority of the sample was between the ages of 25 to 49 years, with almost a quarter (22%) having received no formal education (Table 2). In almost all human development indices, this sample of positive people ranked extremely low. The highest percentage of positive people without any formal education was recorded among the PUD (36%) followed by the general females (28%), transgenders (25%), MSM (20%), FSW (17%) and general males (14%). The highest percentage of positive people with a technical or university degree were found among the general males and MSM (7%) followed by the transgenders (6%). Interestingly 53% of the FSW had studied up to higher secondary classes. While almost a third (36%) of the sample belonged to rural areas, the FSW and transgenders hailed mostly from urban areas. Nearly a quarter (22%) reported to be unemployed with the highest reportage among the general female sub population. Expectedly, the highest number of Below Poverty Line (BPL)

## KEY FINDINGS

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households were found among the general females (48%) followed by transgenders (41%), general males (31%), MSM (27%), FSW (17%) and PUD (13%). 22% of all respondents reported having faced scarcity of food for some days in the one month period prior to this study. This included 73% of the PUD, 24% of the general females, 22% of the general females, 17% of transgenders and FSW and 11% of MSM. This was despite the fact that PUD had the highest per capita income among all sub-populations, probably because a large part of their income was spent on drugs.

Nearly 14% of the sample was living with HIV for more than 15 years while 7% had been detected as positive only during the last one year. Almost half of the sample (47%) reported being in a current relationship with the majority living with their partners. While relationship status was divided between cohabiting (41%), single (21%) and widowed (23%), the majority of respondents in each sub population, with the exception of general female, reported to be sexually active.

In order to ascertain whether the study sample was really representative, we compared most of the demographic characteristics with those drawn from the Behavioral Surveillance Survey (BSS) Round 3 of 2009<sup>1</sup>. For general female, we used a situation assessment report<sup>2</sup> of APAC conducted in Tamil Nadu among 986 HIV infected women. Most demographic characteristics were found to be comparable, thus, indicating that the study sample was representative of PLHIV in the state. The table below presents the characteristics of the study sample and samples from other surveys.

**Table 1. Comparison of demographic characteristics of study sample and samples of other studies**

Characteristics	General male		FSW		MSM		General female		PUD	
	Study Sample	BSS 3	Study Sample	BSS 3	Study Sample	BSS 3	Study Sample	APAC Report 2010	Study Sample	BSS XII
Median Age	37.3	32.4	36.2	34.7	34.7	30.6	33.6	32.0	42.0	27.7
Education: Primary and above	85.89%	96.50%	81.63%	81.70%	81.70%	83%	72.01%	69.3%	64.29%	76.70%
Median monthly family income	2500	3261	4000	2464	2464	3433	1667	~1000	4167	2934
Cohabiting with partner	65%	58.40%	89.80%	96.90%	18.0%	14.30%	37.0%	56.0%	36%	26.5%

<sup>1</sup> Behavioral Surveillance Survey, NACO, 2009

<sup>2</sup> Reproductive, Child, and Sexual Health needs of women living with HIV/AIDS, AIDS- a Situation Assessment Report, Prevention and Control Project, 2010



## KEY FINDINGS

**Table 2. Selected demographic characteristics of the PLHIV Stigma Index sample**

Selected characteristics	General Male	General Female	Trans genders	MSM	FSW	PUD	TOTAL
<b>EDUCATION STATUS</b>							
No formal school	68 (14%)	164 (28%)	40 (25%)	39 (20%)	17 (17%)	20 (36%)	348 (22%)
Up to primary school	196 (40%)	199 (34%)	83 (51%)	86 (44%)	25 (26%)	26 (46%)	615 (39%)
Up to secondary school	191 (39%)	212 (36%)	28 (17%)	58 (30%)	52 (53%)	9 (16%)	550 (35%)
Technical college / university	33 (7%)	16 (3%)	10 (6%)	13 (7%)	3 (3%)	1 (2%)	76 (5%)
No response	1 (0%)	2 (0%)	1 (1%)	0 (0%)	1 (1%)	0 (0%)	5 (0%)
<b>TOTAL</b>	<b>489 (100%)</b>	<b>593 (100%)</b>	<b>162 (100%)</b>	<b>196 (100%)</b>	<b>98 (100%)</b>	<b>56 (100%)</b>	<b>1594 (100%)</b>
<b>EMPLOYMENT STATUS (MULTIPLE OPTIONS POSSIBLE)</b>							
Full time employment (as an employee)	88 (18%)	53 (9%)	9 (6%)	28 (14%)	26 (27%)	14 (25%)	218 (14%)
Part time employment (as an employee)	166 (34%)	202 (34%)	44 (27%)	84 (43%)	28 (29%)	24 (43%)	548 (34%)
Working full time but not as an employee (self employed)	48 (10%)	33 (6%)	8 (5%)	19 (10%)	17 (17%)	0 (0%)	125 (8%)
Doing casual or part time work (self employed)	132 (27%)	97 (16%)	66 (41%)	25 (13%)	14 (14%)	5 (9%)	339 (21%)
Unemployed and not working at all	52 (11%)	206 (35%)	33 (20%)	39 (20%)	13 (13%)	13 (23%)	356 (22%)
No response	3 (1%)	2 (0%)	2 (1%)	1 (1%)	0 (0%)	0 (0%)	8 (1%)
<b>TOTAL RESPONDENTS</b>	<b>489 (100%)</b>	<b>593 (100%)</b>	<b>162 (100%)</b>	<b>196 (100%)</b>	<b>98 (100%)</b>	<b>56 (100%)</b>	<b>1594 (100%)</b>

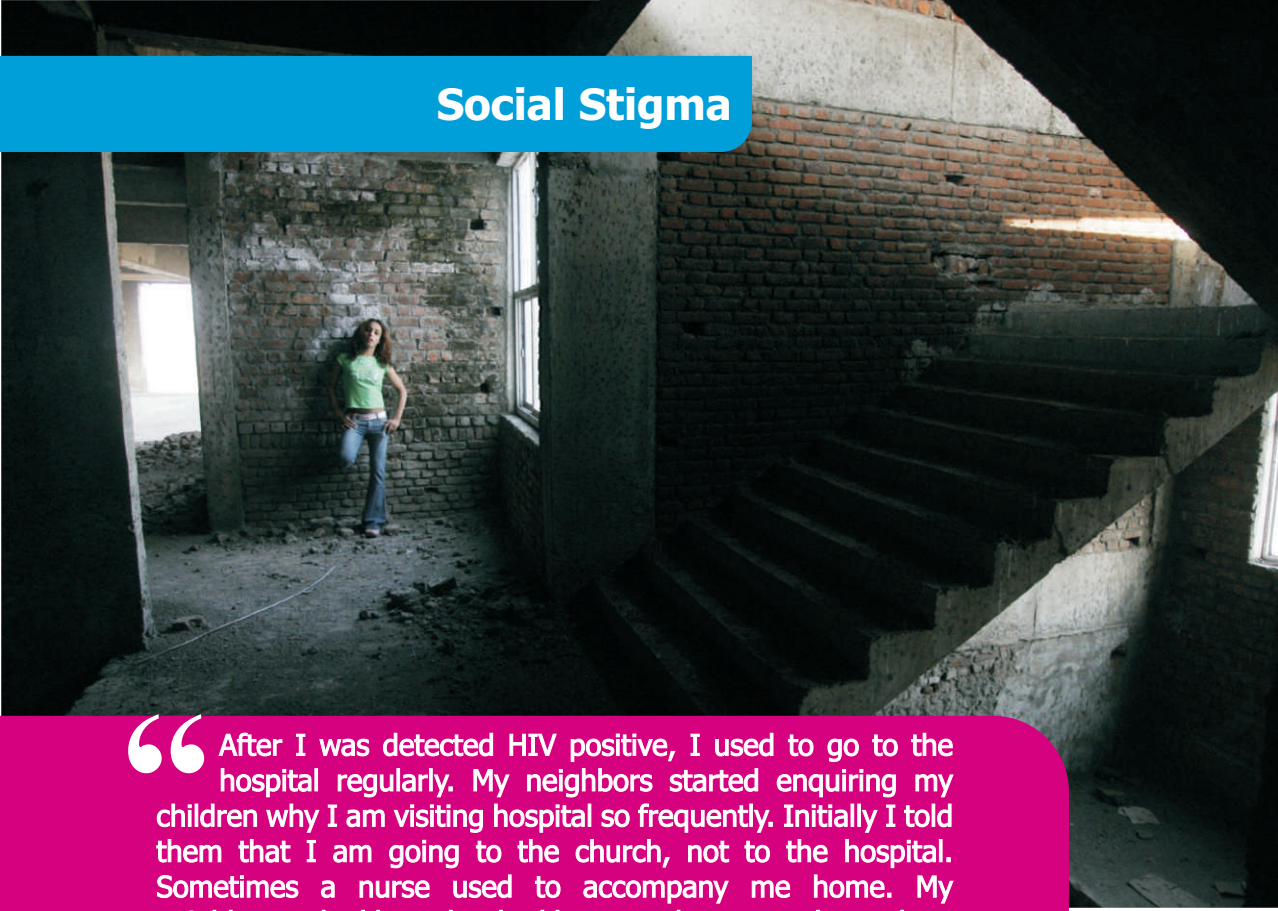
## KEY FINDINGS

# KEY FINDINGS

Selected characteristics	General Male	General Female	Trans genders	MSM	FSW	PUD	TOTAL
<b>CURRENT RELATIONSHIP STATUS</b>							
Cohabiting living with spouse	317 (65%)	218 (37%)	15 (9%)	35 (18%)	51 (52%)	20 (36%)	656 (41%)
Cohabiting spouse live away from household	9 (2%)	10 (2%)	10 (6%)	14 (7%)	3 (3%)	0 (0%)	46 (3%)
In a relationship but not living together	8 (2%)	3 (1%)	17 (10%)	9 (5%)	4 (4%)	0 (0%)	41 (3%)
Single	63 (13%)	16 (3%)	103 (64%)	113 (58%)	10 (10%)	30 (54%)	335 (21%)
Divorced/ separated	37 (8%)	59 (10%)	14 (9%)	22 (11%)	9 (9%)	4 (7%)	145 (9%)
Widow / widower	52 (11%)	283 (48%)	0 (0%)	3 (2%)	20 (20%)	2 (4%)	360 (23%)
No response	3 (1%)	4 (1%)	3 (2%)	0 (0%)	1 (1%)	0 (0%)	11 (1%)
<b>TOTAL</b>	<b>489 (100%)</b>	<b>593 (100%)</b>	<b>162 (100%)</b>	<b>196 (100%)</b>	<b>98 (100%)</b>	<b>56 (100%)</b>	<b>1594 (100%)</b>
Median Length of Relationship (years)	11.84	10.80	10.00	11.43	7.61	11.88	11.02
<b>WHETHER SEXUALLY ACTIVE</b>							
Sexually Active	319 (65%)	191 (32%)	115 (71%)	184 (94%)	68 (69%)	55 (98%)	932 (58%)
<b>Period living with HIV</b>							
0-1 Year	54 (11%)	39 (7%)	11 (7%)	4 (2%)	9 (9%)	1 (2%)	118 (7%)
1-4 Years	187 (38%)	188 (32%)	67 (41%)	79 (40%)	35 (36%)	9 (16%)	565 (35%)
5-9 Years	195 (40%)	282 (48%)	65 (40%)	65 (33%)	44 (45%)	31 (55%)	682 (43%)
10-14 Years	44 (9%)	67 (11%)	10 (6%)	28 (14%)	7 (7%)	12 (21%)	168 (11%)
Above 15 Years	7 (1%)	12 (2%)	5 (3%)	19 (10%)	3 (3%)	3 (5%)	49 (3%)
No Response	2 (0%)	5 (1%)	4 (2%)	1 (1%)	0 (0%)	0 (0%)	12 (1%)
<b>TOTAL</b>	<b>489 (100%)</b>	<b>593 (100%)</b>	<b>162 (100%)</b>	<b>196 (100%)</b>	<b>98 (100%)</b>	<b>56 (100%)</b>	<b>1594 (100%)</b>

## KEY FINDINGS

### Social Stigma



“After I was detected HIV positive, I used to go to the hospital regularly. My neighbors started enquiring my children why I am visiting hospital so frequently. Initially I told them that I am going to the church, not to the hospital. Sometimes a nurse used to accompany me home. My neighbors asked her what had happened to me and somehow they came to know my HIV status. Then they started gossiping among themselves “this lady will die soon.””  
(In-depth interview)

#### Forms of social stigma

**While more than half of the sample experienced at least one form of social stigma in the previous one year, it was among the marginalized populations (MSM, FSW, TG and PUD) that it was most concentrated.**

Social exclusion in the form of not being allowed to participate in religious activities and family activities, verbal and physical assault was reported to be “often” experienced by transgenders (14%), FSW (11%) and MSM (10%). The most violent forms of discrimination were experienced at the hands of family members. Nearly half (48%) of general females, who reported physical assault at least once, were assaulted by their husbands or partners and another one-third (36%) of them faced assault from other members of the family. In addition, 52% of general male, 31% of transgender, 12% of MSM, 15% of FSW were assaulted by family members. Physical assault by unknown person was reported mostly by PUD (36%) and transgenders (40%).

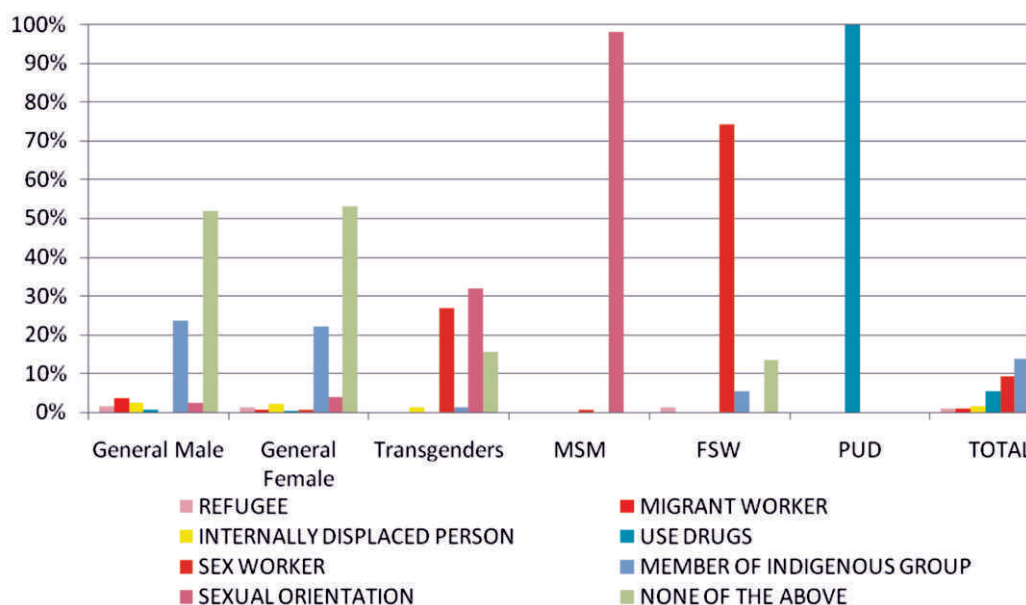
## KEY FINDINGS

### Reasons for social stigma

When asked about the reason for their social exclusion, while general males (75%) and females (74%) blamed it on their HIV status, the transgenders (68%), MSM (66%), FSW (53%) and PUD (33%) were of the opinion that their identity too, apart from HIV, played a role behind their exclusion from social gatherings, thus laying credence to the general observation that much of stigma experienced by KPs is perceived to arise from behavioral and sexual identity. Furthermore, belonging to the scheduled castes and tribes also appear to confound the perception of stigma as 24% of the general males and 22% of the general females believed they were stigmatized as they belonged to such communities. When asked about their perception for the reasons of stigma due to their HIV status, the majority replied that it was because of the fear of infection.

“ At one stage my neighbours did not allow me to fetch water from the community tube-well. They complained to the police and the police arrested me and kept me in jail for three days. My brother bailed me. My neighbours ultimately compromised with me once the complainant understood that being HIV positive was not my fault. But still, I feel, they are scared to use the tube-well. In spite of repeated explanation about the mode of HIV transmission of HIV, they are not very convinced. Now I am totally fed up and stopped paying any attention to their comments. (In-depth interview) ”

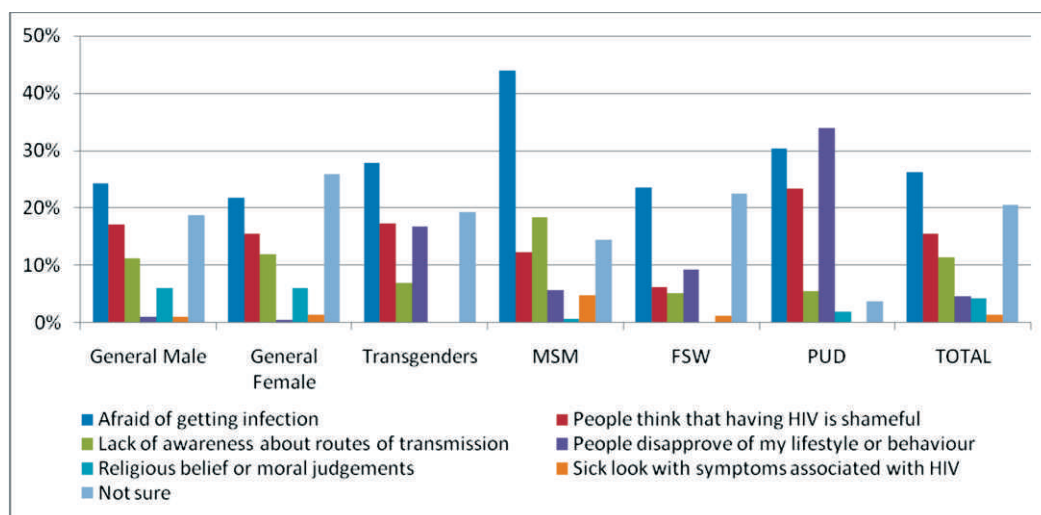
**Fig1. According to you, what other reasons, apart from your HIV status, might explain the stigma against you**





## KEY FINDINGS

**Fig 2. According to you, why do people discriminate against people living with HIV**



### Other manifestations of stigma

While 20% of the respondents said that they were subjected to psychological pressure or manipulation a few times in the previous 12 months by their spouses or partners in which their HIV status was used, 15% reported they had experienced sexual rejection a few times. However, the most affected sub-population were MSM: 59% of them had been subjected to psychological pressure by their spouses or partners, 68% had faced sexual rejection, 25% of them had faced discrimination by other PLHIV, and 47% reported that their family members had been discriminated due to their HIV status.

### MSM with a partner/spouse & experiences of enacted and self stigma

We were interested to see the difference in the experience of stigma between MSM having a stable relationship and those who were single. Since we did not ask about marital status with a female spouse, it is difficult to know whether the partners cited in the responses were female or male. It is interesting to note, however, that the majority of MSM who were living with a partner felt less self stigma and experienced fewer acts of discrimination than those who were single. Thus, having a stable relationship (with either a male or female partner) appears to confer positive benefits to MSM.

## KEY FINDINGS

# KEY FINDINGS

**Table 3. Experiences of discrimination among MSM who were living with a partner and MSM who were single**

Experience of discrimination & self stigma		Cohabiting with partners	Single or not cohabiting with partners	Total	Cohabiting with partners	Single or not cohabiting with partners	Chi Square
Excluded from social gatherings	Never	25	66	91	71%	41%	0.000
	Once	6	11	17	17%	7%	
	A few times	3	82	85	9%	51%	
	Often	1	2	3	3%	1%	
	Total	35	161	196	100%	100%	
Excluded from religious activities	Never	29	72	101	85%	45%	0.000
	Once	1	4	5	3%	3%	
	A few times	4	82	86	12%	51%	
	Often	0	2	2	0%	1%	
	Total	34	160	194	100%	100%	
Excluded from family activities	Never	27	61	88	77%	39%	0.000
	Once	6	8	14	17%	5%	
	A few times	2	87	89	6%	55%	
	Often	0	2	2	0%	1%	
	Total	35	158	193	100%	100%	
Verbally insulted	Never	26	38	64	74%	24%	0.000
	Once	3	13	16	9%	8%	
	A few times	6	106	112	17%	66%	
	Often	0	4	4	0%	2%	
	Total	35	161	196	100%	100%	
Physically assaulted	Never	31	64	95	89%	40%	0.000
	Once	1	21	22	3%	13%	
	A few times	3	74	77	9%	46%	
	Often	0	2	2	0%	1%	
	Total	35	161	196	100%	100%	

## KEY FINDINGS

Experience of discrimination & self stigma		Cohabiting with partners	Single or not cohabiting with partners	Total	Cohabiting with partners	Single or not cohabiting with partners	Chi Square
<b>Sexual Rejection</b>	Never	14	45	59	40%	28%	0.520
	Once	0	1	1	0%	1%	
	A few times	20	110	130	57%	69%	
	Often	1	3	4	3%	2%	
	Total	35	159	194	100%	100%	
<b>Discriminated by other PLHIV</b>	Never	32	108	140	91%	68%	0.038
	Once	1	4	5	3%	3%	
	A few times	2	45	47	6%	28%	
	Often	0	1	1	0%	1%	
	Total	35	158	193	100%	100%	
<b>Discriminated by family members</b>	Never	18	49	67	51%	32%	0.000
	Once	14	15	29	40%	10%	
	A few times	3	83	86	9%	55%	
	Often	0	5	5	0%	3%	
	Total	35	152	187	100%	100%	
<b>Forced to change place of residence</b>	Never	29	70	99	83%	44%	0.000
	Once	4	14	18	11%	9%	
	A few times	2	70	72	6%	44%	
	Often	0	6	6	0%	4%	
	Total	35	160	195	100%	100%	
<b>Lost job / work opportunity</b>	Never	27	77	104	79%	60%	0.017
	Once	4	8	12	12%	6%	
	A few times	2	42	44	6%	33%	
	Often	1	2	3	3%	2%	
	Total	34	129	163	100%	100%	

## KEY FINDINGS

### Access to work, healthcare and education



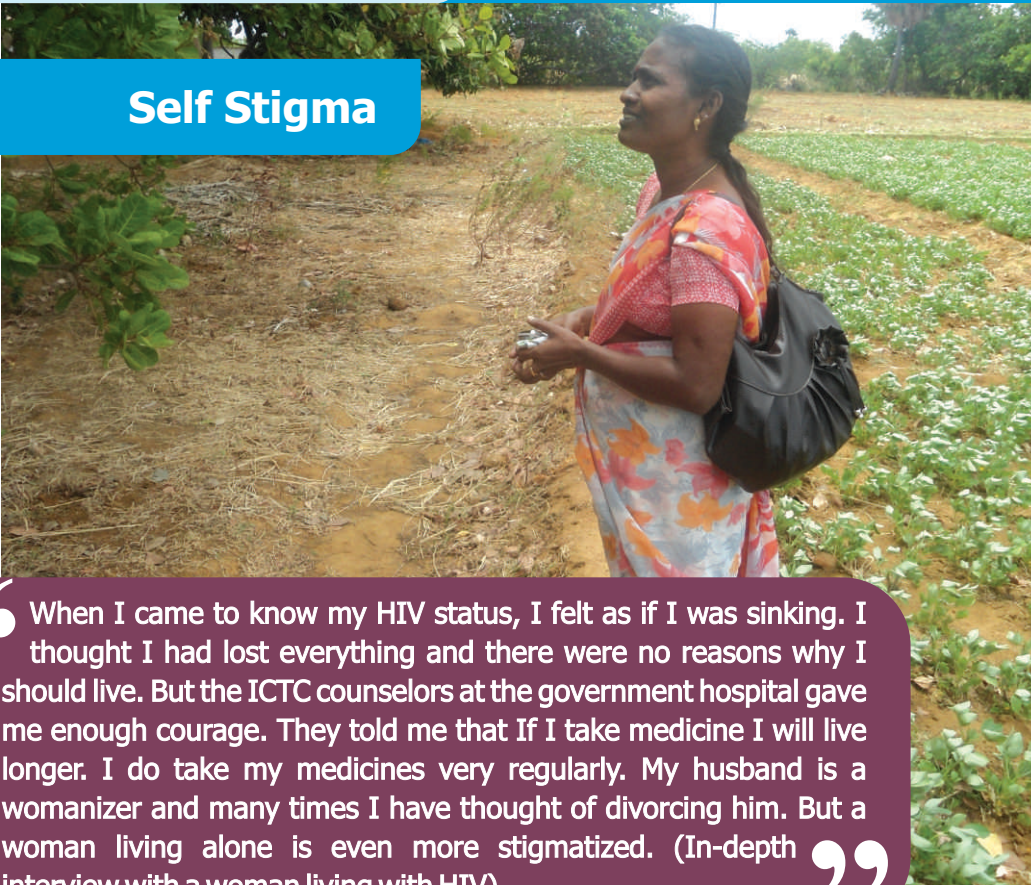
“ I faced a lot of discrimination there when I was admitted to a government hospital for my delivery. The person accompanying me disclosed my HIV status to the nurse and to my relatives. The hospital staff and my relatives did not touch my new-born baby. But I received very good behaviour from the doctor. (In-depth interview) ”

**Although acts of discrimination were not very high, yet reports of 16% of respondents being forced to change their residence, 11% losing their job, 6% being refused a job opportunity and 6% being denied health services at least once in the last 12 months highlights still prevalent stigma.** MSM and TG were the most affected in being forced to change their residence and 36% of them said that it was due to their HIV status while 41% attributed some other reasons to it. Again, MSM appear to have lost jobs more often than others (30%), followed by PUD (16%), general male (9%), TG (8%), general female (6%) and FSW (3%). About a third of the respondents (36%) felt that it was due to their HIV status. Most of the respondents who were refused promotion were unable to perform due to poor health. Denial of health services at least once in the past one year was reported by general male, general female, FSW, MSM and TG. Incidents of dismissal, suspension and of being prevented from attending educational institutions due to one's HIV status were negligibly few. Only 1% of general male and female reported such events of education being denied to their children.



## KEY FINDINGS

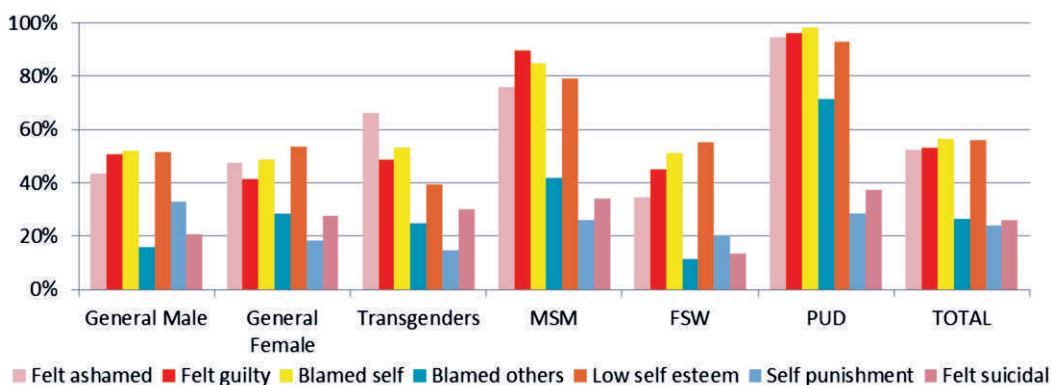
### Self Stigma



“When I came to know my HIV status, I felt as if I was sinking. I thought I had lost everything and there were no reasons why I should live. But the ICTC counselors at the government hospital gave me enough courage. They told me that If I take medicine I will live longer. I do take my medicines very regularly. My husband is a womanizer and many times I have thought of divorcing him. But a woman living alone is even more stigmatized. (In-depth interview with a woman living with HIV)”

**High levels of self stigma were present in all the respondents, more specifically among PUD, MSM and FSW.** Fifty six percent of the respondents blamed only themselves for their condition and had very low self-esteem. 53% felt ashamed and guilty of their HIV status, 26% blamed it on others, while 24% felt that they should be punished. More alarmingly, 26% of the respondents expressed suicidal intent. Most intense internal stigma was recorded among the PUD, MSM, and FSW. 98% of PUD, 97% of the MSM and 94% of the FSW had imbibed at least one of the above feelings in last 12 months. This was followed by the TG (73%), general females (70%) and general males (70%).

**Fig 3. Whether you have ever experienced the following feelings**





## KEY FINDINGS

KEY FINDINGS

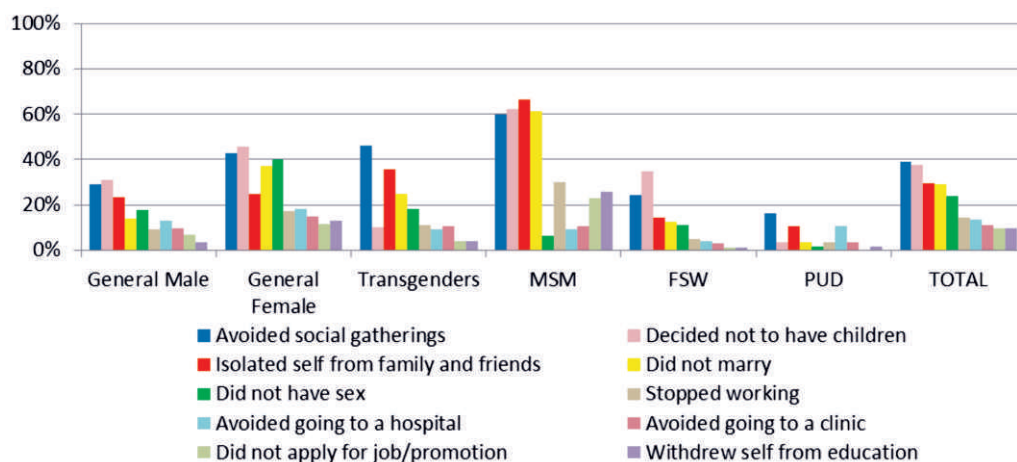


### Impact of self stigma

“ When I was first diagnosed as HIV positive in private Hospital in 1992, they told me that I would die within a year. I felt that I should not live for another day. I thought of committing suicide. For two months I confined myself within four walls of my room. I didn't feel hungry. I didn't take any food. I didn't see anybody. It was one of my friends who changed my mind and brought me to my senses. (In-depth interview with an MSM) ”

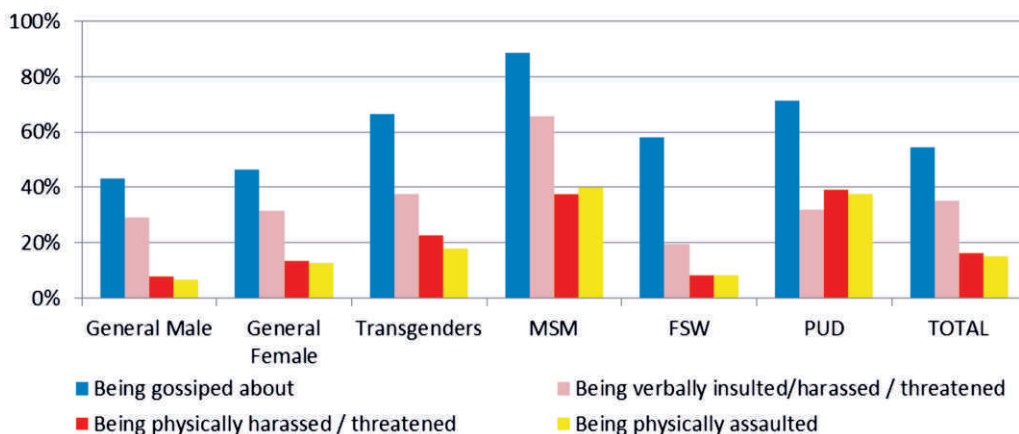
Most of the respondents (69%) took decisions in the past year that were the direct result of their internal stigma: 39% of the respondents had chosen not to attend any social gathering due to stigma, 37% decided not to have any more children, 29% isolated themselves from their friends and families and 29% decided not to get married, 24% thought they should not have sex any more and 14% stopped working, 13% avoided going to a hospital even in an emergency, 11% did not even visit a local clinic, 10% decided not to apply for a new job or promotion, 10% withdrew themselves from an educational institute (Fig 4). Once again, MSM were in the majority who took at least one such decision in the past year. The feeling of being discreditable has perhaps more adverse effects on human life rather than being actually discredited. That perhaps explains why PLHIV are afraid of being gossiped about, verbally insulted, physically threatened and assaulted (Fig 5). Fear of gossip and verbal insults has been reported by all respondents, while fear of physical assault is more concentrated among PUDs and MSM. Among all respondents, 19% felt they were not in a position to seek sexual intimacy from anybody any more.

**Fig 4. Whether you have done the following**



## KEY FINDINGS

**Fig 5. Have you been afraid of the following (irrespective of whether or not actually happened)**



### Belonging to a network and perception of self stigma

We were interested to know whether membership of a support network contributed to assuaging feelings of internalized stigma. While belonging to networks did seem to confer positive benefits to general men, women, sex workers, PUD, the same were not seen for MSM. Perhaps, the group of MSM not in any network did not have much self stigma to begin with. However, we have to interpret these findings with caution as the number of non network members were very low and the findings may be merely based on selection bias. When it came to voluntarily avoiding certain activities due to self stigma, it was the men, women, sex workers not belonging to networks who reported more of these. However, for MSM and TG, results were contradictory as those belonging to networks appeared to have higher avoidance due to self stigma. Perhaps, networks of MSM and TG need to do more about addressing self stigma, and efforts should be made to both bring non members of different sub populations into the fold of networks while at the same time also targeting them through mass media campaigns.

**Table 4. Network and non network members and experience of self stigma**

Selected self stigma Characteristics	Sample	Network Members	Not Network Members	Network Members	Not Network Members
<b>Felt guilty</b>	<b>General Male</b>	<b>157</b>	<b>87</b>	<b>49%</b>	<b>59%*</b>
	General Female	173	66	41%	45%
	Transgenders	43	33	48%	52%
	<b>MSM</b>	<b>153</b>	<b>21</b>	<b>96%</b>	<b>68%***</b>
	Sex Workers	20	24	47%	47%
	PUD	47	7	98%	100%

## Testing and Diagnosis



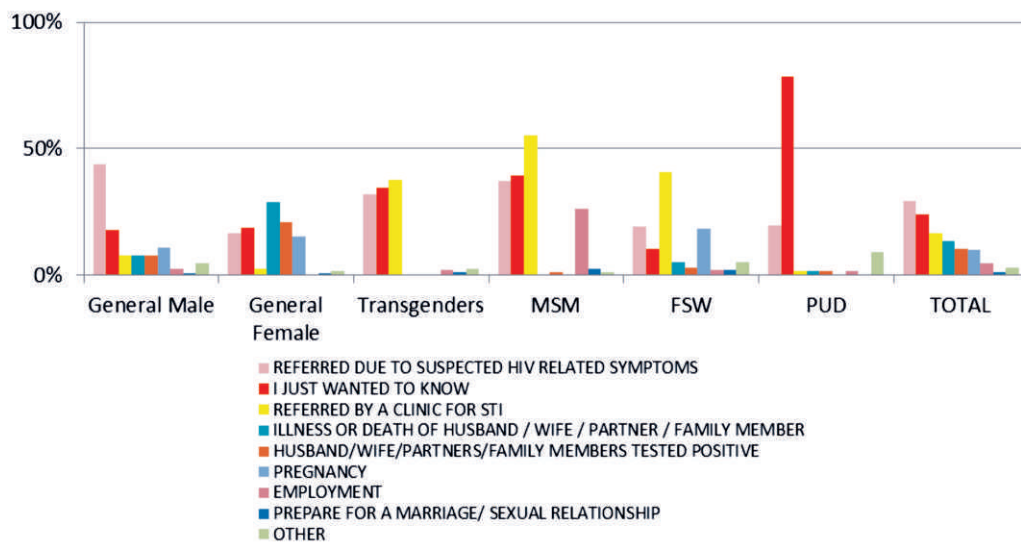
“ I am a widow. My husband used to fall ill often He had warts in his body and he went to a hospital. He was asked to do a number of tests and the doctor disclosed his test result to his elder brother. Three days later I came to know from my elder brother that he is infected with HIV. I learnt that the doctor has asked me too to do the test. . I screamed, “Why should I come for the test ? I am not sick.” I was told that the doctor had said it was just for nothing. Nothing would happen to me. After a little persuasion, I agreed and went to the hospital to take the test. After four days I heard my brother, in-laws and my husband were discussing something about me. When I shouted at them “Why are you discussing me ? What has happened ?” They said, “Nothing, you have to take care of your health.” But I guessed what it was. I attempted suicide three times by hanging from the fan. I could not tolerate neighbors gossiping about me. (In-depth interview with a woman living with HIV) ”

**Important strides have been made in improving testing and diagnosis as evidenced by the majority of the respondents (75%) confirming that they voluntarily took the decision to undergo HIV testing, yet the occasional instances of feeling pressured (23%), coerced (1%) and tested without knowledge (5%) still remain.** Most of the referrals for testing were made on suspicion of HIV related symptoms, followed by referrals from STD clinics. Most women from the general population were tested after the death of their spouse, while wanting to know out of curiosity was reported by an

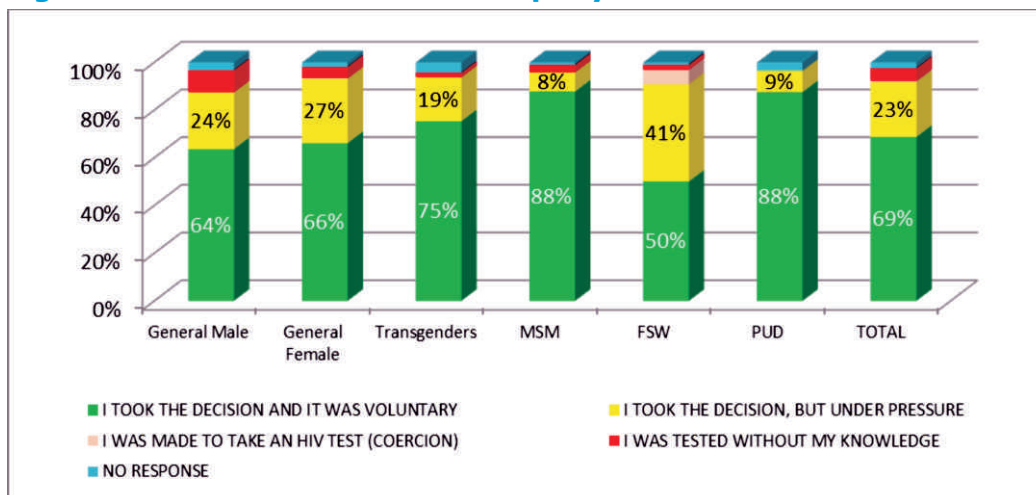
## KEY FINDINGS

overwhelming majority of PUD (79%) followed by MSM (39%), and TG (35%). FSW (41%) were the ones who took the test under pressure. There is also much left to be desired in terms of quality of counseling as a quarter of the sample (24%) received only post test counseling and no pre test counseling. Slightly less than half of FSW (41%), 34% of the general males and 25% of the general females, 10% of the transgenders, 9% of the PUD and 5% of MSM received only post-test counseling, while 9% of the respondents received neither pre-test or nor post-test counseling, and 2% of respondents received only pre-test counselling.

**Fig 6. Why were you tested for HIV**



**Fig 7. Was the decision to be tested up to you**





## KEY FINDINGS

# KEY FINDINGS



### Disclosure

“ Seven years back I was frequently falling ill and I spent a lot of money on priests and chanting to get rid of the evil spirit out of me. But when nothing worked I went to St Thomas Hospital. I stayed there for a week and took a number of tests. One day the doctor told me that there was some infection in my blood and I had to take another blood test from a private laboratory. I took the test and was diagnosed HIV positive. I was shocked. I cried like anything. I rushed to home, called my wife and son and told them that I was HIV positive. They all started crying ”

Disclosure status was moderately high in the state. For 91% of the respondents (for whom it was applicable) spouses and partners were aware of their HIV status. Most of them (74%) disclosed themselves, while in 3% of the cases, disclosure was done by someone else without their consent. Those who disclosed reported receiving supportive behavior from the person they had disclosed to. It was only among the TG (50%) that disclosure to spouses and partners were less. Non disclosure was also confined mostly to “clients” of FSW and MSM. However, we are not certain about what type of clients is referred to for MSM. Status was kept confidential mostly from other adult members of the family (32%), children (59%), friends and neighbours (57%), co-workers (67%) and employers (71%). Although, the majority (71%) felt no pressure to disclose, about one-fourth confirmed some kind of pressure, especially from PLHIV and networks. People felt pressure from both sides – PLHIV and networks as well as from people not living with HIV (family

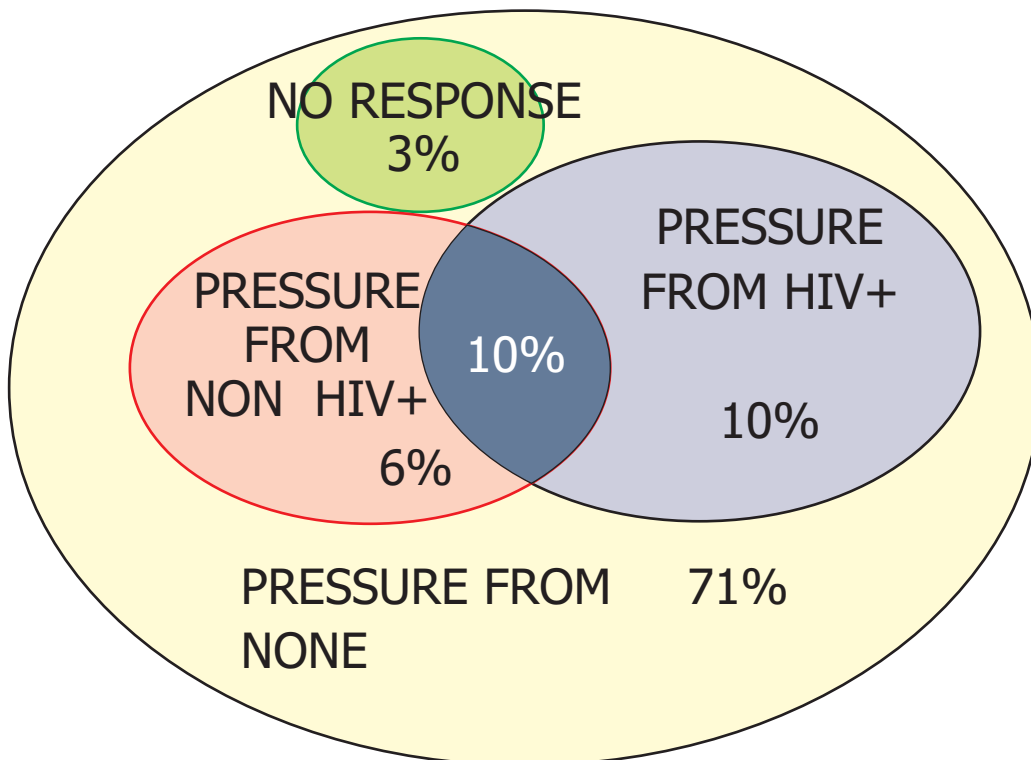


## KEY FINDINGS

members, social workers, NGOs) - to undergo test. Slightly more than one quarter (26%) of the respondents confirmed that they were under pressure to take the HIV test from either side, 10% said that they were pressurised from both sides. As revealed by the study, pressure from PLHIV and networks (21%) was more than the pressure from people not living with HIV (17%). Furthermore, despite the majority reporting faith in the medical establishment in maintaining confidentiality of medical records, there was still some doubt among 35% of MSM, 28% of TG, 17% of general male, 14% of general female, and 5% of FSW, clearly indicating that there was not complete trust in the medical establishment.

On enquiry, 36% of the respondents felt that disclosure of HIV status was an empowering exercise for them. However, 39% of the respondents thought otherwise.

### PRESSURE TO DISCLOSE YOUR STATUS



## KEY FINDINGS

# KEY FINDINGS

## Treatment

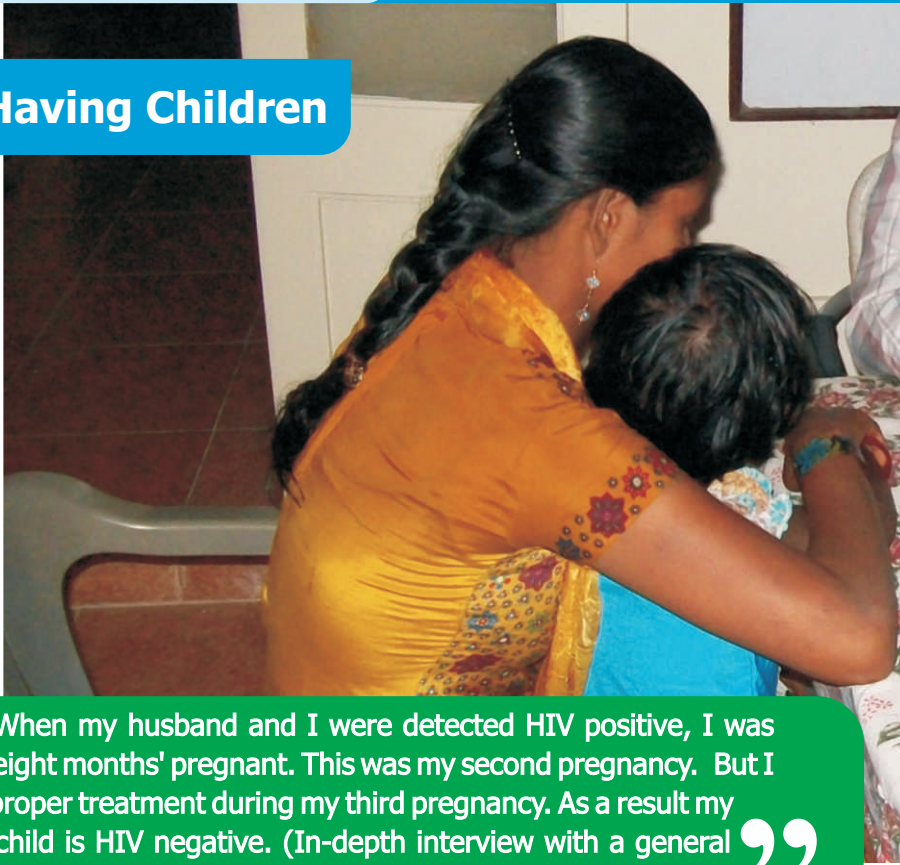


“ My husband died ten years ago, within two months of his diagnosis. He did not get ART. Six years ago my daughter died at the age of five. She was HIV positive. She died from diarrhoea. She did not take ART. For the last eight years I have been on ART. I get depressed very frequently. But I have to survive for my son. He is negative. (In-depth interview with a general woman) ”

**Most respondents appeared to be in good health. The majority reported that they had access to antiretroviral medication and treatment for opportunistic infections. However, 17% reported that they found it difficult to access ARV and treatment for opportunistic infections.** 21% of the general females, 18% of the general males, 15% of the transgenders, 12% of the FSW, 8% of the MSM and 4% of PUD reported not having access to ARV. Surprisingly, while marginalized groups such as MSM, TG and PUD reported having had constructive discussions with health care providers on treatment options and sexual and reproductive health; the other groups such as general male, female and FSW had less opportunity to discuss these issues. Contrary to popular perception positive people living in rural areas and small towns seem to have better access to ARV and treatment of opportunistic infections than those living in the large towns and cities. 85% of those living in small towns and 82% of those living in rural areas reported having access to ARV as against 73% living in large towns and cities. This difference is statistically significant (p-value = 0.000). However, rural-urban differences over access to ARV and treatment of opportunistic infection are not statistically significant when small towns and cities are combined together as urban.

## KEY FINDINGS

### Having Children



“When my husband and I were detected HIV positive, I was eight months' pregnant. This was my second pregnancy. But I took proper treatment during my third pregnancy. As a result my third child is HIV negative. (In-depth interview with a general woman)”

**Beliefs and opinions about the preferability of not giving birth to children of HIV infected persons still abound albeit reported by low proportions of the respondents. Knowledge of prevention of mother to child transmission is not widely available.** Sixty percent of the respondents had children. However, those having HIV positive children constituted 14% of the sample. While 20% of the respondents confirmed that they had received counselling about reproductive options since they had been diagnosed HIV positive, 12% including general men, women, FSW and IDU were advised not to have a child since they had been diagnosed as HIV positive; 4% of the respondents expressed that they were coerced to undergo sterilization.; 8% of the respondents mentioned that combinations of ARVs they are taking are conditional on the use of certain forms of contraception. In terms of termination of pregnancy, 4% of the general females and 7% of the FSWs reported having been coerced by healthcare professionals to do so in last 12 months while 14% of the general females and 5% of FSWs were coerced in relation to the method of giving birth, and 38% of the general females and 5% the FSWs were coerced in relation to infant feeding practices. Over a third of the general females (38%) and 13% of the FSWs (of those for whom it was applicable) confirmed having received ARV prophylaxis during pregnancy to prevent mother to child transmission of HIV. A little over a quarter (28%) of the general females and 69% of the FSWs were not aware that such treatment existed. While 32% of the general females and 19% of the FSWs said that they did not have access to ARV when they were pregnant. Only 1% of the general females said that they were refused this treatment.



## Rights, Laws and Policies



“ I earn Rs 700 a month through national rural employment guarantee scheme. My husband sold the house to meet his medical expenses. I survived because my network helped me. Last year I applied for a house in my village under the government's free housing plan for the poor people but the head of my panchayat, who was a woman, acted against my application. She has given petition to the district collector so that I do not get the free house. She also mobilised the villagers against me. I approached a press reporter and sought help from police to tackle the agitation against me. The police came, but the villagers were very united and they didn't allow me to get a free house under the government scheme. This is all because I am HIV positive. (in-depth interview with a woman living with HIV) ”

**Very few respondents were aware of the Declaration of Rights of PLHIV or knew what to do when they faced acts of discrimination; however, the majority knew of networks and organizations which they could approach for help.** The government policies on HIV/AIDS were known only to 16% of the respondents. Twenty percent of the respondents reported having been affected by various discriminatory policies such as mandatory HIV testing at work place or travel related policies, 11% were forced to submit for medical or health procedure including HIV testing on some occasions, 2% were denied insurance, 2% had to disclose their HIV status in order to enter another country, 2% were

## KEY FINDINGS

detained, quarantined, isolated or segregated, 1% had to disclose their HIV status to apply for residence or nationality, and 6 respondents (less than 0.5%) were arrested or taken to the court on some charges related to their HIV status. However, only 2 % sought legal redress. About a quarter of these cases had no resolution while among those who withdrew a case almost half did so due to financial constraints. This happened mostly with the FSW (67%), general females (58%), transgenders (50%) and general males (44%). The majority (86%) of the respondents were, however, aware of PLHIV networks, local NGOs, and support groups from about 22% sought help ranging from family counseling to property issues to education of their children. Nearly half of FSW and TG did not belong to any networks whereas most of the other groups did.

According to 35% of the respondents advocating for the rights of all people living with HIV was the best way to address stigma and discrimination, 31% felt the most important thing is to support people living with HIV by providing emotional, physical and referral support. To 20% of the respondents the most important issue was raising awareness and knowledge of the general community about AIDS while 9% felt advocating for the rights of particularly marginalised groups like MSM, People who use Drugs and FSWs and providing support to them was the most important step to address stigma and discrimination. Only 3% of the respondents believed that educating people living with HIV about living with HIV (including treatment literacy) could help.



# LIMITATIONS AND RECOMMENDATIONS

## Limitations

The study has a number of limitations. Since findings are based on self reports, they are likely to have recall bias and socially acceptable response bias. A major limitation has been our inability to rigorously distinguish between MSM and TG. Most respondents who earlier in the interview identified themselves as MSM later on said they were actually TG. Many of them also saw themselves as belonging to both these categories. The problem lies with lack of clearly defined boundaries among the MSM group in India in particular, around sexual and gender identities that fluctuates within a range of local (Panthis, Kothis) to international identities (Gay, MSM). We, therefore, could not verify whether the MSM reported to be living with their partners were married and whether their partners were female, male or TG. Therefore the findings from the MSM and TG groups have to be treated with caution. Since most respondents were purposively selected through networks, there could also be sampling bias. Another issue is about internal consistency of the index: there were some questions which gave inconsistent responses. (-eg, PUD respondents mention being forced to undergo medical examination including HIV testing, while on another question regarding testing, the majority said that they had tested voluntarily as they wanted to know their status). This could also be a consequence of respondent fatigue or lack of probing and quality control by the interviewers. In case there is replication or scale up of the study, these issues can be addressed and the problems overcome.



## LIMITATIONS AND RECOMMENDATIONS

### Recommendations



There are some positive findings from this study that indicate that activities that were previously associated with high levels of perceived stigma, coercion, and discrimination like HIV testing and disclosure are no longer so. Very few PLHIV respondents reported compulsory testing. The majority had disclosed their status without any major negative repercussions. There was not much discrimination reported in health care settings.

However, discrimination has not been totally eliminated as we can see from our results that half of the respondents reported some instances of enacted stigma in the recent past from the community and family leading to high social exclusion. Furthermore, the level of self stigma was very high with respondents isolating themselves from mainstream society due to perceived stigma. The recommendations given below are based on the study's key findings, and drawn from dissemination meetings with major stakeholders in the state.

## LIMITATIONS AND RECOMMENDATIONS

### Programme Recommendation

- \* Support networks and NGOs need to introduce education and information sessions on sexuality, addiction, human rights, sexual and reproductive health rights. Networks of MSM and TG need to address self stigma through introduction of information and education sessions on sexual identity and sexual health rights.
- \* Psychosocial support needs to be made a mandatory component of any HIV intervention
- \* Innovative community based stigma reduction campaigns need to be launched to overcome fears of transmission. Community mobilization and collectivization of marginalized groups needs an added push. Communities affected the HIV are well positioned to address the structural factors that increase their vulnerability to the impact of stigma and human rights and therefore it is critical to invest in such groups to mobilize communities and support through social and community mobilization approaches including capitalizing on their social capital.
- \* Pretest counseling needs to be ensured before any HIV test. Couple counseling as well as family counseling needs to be encouraged in order to reduce domestic violence.
- \* Sensitization of service providers about issues of sexuality, sexual orientation and human rights campaigns profiling marginalized people in consultation with other groups are some other steps in challenging stereotypes. Sensitization of health providers to particularly meet needs of Women living with HIV and FSW in discussing sexual and reproductive health matters and positive prevention. Approaches like Interpersonal communication to provide correct and updated information to address the fear of casual contact among health care providers should be scaled up.
- \* Need for regular meetings with media to avoid publication or broadcast of negative messages. PLHIV including key populations living with HIV should be supported and capacitated to handle the media to de-sensationalise the reporting of incidences of HIV cases and minimize perpetuating the stereotyping of negative information related to behaviours of MSM, TG, SW and PUD.
- \* Dissemination of findings to communities to be analyzed and used for advocacy. In order to do this, communities living with HIV should be technically equipped to interpret and analyse the findings to bring in social change at the community level.
- \* Conduct more in-depth analysis on sex and sexuality of MSM and TG



## LIMITATIONS AND RECOMMENDATIONS

behaviours and develop communication messages to normalize various hidden and emerging identities and de-link the stigma associated with these terms. And explore how HIV interrupts life of marginalized communities such as MSM and TG and their identities and make them more vulnerable to violation of human rights and in particular, sexual health rights.

- \* While the study findings provide a baseline and quantitative aspects of stigma associated with HIV in different domains of a HIV positive individual, a deliberate programmatic focus should be made to delve deep into the meanings that HIV stigma has had on the lives and stories of those who have to experience them on a daily basis and how they cope with the stigma with minimal social and institutional support.
- \* NACP-IV and NRHM programmes should develop a comprehensive communication strategy to address the key factors and elements like power, control, domination, social systems of hierarchy, social and structural inequalities and inequities, exclusion and marginalization that fuel the stigma associated to HIV and other chronic illnesses as a long term strategy.
- \* Scale up PLHIV friendly hospital using check list developed by Population Council based on operational research carried out with few public health hospital settings in Delhi and also use Stigma Index study findings to develop appropriate stigma reduction strategies in the hospital settings
- \* Guarantee special focus on young widows because they are extremely vulnerable and often victims of violence and harassment from family members. Counsellors to be trained to handle issues related to violence against women.
- \* Strict action including disciplinary proceedings and legal cases in government and private settings should be mandated in cases where pregnant women living with HIV are forced into abortion, sterilization or family planning measures. Ongoing training and sensitization programmes are required on PPTCT for all hospital staff .

### Policy Recommendation

- \* NACO to develop a multi-pronged strategy to involve leaderships at various levels and their commitment to a human rights framework.
- \* Mainstream issues of self stigma in NRHM training by involving PLHIV (GIPA) as key resource persons as they are best placed to bring about social change including attitudinal change within health systems where most case of enacted stigma are being reported.

## LIMITATIONS AND RECOMMENDATIONS

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- \* Introduce issues of stigma of PLHIV as well as marginalized groups within a broader medical ethics and human rights framework in medical curricula under institutional systems strengthening to address issues of HIV and other chronic illnesses and associated stigma.
- \* Work place policies, especially in the NGO sector and informal sector need evaluation and anti discrimination laws in work place settings should be rigorously implemented.
- \* Ensure that all social welfare programs and schemes recognize marginalized groups living with HIV including women living with HIV as critical entitlement holders to address poor linkages and integration, economic and gender inequality and low social cohesion.
- \* Establish mechanisms for legal redress for prohibition to rent houses or being evicted for one's sexual identity and developing inclusive criteria for health and life insurance for those affected by HIV.
- \* NACO must prioritise its advocacy effort to table and pass the HIV/AIDS Bill in parliament and reading down of IPC 377 in Supreme Court for creating an enabling environment for people and systems to operate within a human rights framework.
- \* NACO should develop an operational plan with committed resources to increase the involvement of PLHIV in decision making processes and ensuring equity and meaningful participation at all levels.
- \* State level task force on stigma should be institutionalized to address grievances and monitor programmes. Formation of this task force should be transparent and inclusive and led by PLHIV.

### Research Recommendation

- \* Indicators need to be developed to delineate causes, effects, manifestations of stigma so that findings can inform intervention design.
- \* The study can be repeated on an ongoing basis to measure the trend of stigma experienced by PLHIV including whether it is declining or resurfacing due to other factors. The results could be triangulated with other similar quantitative surveys being conducted at different settings with different populations.
- \* Qualitative research in order to understand in depth some of the findings from the quantitative survey is suggested.
- \* Further research on impact of self stigma, disclosure and coping mechanisms on realizing and fulfilling human and civil rights.
- \* Operations research to evaluate innovative programs for stigma reduction.



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