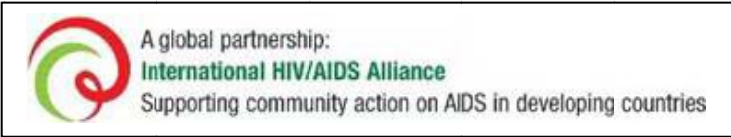




**MPG**



*Social*  
**insight**

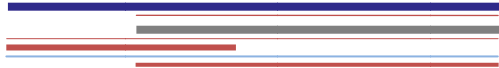
1. Brief Insights
2. Background and Methodology
3. Respondent Profile
4. Experience of Stigma and Discrimination
5. Access to Work, Health and Education Services
6. Internal Stigma
7. Rights, Laws and Policies
8. Effecting Change, Challenges and problems excerpts from interviews
9. Testing Diagnosis
10. Disclosure and Confidentiality
11. Treatment
12. Having Children

1/15/2010

**PRESENTATION OF KEY FINDINGS**

# PEOPLE LIVING WITH HIV STIGMA INDEX

**MYANMAR**



MMRD Research Services

# PEOPLE LIVING WITH HIV STIGMA INDEX

## MYANMAR

### 1. Brief Insights

For gender comparison, of the stigma index data, the MPG numerators divided their sample allocation evenly by gender of respondents currently living with HIV. The final sample for tabulations is divided with fifty-one percent female respondents and forty-nine percent male respondents, respectively 166 and 158 persons that make the sample size amount to a total of 324 respondents. For the purpose of this HIV stigma index, all respondents have a status of HIV-positive.

The majority of respondents are between the ages of 30-39, with the second largest number of respondents between the ages of 25-29. However there were several respondents between the ages of 15-19 and several respondents over the age of 50.

Nearly 70% of all respondents have been living with HIV for a period of 1-4 years. Several respondents have been living with HIV for 5-9 years, while only 1% of respondents found to participate in this survey have been living with HIV for more than 10 years.

1/3 of respondents are currently living with their spouse or partner in the same household. However, among the various categories, respondents classified as MSM account for the majority of respondents who are single, with over 50% of MSM stating that they are currently single. In contrast, of the respondents categorized as FSW, only 8% stated being single, with nearly 40% of FSW stating that they live with their spouse or partner in the same household. Of respondents categorized as IDU, nearly half are currently living with their spouse or partner in the same household.

For the stigma index sample allocation, respondents were put into four different category groups with samples distributed as MSM, FSW, IDU and others, as well as Gender, Region, and Age.

85% of the total respondents of the HIV Stigma Index are currently sexually active.

26% of respondents stated that they belong to the social category of Migrant Worker, commuting between the various regions of the study within Myanmar. Another 23% stated that they belong to the social category of Female Sex Worker, while 17% at one point belonged to the social category of Prisoner.

Only 8% of female respondents completed a Technical College or University-level education. The majority of respondents' highest level of education completed was secondary school. However, for the female respondents, the majority only completed the level of primary school.

Education levels among the geographic areas of the sample are quite similar throughout each region; however, more respondents surveyed in metropolitan areas had graduated from Technical College or University.

Nearly 1/3 of all respondents listed themselves as being self-employed, while nearly ¼ of respondents are currently unemployed. Only 13% of all respondents stated that they currently have full-time employment.

The average yearly income among respondents was found to be 1,380,466 Kyats. At the current exchange rates, that would be equal to yearly earnings of \$1,374 US dollars a year. Among the higher-income earners who had an average yearly income of 2,000,000 Kyats or above, those belonging to the categories of MSM and IDU made up a larger percentage.

Among the respondents' area of residence, the majority actually live in small towns or villages, not in large towns or cities in which 51% of total respondents are living in small towns or villages, and 54% of all female respondents living in small towns or villages. This data correlates with the high percentage of respondents who classify themselves as Migrant Workers. A majority of the respondents in the categories of MSM, FSW, and IDU also live in small towns or villages.

30% of total respondents stated that they have been excluded from social gatherings because of their HIV-positive status.

Among the various categories of respondents, 16% of FSW respondents stated that they were often excluded from social gatherings. While 15% of all categories stated that they had been excluded from social gatherings 3 or 4 times within the past 12 months.

20% of respondents stated that they have been excluded from family events in the past 12 months.

45% of all respondents stated they were aware of gossip about them due to their HIV-positive status, and over half of all female respondents were aware of gossip about them due to their HIV-positive status.

Among the various categories, respondents belonging to the group of FSW showed the most awareness of gossip.

Over 20% of HIV-positive female respondents stated that they were often verbally insulted, harassed, or threatened in the past 12 months, while over half of the total respondents stated they had never been verbally insulted, harassed, or threatened in the past 12 months.

15% of respondents stated they had been physically assaulted in the past 12 months.

Over 10% of respondents stated that they had been subject to psychological pressure or manipulation by their husband/wife or partner in which their HIV-positive status was used against them.

91% of respondents that are currently sexually active stated that they had never experienced sexual rejection as a result of their HIV-positive status in the past 12 months.

12% of the total respondents stated that they often experienced discrimination from members of their own household during the past 12 months, while over 75% stated they had never experienced discrimination from members from their household.

Over 20% of respondents had been forced to change their residence during the last 12 months. Of those respondents forced to change residence, 70% of them stated it was either directly or indirectly related to their HIV-positive status.

41% of respondents who lost their jobs in the past 12 months stated it was a result of their HIV-positive status. Of those respondents, 24% stated that their loss of employment was caused by discrimination by their employer or co-workers because of their HIV-positive status.

15% of total respondents stated that they had been refused employment because of their HIV status.

Over 35% of respondents stated that they had been denied access to family planning services in the past 12 months as a result of their HIV-positive status. 20% of respondents had also been denied sexual and reproductive health services in the last 12 months as a result of their HIV-positive status.

While earlier data shows that a number of respondents do face external discrimination, this index shows that a large number of respondents are dealing with emotional, internal stigma as a result of their HIV-positive status, with over 60% of respondents stating that they “feel ashamed,” 35% of respondents stating that they “feel they should be punished,” and 25% of all respondents stating that they “feel suicidal.” For respondents belonging to the category of FSW, over 85% stated they have “low self-esteem” and 36% currently “feel suicidal.”

Over half of all respondents have a social fear of being verbally insulted, harassed, and/or threatened. Over 60% stated they have a constant fear of being the subject of gossip. Over 1/3 of all respondents have a fear of being physically harassed, threatened, or assaulted.

Nearly half of all respondents stated that they are “afraid that someone would not want to be sexually intimate with them because of their HIV-positive status” in the past 12 months.

10% of respondents stated they had been detained, quarantined, isolated, or segregated in the past 12 months as a result of their HIV-positive status, while a smaller percentage stated they had been forced to submit to a medical or health procedure or disclose their HIV status to enter another country.

The majority of total respondents were tested for HIV out of curiosity because they “just wanted to know,” while a large number of male respondents were referred for testing due to suspected HIV-related symptoms. Over 1/3 of female respondents had an HIV test performed because their husband/partner/family member had tested positive.

The majority of respondents stated that the decision to be tested was made on their own. A smaller percentage stated they made the decision to be tested but were under pressure from other persons. Only a small number of respondents reported that they were coerced into taking an HIV test. However, a larger number of respondents who belonged to the

category of IDU reported that they were only aware of the HIV test being performed after it had been performed on them.

The majority of respondents stated that when they were tested for HIV, they received both pre and post-test HIV counseling. However, 16% of respondents reported not receiving any HIV counseling when tested.

Over 85% of all respondents reported that they never face pressure from individuals or groups/networks living with HIV to disclose their own status of being HIV-positive.

10% of respondents reported that a healthcare professional had disclosed their HIV-positive status to other people without their consent.

However, the majority of respondents, over 70%, stated that they believed their medical records related to their HIV status are kept completely confidential, while over 20% stated they don't know if their medical records are confidential.

When respondents were asked to rate the initial reaction of various people from their community including wife/husband/partner, friends, religious and community leaders, healthcare workers and the government officials, the majority of respondents rated these various peoples' reactions as ranging from no difference to supportive. The respondents were asked to score the various peoples' reactions on a scale from 1-5, 1 being very discriminatory, and 5 being very supportive, with the majority of scores averaging above 3.

Over 60% of all respondents found disclosure of their HIV status as an "empowering experience."

The majority of respondent's opinion of their current health condition was stated as being good, while several respondents rated their current health condition as being fair to poor. Fewer than 5% of all respondents rated their current health condition as being excellent.

**48% of total respondents and 51% of female respondents reported that they are currently not taking anti-retroviral treatment.**

**41% of all HIV-positive respondents reported that they currently do not have access to anti-retroviral treatment.**

## **2. Background and Methodology**

HIV related stigma and discrimination are widely recognised as barriers to accessing HIV prevention, treatment and care services. Without addressing stigma, the goal of universal access will be impossible to achieve. Much of what we know about the stigma attached to HIV, and resulting discrimination, is anecdotal or fragmented and does not always include the perspective of people living with HIV.

Over the last few years, the International Planned Parenthood Association (IPPF) and the Joint United Nations Programme on HIV/AIDS (UNAIDS), *in collaboration with their partners*, the Global Network of People living with HIV/AIDS (GNP+) and the International Community of Women living with HIV/AIDS (ICW) have embarked on a participatory process and developed an index to measure the stigma and discrimination experienced by People Living with HIV. The aim of the Index is to collect information on stigma, discrimination and the rights of people living with HIV in order to broaden understanding of the extent and forms of stigma and discrimination faced by PLHIV HIV in different countries. Moreover it also aims to make that knowledge widely available so that it can be used as a local, national and global advocacy tool to fight for improved rights for PLHIV.

Myanmar Positive Group (MPG) under the training and monitoring of MMRD Research Services carried out the field work and quantitative data collection for the development of a People Living with HIV Stigma Index in Myanmar.

Following development of research tools and training, MPG then accessed existing social networks of People living with HIV to find respondents to participate in the survey. The sample allocation is presented on the following page.

1. Myanmar version of the Stigma Index questionnaires Developed
2. Training curriculum on interviewing technique, sampling methodology, data management which includes data collection and quality assurance on data and field planning developed
3. Quality assurance guidelines for supervisors and enumerators developed
4. 12 PLHIV trained as enumerators and 4 PLHIV trained as supervisors
5. Field work and data collection performed by MPG
6. Quality assurance support provided in field work
7. **PLHIV stigma index study report**

## Respondent allocation by area,sex and type

Sr.No	Area	State/Division	Recorded Positive populatio	Township	Township name	Male			Female		Sample/ township	Total sample
						MSM	IDU	Others	FSW	Others		
1	Metropolitan	Yangon	3266	6	Pabeden	2	1	1	3	3	10	60
					Latha	2	1	1	3	3	10	
					Thingangyun	2	1	2	3	2	10	
					Mayangone	2	2	1	5	0	10	
					Kamayut	2	1	2	1	4	10	
					Kyee Myin Dine	3	2	1	2	2	10	
	Mandalay	1138	4	Chan Aye Tharzan	3	2	1	2	3	11	44	
				Pyi Gye Tagon	2	2	2	3	2	11		
				Chan Mya Tharsi	2	1	2	3	3	11		
				Aung May Tharzan	3	1	1	3	3	11		
2	Plain area	Bago	133	2	Bago	3	0	2	2	4	55	
					Pyay	4	0	3	3	1		11
	Mon	518	3	Mawlamyine	4	0	1	3	3	11		
				Thaton	3	1	2	1	4	11		
				Mudon	3	1	2	1	4	11		
3	Dry Zone	Magway	86	2	Magway	2	1	2	3	3	55	
					Pakokku	1	0	5	1	4		11
	Sagaing	244	2	Monywar	2	1	2	2	4	11		
				Kalay	2	1	2	2	4	11		
Mandalay (sub)	258	1	Kyauk Pataung	3	0	2	1	5	11			
4	Hilly	Kachin		1	Myit Kyi Na	3	2	1	2	3	55	
		Shan (North)	379	2	Lashio	3	3	0	2	3		11
					Muse	2	3	1	2	3		11
		Shan (South)	90	2	Taunggyi	0	2	2	2	5		11
					Aungpan	1	0	4	3	3		11
5	Coastal	Rakhine		2	Sittway	2	1	2	3	3	55	
					Buthitaung	0	1	4	3	3		11
		Taninthayi	269	3	Dawei	1	0	3	0	7		11
					Laung Lon	1	0	5	0	5		11
					Thayetchaung	3	0	2	0	6		11
<b>Total</b>						<b>66</b>	<b>31</b>	<b>61</b>	<b>64</b>	<b>102</b>	<b>324</b>	

DEVELOPMENT OF RESEARCH TOOLS AND TRAINING PROGRAM, TRANSLATION OF QUESTIONNAIRE AND PILOT TESTING FOR FINALIZING



**FIVE DAY TRAINING PROGRAM TO PREPARE MPG VOLUNTEER FOR FIELD RESEARCH:**

ADVANTAGES AND DISADVANTAGES OF METHODOLOGIES FOR USE IN SOCIAL RESEARCH

QUANTITATIVE AND QUALITATIVE RESEARCH AND DATA COLLECTION METHODOLOGIES

DATA ANALYSIS AND THE USE OF INDICATORS TO QUANTIFY PROGRESS AND SUCCESS

INTRODUCTION TO SPSS SOFTWARE AND TECHNOLOGIES USED IN STATISTICAL ANALYSIS

DATA PROCESSING AND DATA ENTRY METHODS FOR BUILDING DATA BASE

TESTING OF RESEARCH TOOLS, TIMING AND LOGISTIC PLANNING FOR DATA COLLECTION AND PROCESSING

DATA PROCESSING/TRAINING AND DATA ENTRY FOLLOWING MPG DATA COLLECTION



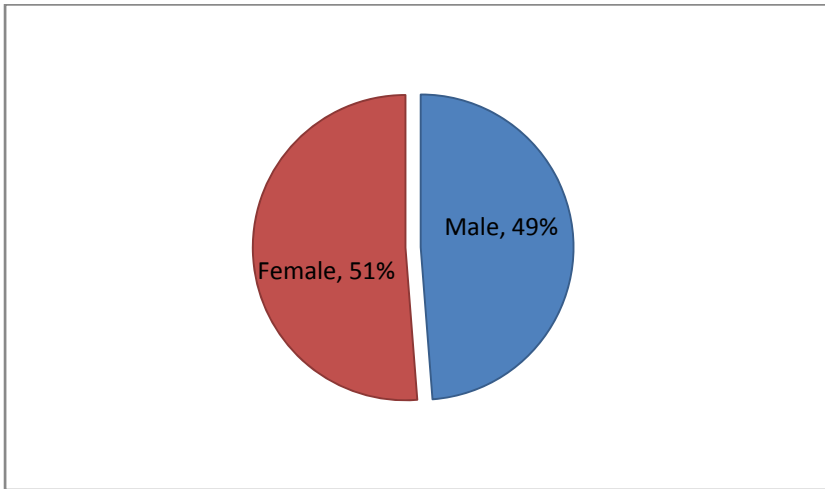
DATA ANALYSIS AND INDEX GENERATION

PRESENTATION OF INSIGHTS AND FINDINGS TO ORGANIZATIONS INVOLVED



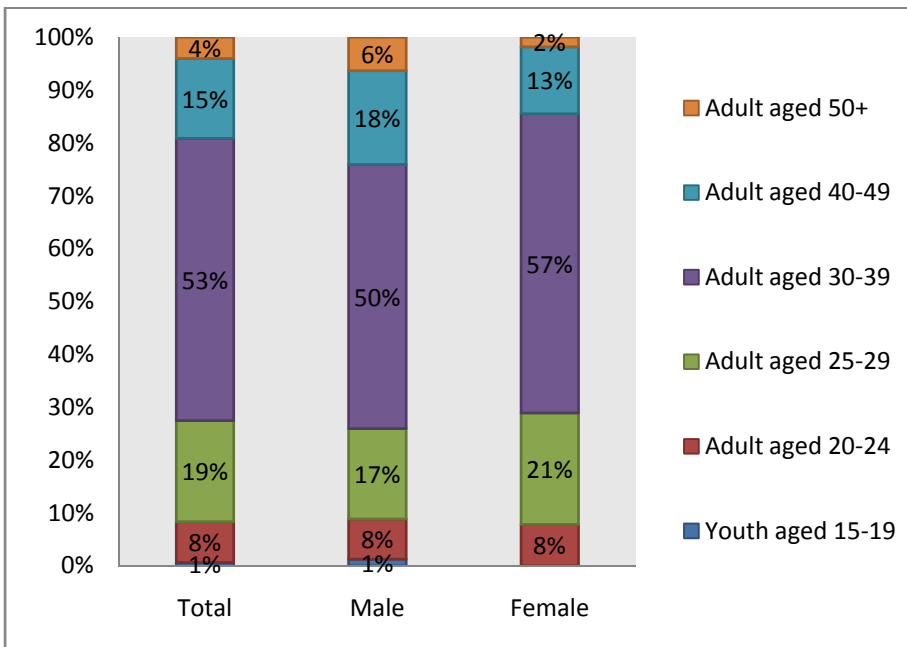
### 3. Respondent Profile

Figure 1 Gender Ratio of Respondents



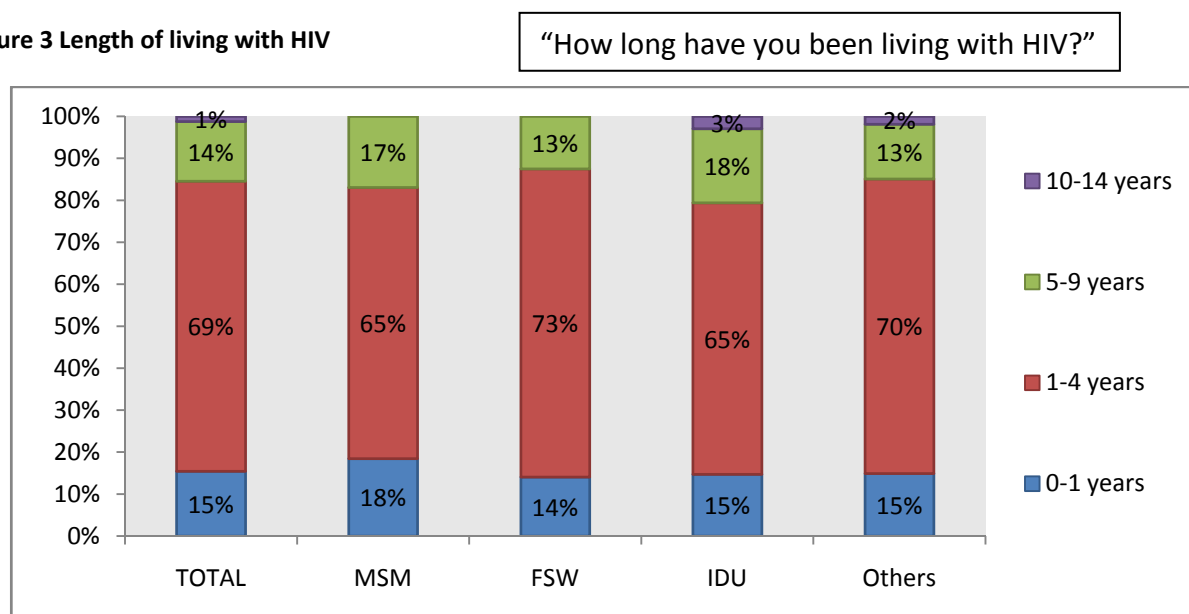
For gender comparison, of the stigma index data, the MPG numerators divided their sample allocation evenly by gender of respondents currently living with HIV. The final sample for tabulations is divided with fifty-one percent female respondents and forty-nine percent male respondents. For the purpose of this HIV stigma index, all respondents have a status of HIV-positive.

Figure 2 Respondents Age



The majority of respondents are between the ages of 30-39, with the second largest number of respondents between the ages of 25-29. However there were several respondents between the ages of 15-19 and several respondents over the age of 50.

Figure 3 Length of living with HIV



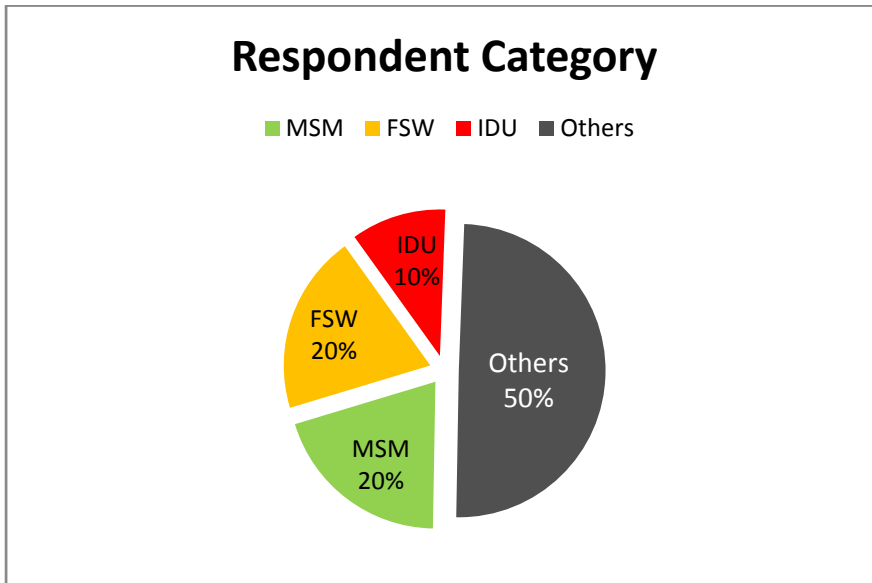
Nearly **70%** of all respondents have been living with HIV for a period of 1-4 years. Several respondents have been living with HIV for 5-9 years, while only 1% of respondents found to participate in this survey have been living with HIV for more than 10 years.

Table 1 Current Relationship Status

Current relationship status	MSM	FSW	IDU	Others	Total
Spouse or partner currently living in household	17%	39%	47%	39%	35%
Spouse or partner living temporarily	3%	2%		7%	4%
Living/working away from the household	23%	8%	6%	4%	9%
Single	54%	8%	26%	7%	19%
Divorced/separated	3%	22%	12%	9%	11%
Widow/ widower		22%	9%	34%	22%

1/3 of respondents are currently living with their spouse or partner in the same household. However, among the various categories, respondents classified as MSM account for the majority of respondents who are single, with over 50% of MSM stating that they are currently single. In contrast, of the respondents categorized as FSW, only 8% stated being single, with nearly 40% of FSW stating that they live with their spouse or partner in the same household. Of respondents categorized as IDU, nearly half are currently living with their spouse or partner in the same household.

Figure 4 Respondent Category

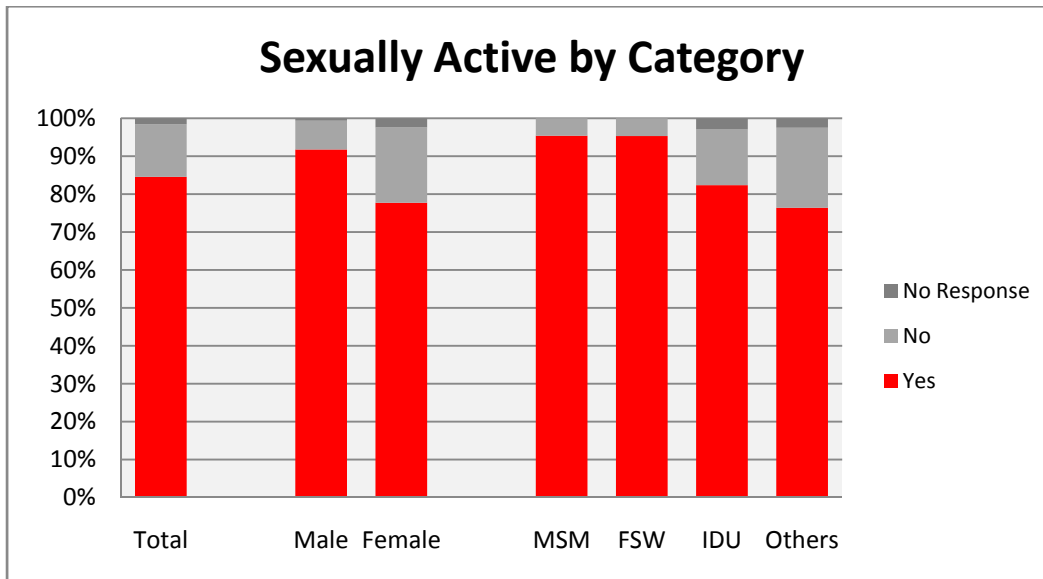


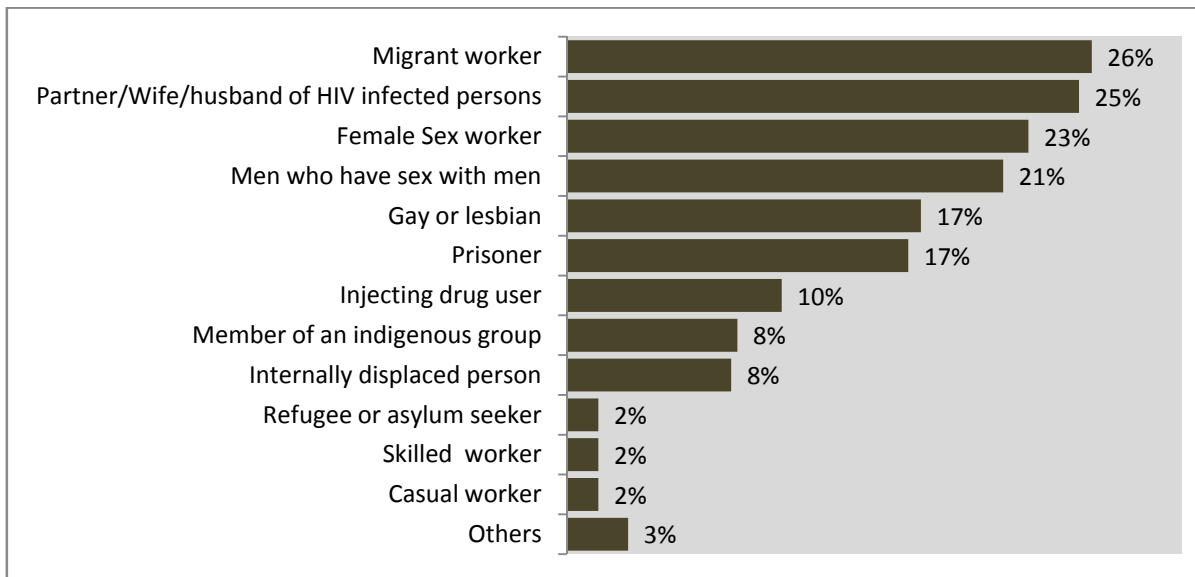
For the stigma index sample allocation, respondents were put into four different category groups with samples distributed as MSM, FSW, IDU and others, as well as Gender, Region, and Age.

85% of the total respondents of the HIV Stigma Index are currently sexually active.

Figure 5 Sexually Active Respondents

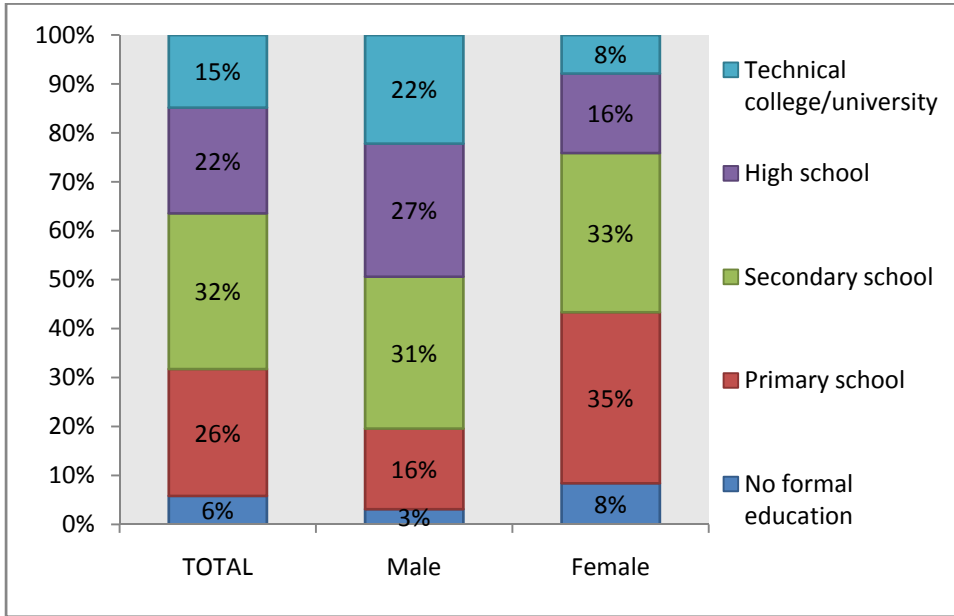
“Are you still sexually active?”



**Figure 6 Social Categories of Respondents (multiple answers allowed)**

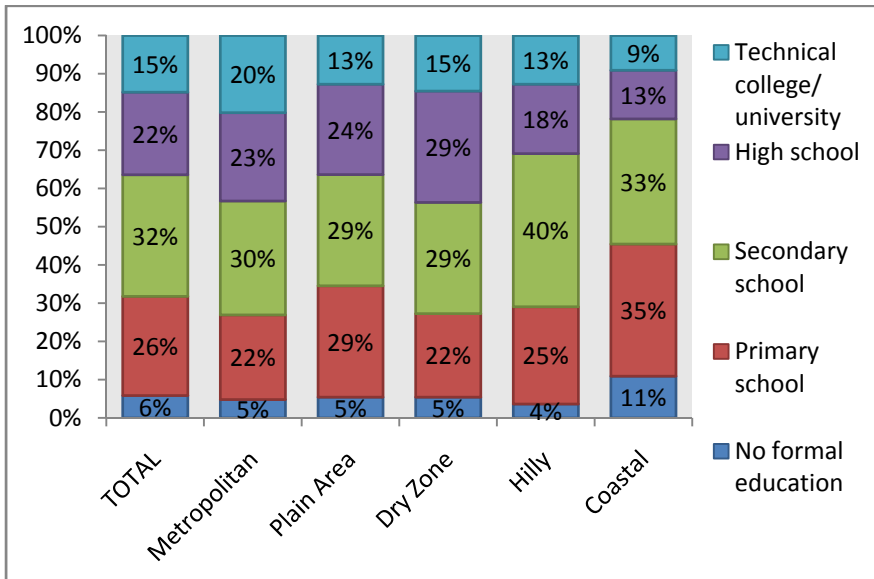
**26%** of respondents stated that they belong to the social category of Migrant Worker, commuting between the various regions of the study within Myanmar. Another 23% stated that they belong to the social category of Female Sex Worker, while 17% at one point belonged to the social category of Prisoner.

Figure 7 Education Level by Gender



Only **8%** of female respondents completed a Technical College or University-level education. The majority of respondents' highest level of education completed was secondary school. However, for the female respondents, the majority only completed the level of primary school.

Figure 8 Education Level by Region



Education levels among the geographic areas of the sample are quite similar throughout each region; however, more respondents surveyed in metropolitan areas had graduated from Technical College or University.

Nearly  $\frac{1}{3}$  of all respondents listed themselves as being self-employed, while nearly  $\frac{1}{4}$  of respondents are currently unemployed. Only 13% of all respondents stated that they currently have full-time employment.

Figure 9 Current Employment Status (multiple answers allowed)

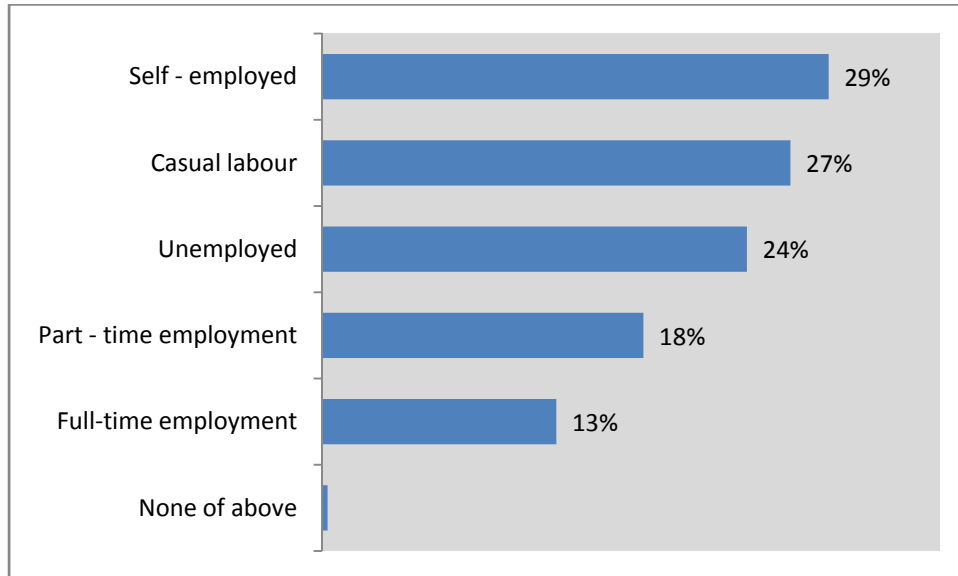
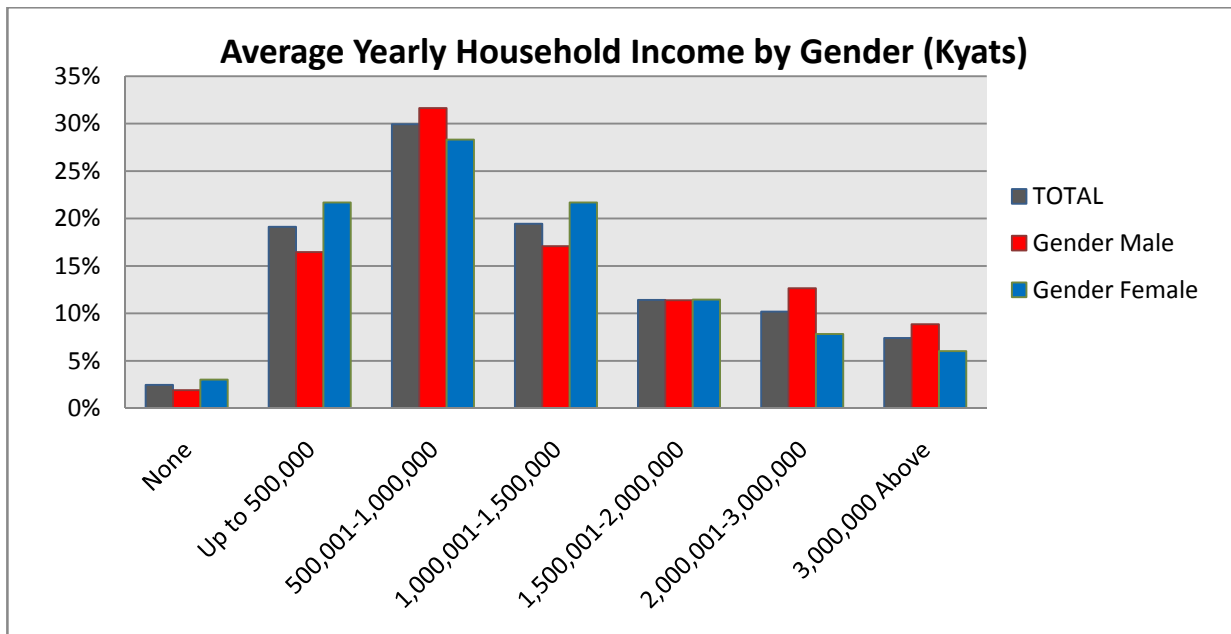


Figure 10 Average Yearly Income by Gender



The average yearly income among respondents was found to be 1,380,466 Kyats. At the current exchange rates, that would be equal to yearly earnings of \$1,374 US dollars a year. Among the higher-income earners who had an average yearly income of 2,000,000 Kyats or above, those belonging to the categories of MSM and IDU made up a larger percentage.

Figure 11 Average Yearly Income by Category

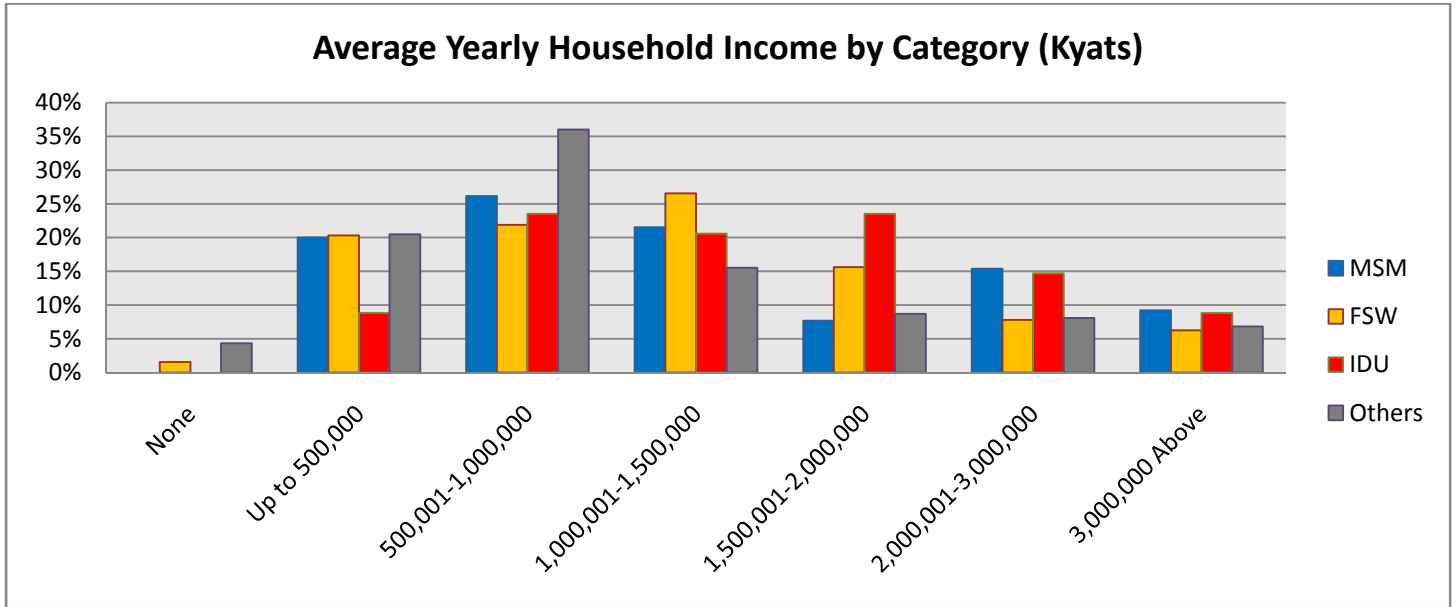
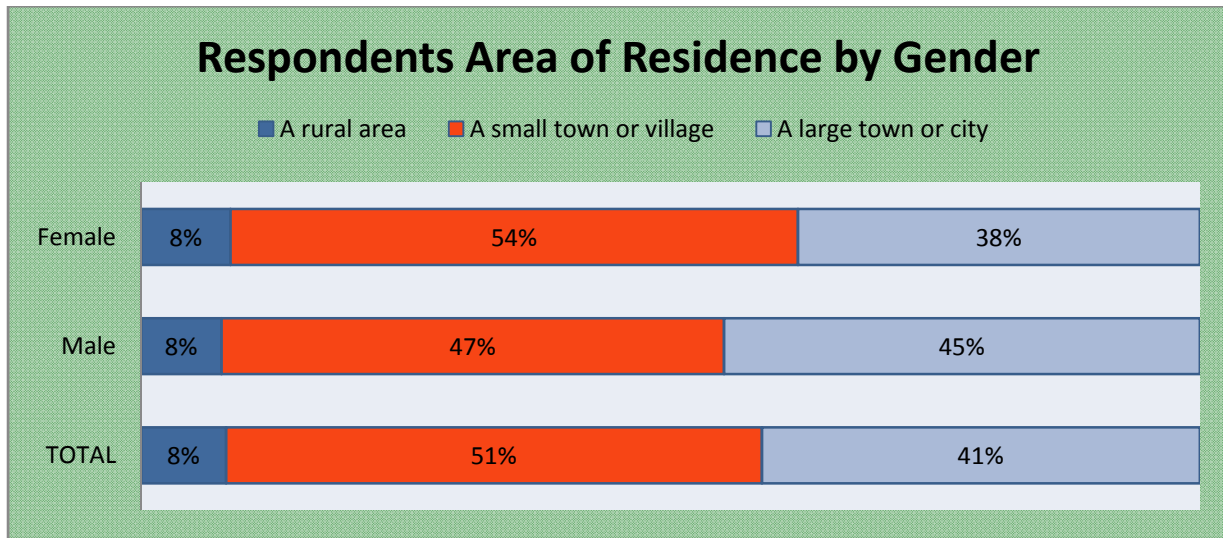
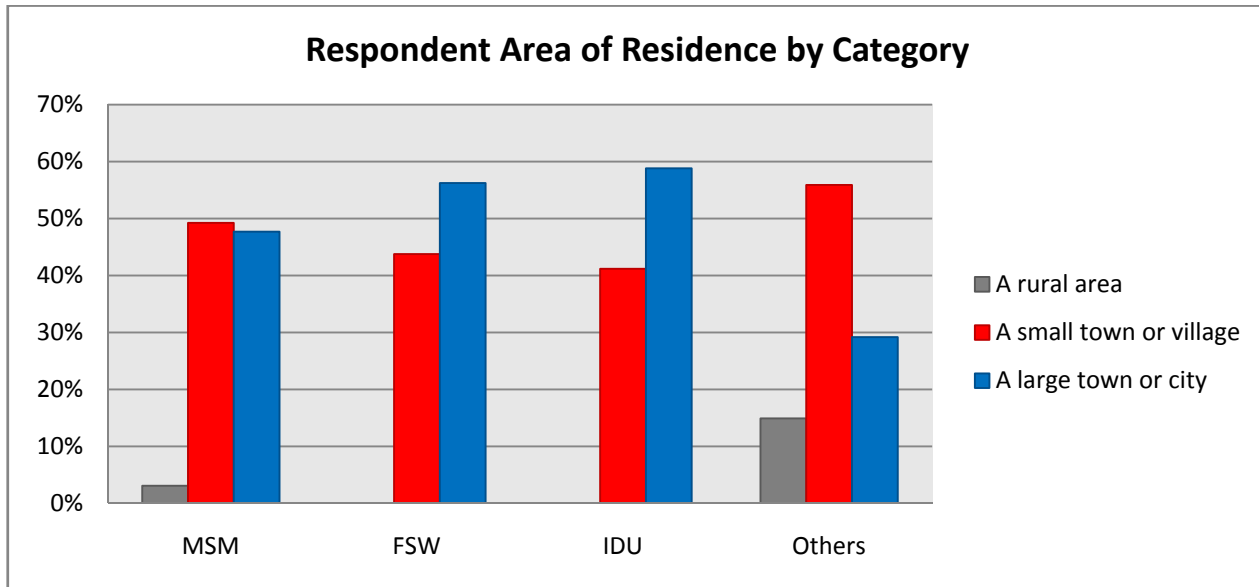


Figure 12 Area of Residence



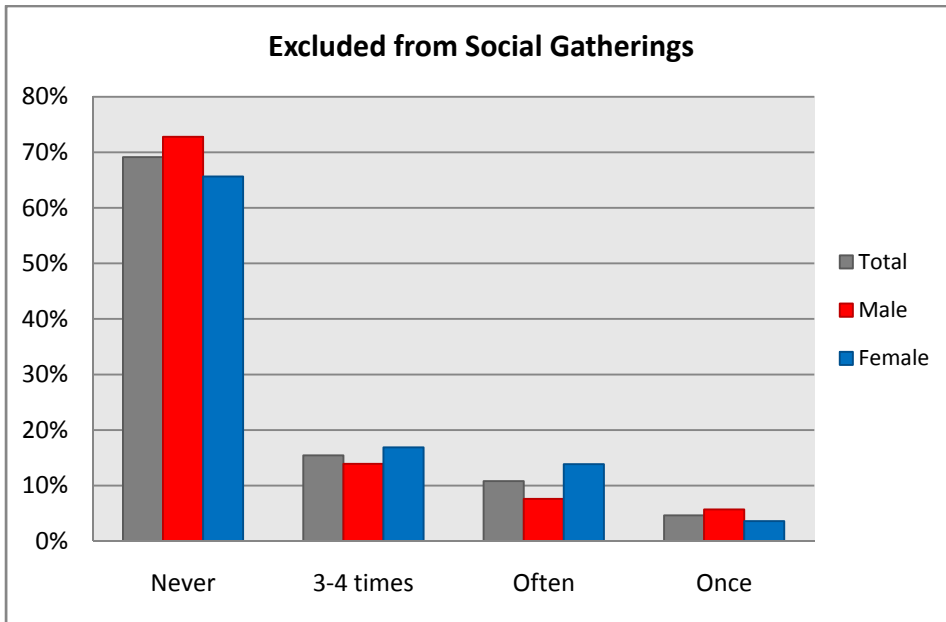
Among the respondents' area of residence, the majority actually live in small towns or villages, not in large towns or cities. With 51% of total respondents are living in small towns or villages and 54% of all female respondents living in small towns or villages. This data correlates with the high percentage of respondents who classify themselves as Migrant Workers. A majority of the respondents in the categories of MSM, FSW, and IDU also live in small towns or villages.

Figure 13 Area of Residence by Category



#### 4. Experience of Stigma and Discrimination

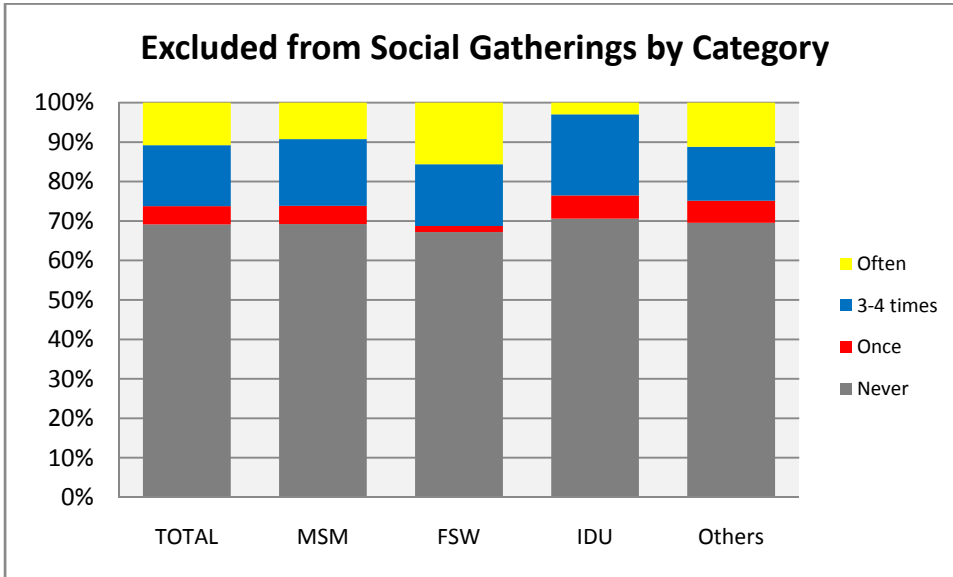
Figure 14 Exclusion from Social Gathering



The majority of respondents, nearly 70%, from the People Living with HIV Stigma Index stated that they had never been excluded from social gatherings as a result of their HIV-positive status. However, 11% of total respondents stated that they were often excluded from social gatherings because of their HIV-positive status.

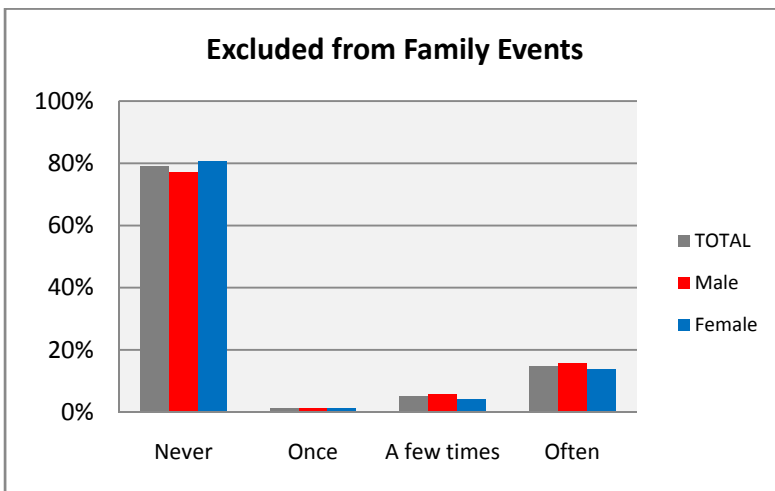


Figure 15 Exclusion from Social Gathering by Category



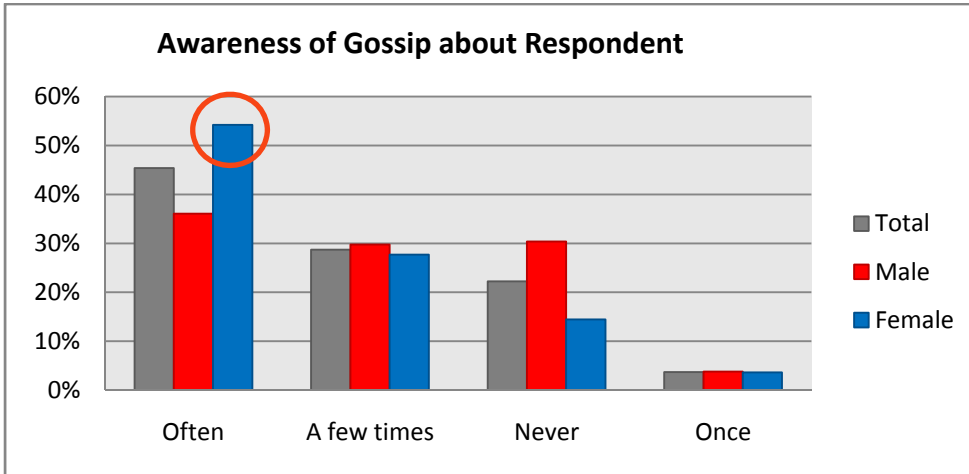
Among the various categories of respondents, 16% of FSW respondents stated that they were often excluded from social gatherings. While 15% of all categories stated that they had been excluded from social gatherings 3 or 4 times within the past 12 months.

Figure 16 Exclusion from Family Events



Nearly 80% of all respondents have never been excluded from family events while being HIV-positive. However, 15% of respondents stated that they were often excluded from family events in the past 12 months.

Figure 17 Awareness of Gossip



45% of all respondents stated they were aware of gossip about them due to their HIV-positive status, and over half of all female respondents were aware of gossip about them due to their HIV-positive status.

Among the various categories, respondents belonging to the group of FSW showed the most awareness of gossip.

Figure 18 Awareness of Gossip by Category

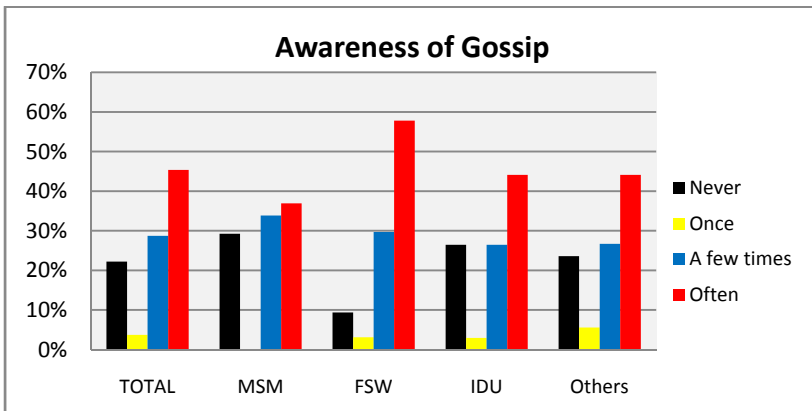
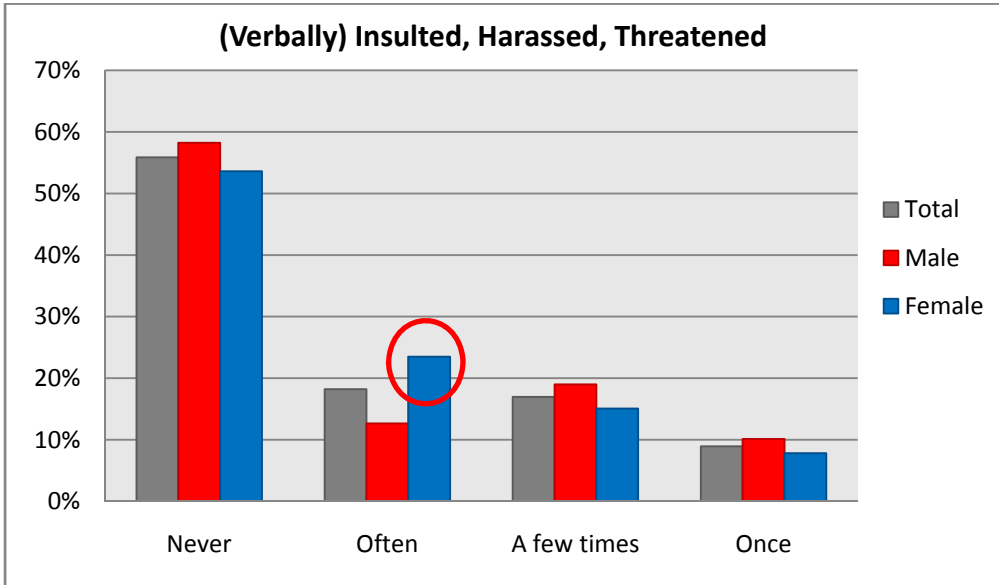
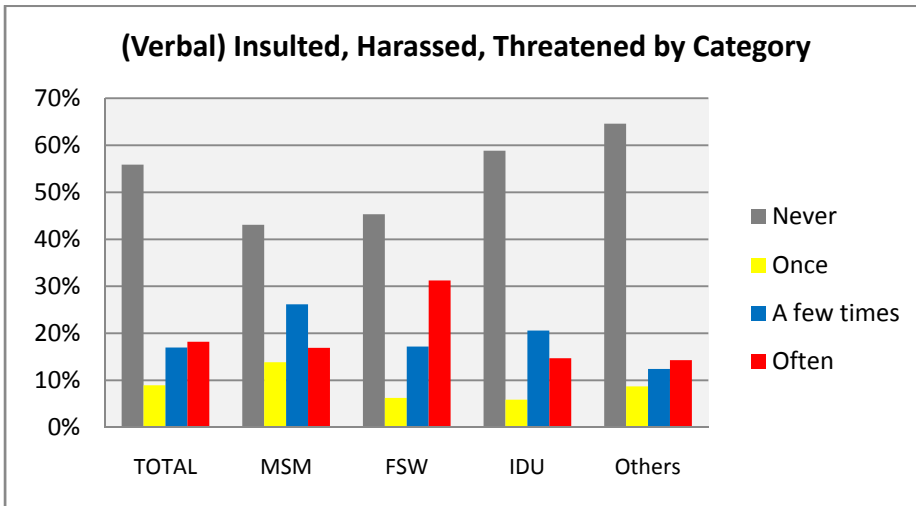


Figure 19 Verbally Insulted, Harassed, Threatened



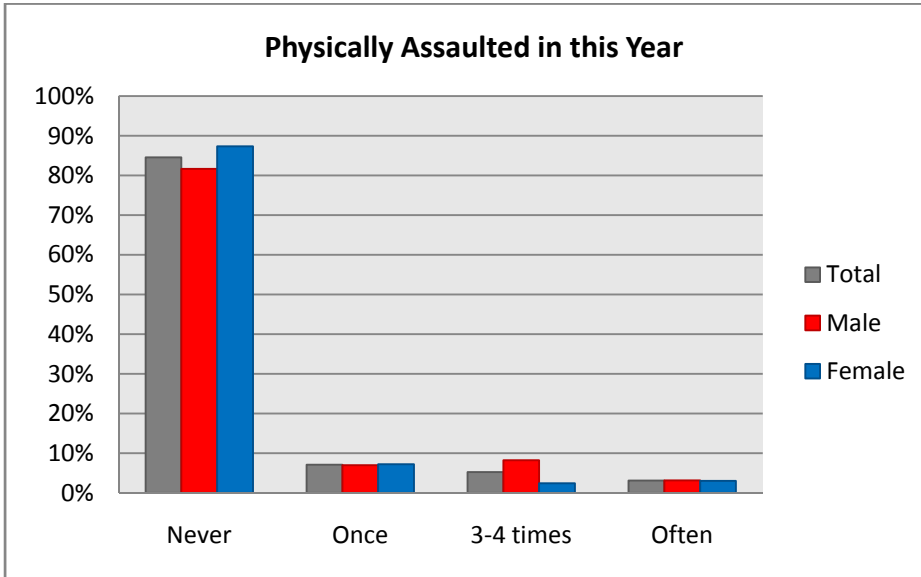
Over 20% of HIV-positive female respondents stated that they were often verbally insulted, harassed, or threatened in the past 12 months, while over half of the total respondents stated they had never been verbally insulted, harassed, or threatened in the past 12 months.

Figure 20 Verbally Insulted, Harassed, Threatened by Category



**31%** of FSW stated that they were often verbally insulted, harassed or threatened.

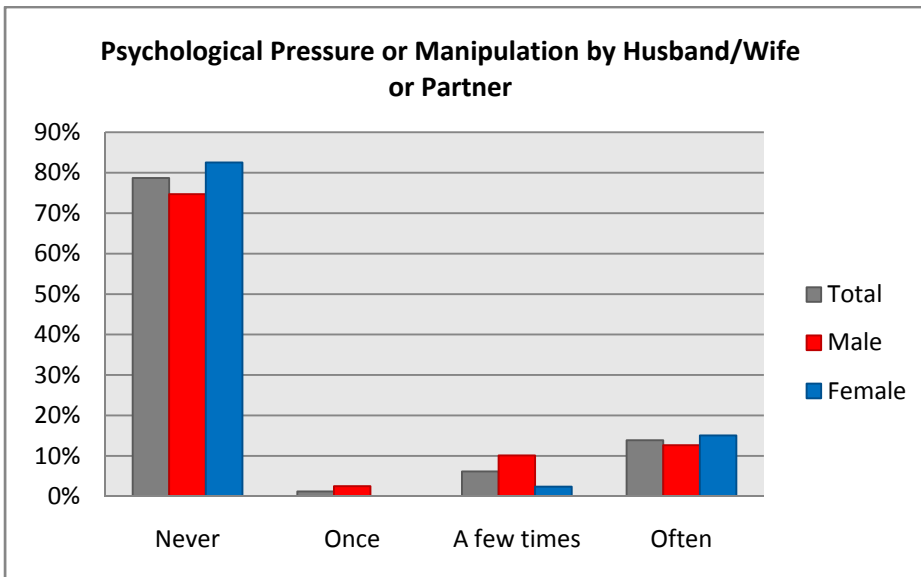
Figure 21 Physically Assaulted in the past Year



**15%** of respondents stated they had been physically assaulted in the past 12 months, while 85% stated they had never been physically assaulted in the past 12 months.

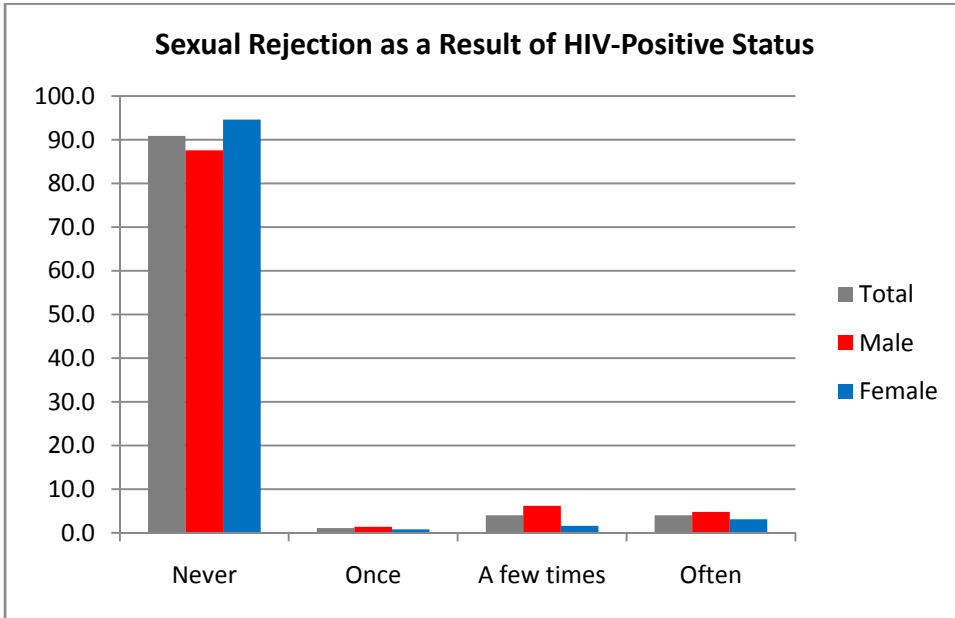
“How often was your HIV-positive status used against you in psychological pressure or manipulation by your husband/wife or partner?”

Figure 22 Psychological Pressure or Manipulation



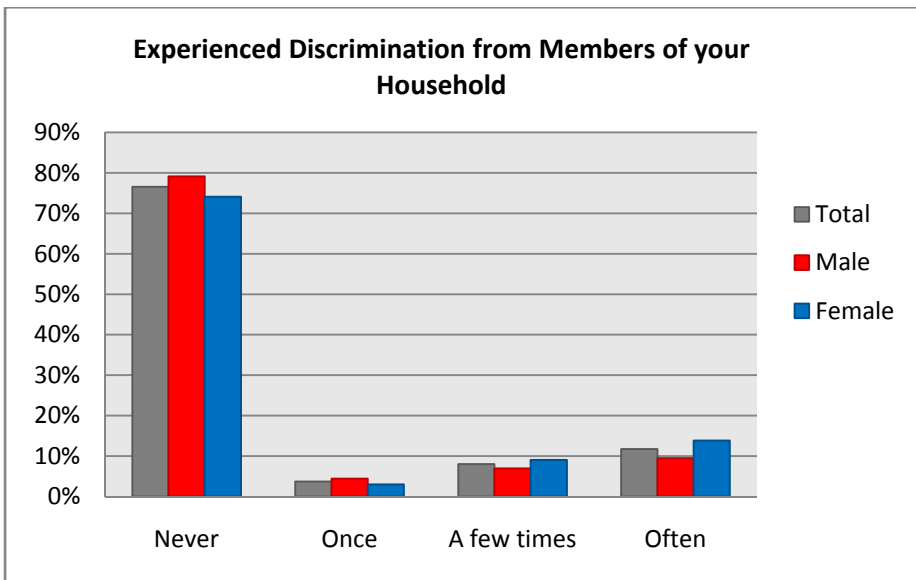
**21%** of respondents stated that they had been subject to psychological pressure or manipulation by their husband/wife or partner in which their HIV-positive status was used against them.

Figure 23 Sexual Rejection as a result of HIV-positive status



91% of respondents that are sexually active stated that they had never experienced sexual rejection as a result of their HIV-positive status in the past 12 months.

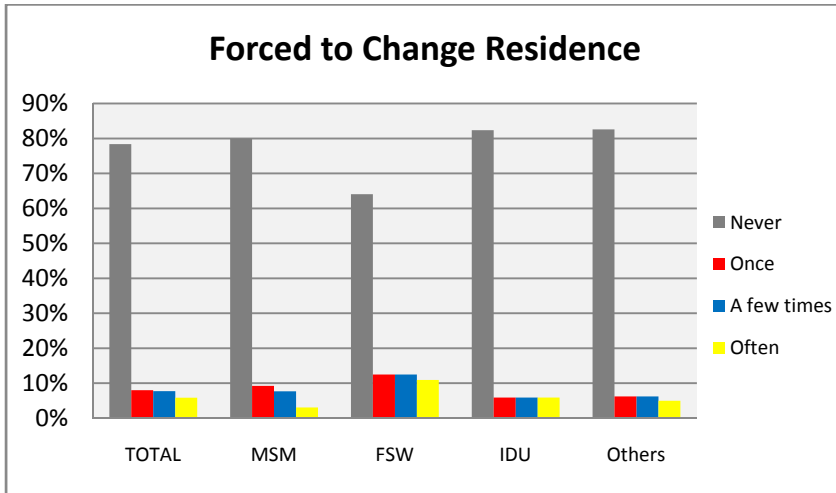
Figure 24 Experienced Discrimination from member of the Household



12% of the total respondents stated that they often experienced discrimination from members of their own household during the past 12 months, while over 75% stated they had never experienced discrimination from members from their household.

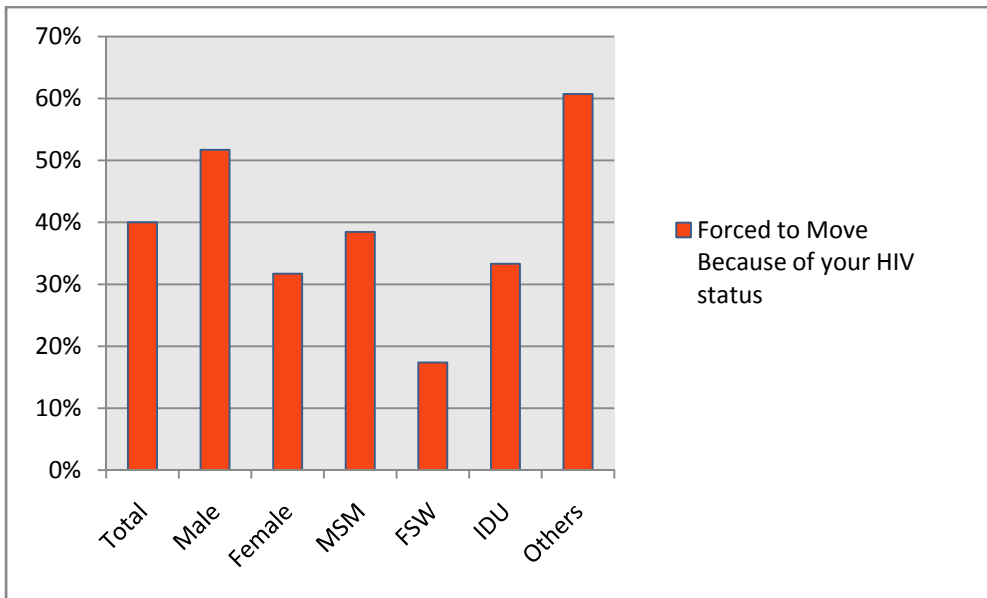
### 5. Access to Work, Health and Education Services

Figure 25 Forced to Change Residence or unable to Rent Accommodation in the last 12 months



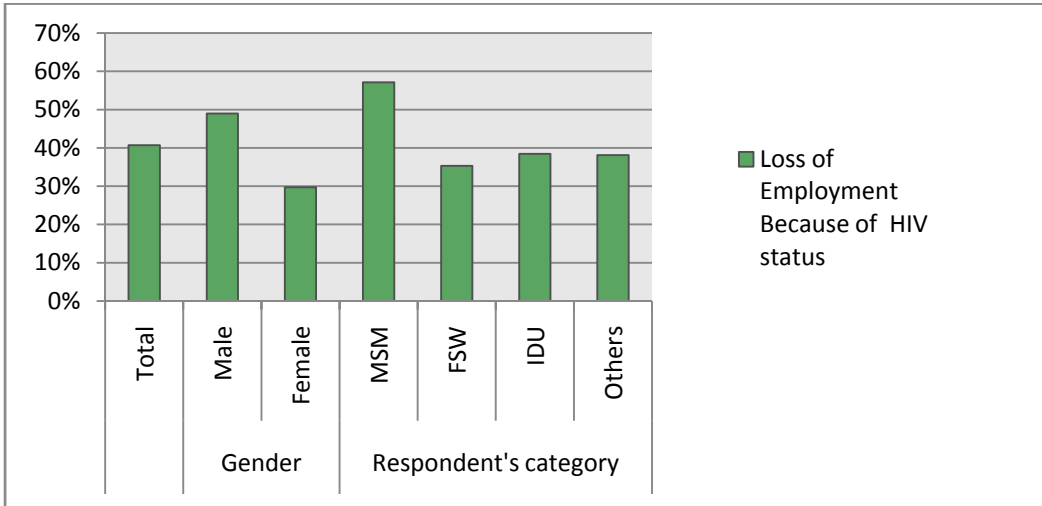
Over 20% of respondents had been forced to change their residence during the last 12 months. Of those respondents forced to change residence, **70%** of them stated it was either directly or indirectly related to their HIV-positive status.

Figure 26 Percentage of respondents that were forced to move that stated the reason was their HIV-status



**40%** of the respondents that were forced to move in the past 12 months stated it was a direct result of their HIV-positive status.

**Figure 27 Percentage of respondents that lost employment because of their HIV-status**

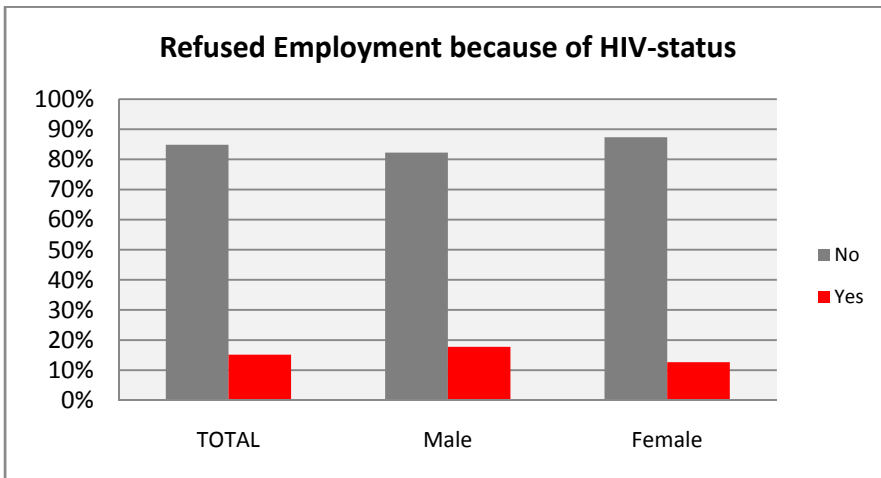


**41%**  
of respondents who lost employment in the past 12 months stated it was a result of their HIV-positive status.

**Table 2 Stated reasons for loss of employment**

Reasons	Total	Male	Female
Discrimination by your employer or co-workers	24%	24%	25%
Felt obliged to stop working due to poor health	16%	14%	19%
Stop working because health condition was too poor	12%	16%	6%
A combination of discrimination and poor health	9%	8%	11%

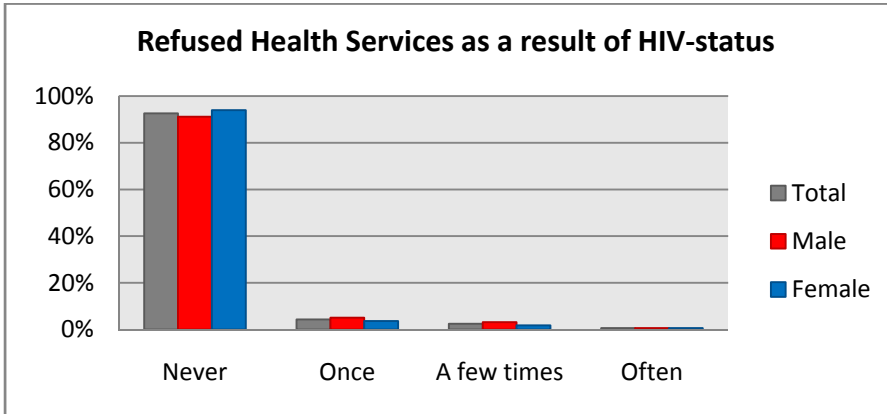
**Figure 28 Refused Employment because of HIV-status**



**24%** of respondents who lost their job stated that they faced discrimination by their employer or co-workers because of their HIV-positive status, while 30% stated that they felt obliged to, or had stopped working because of their poor health condition.

**15%** of total respondents stated that they had been refused employment because of their HIV status.

Figure 29 Denied Health Services (including Dental) as a result of HIV status



The majority, with over 90% of all respondents, stated they had never been refused health services as a result of their HIV-positive status.

However, over **35%** of respondents stated that they had been denied access to family planning services in the past 12 months as a result of their HIV-positive status. **20%** of respondents had also been denied sexual and reproductive health services in the last 12 months as a result of their HIV-positive status.

Figure 30 Denied Family Planning Services as a result of HIV status

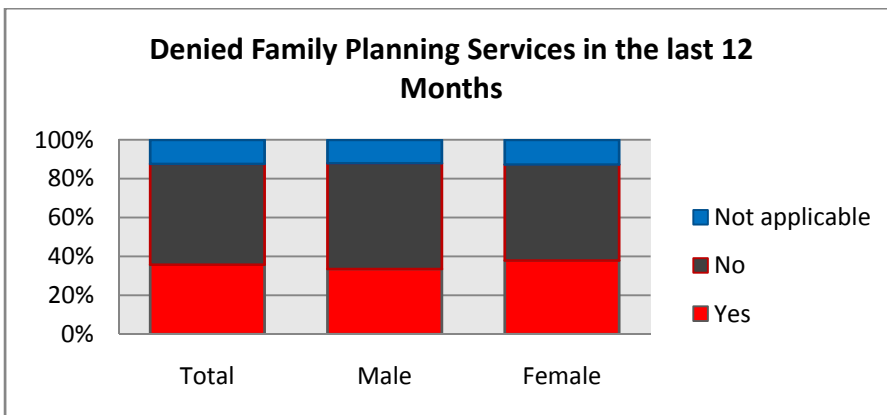
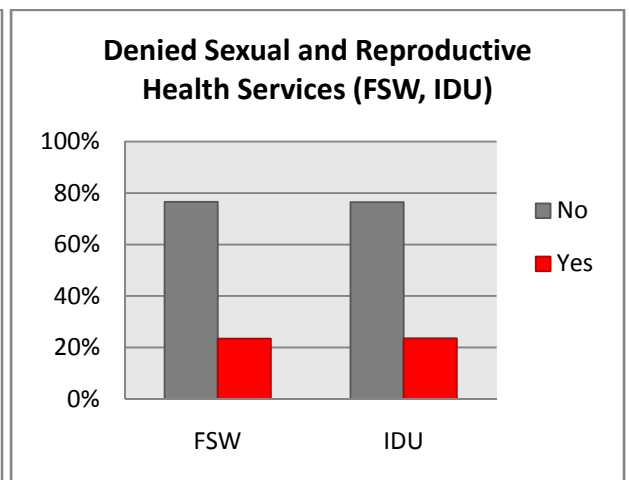
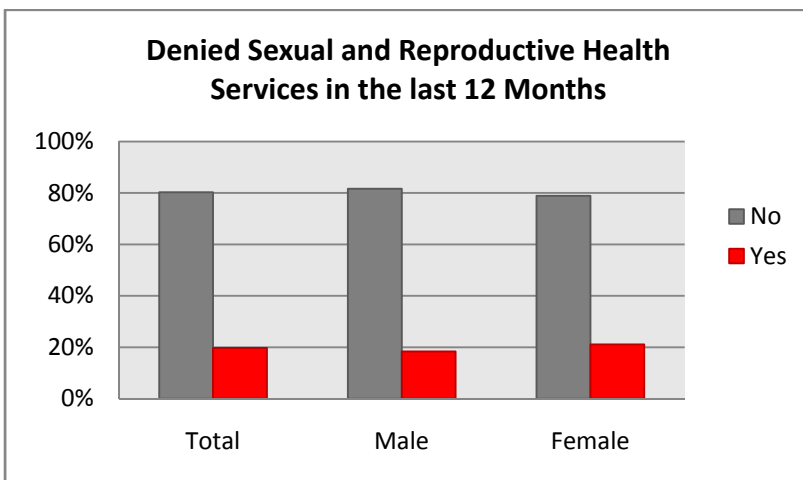


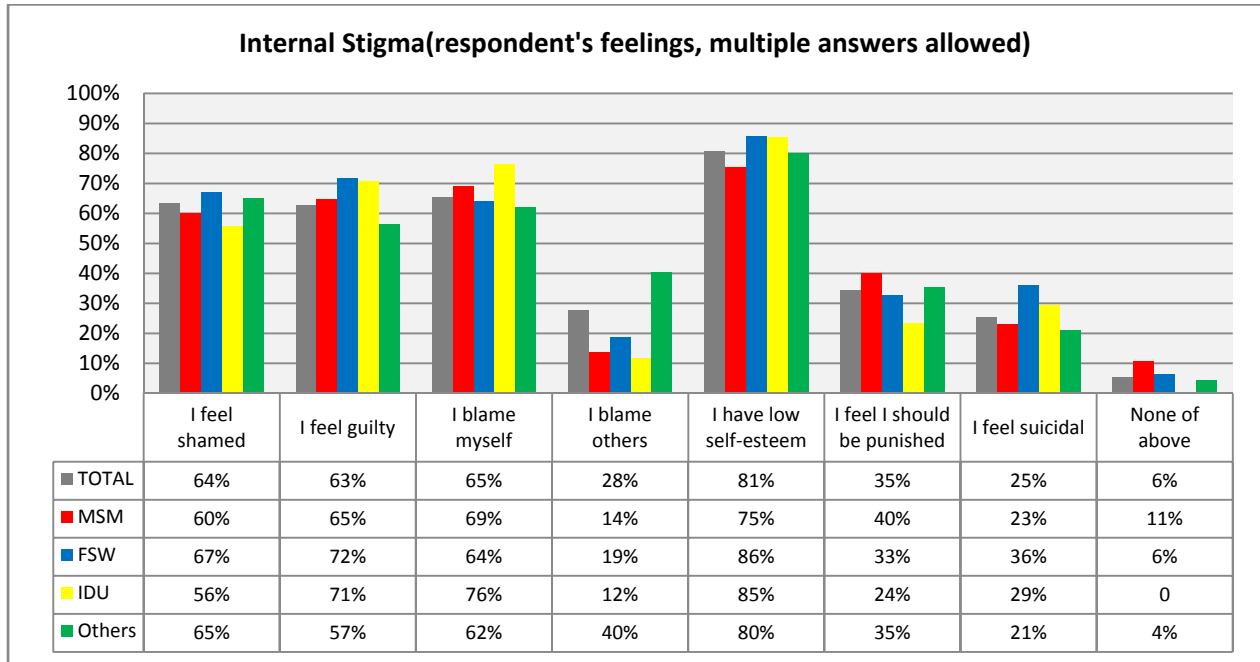
Figure 31 Denied Sexual and Reproductive Health Services as a result of HIV status





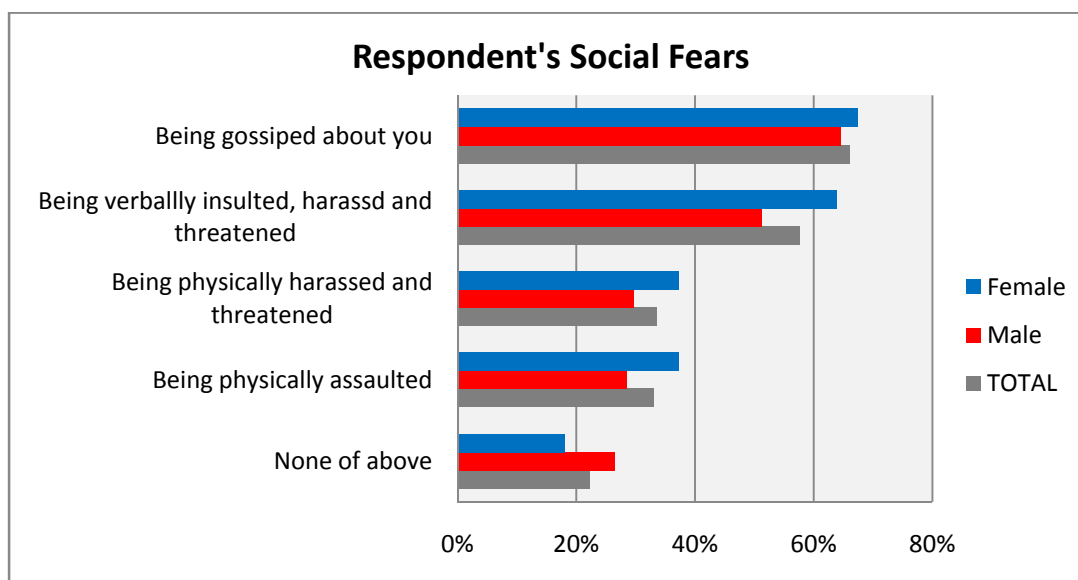
## 6. Internal Stigma (the way the respondent feels about themselves) and Fears

Figure 32 Respondent's feelings about themselves



While earlier data shows that a number of respondents do face external discrimination, this index shows that a large number of respondents are dealing with emotional, internal stigma as a result of their HIV-positive status, with over **60%** of respondents stating that they “**feel ashamed**”, **35%** of respondents stating that they “**feel they should be punished**”, and **25%** of all respondents stating that they “**feel suicidal**”. For respondents belonging to the category of FSW, over **85%** stated they have “**low self-esteem**” and **36%** currently “**feel suicidal**”.

Figure 33 Fearful of the following things (multiple answers)

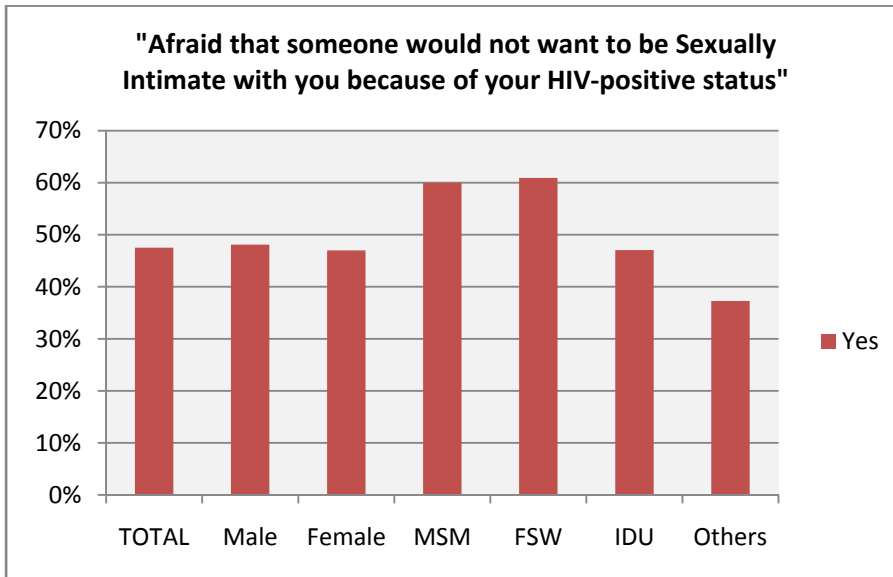


Over half of all respondents have a social fear of being verbally insulted, harassed, and/or threatened. Over 60% stated they have a constant fear of being the subject of gossip. Over 1/3 of all respondents have a fear of being physically harassed, threatened, or assaulted.

Table 3 Decisions made as a result of HIV-positive status

Decisions made as a result of HIV positive status	Total	Male	Female	MSM	FSW	IDU	Others
Decided not to have more children	71%	66%	75%	65%	78%	65%	71%
Decided not to get married	51%	51%	50%	60%	44%	44%	51%
Isolated myself from my family or friends	40%	35%	45%	37%	48%	44%	38%
Decided not to attend social gatherings	33%	29%	37%	29%	33%	38%	34%
Withdrew from education training	32%	30%	33%	29%	30%	47%	30%
Decided not to apply for a job or promotion	28%	26%	31%	22%	27%	35%	30%
Decided not to have sex	24%	19%	28%	17%	14%	21%	31%
Decided to stop working	23%	18%	28%	18%	41%	21%	18%
Avoided going to local clinic	7%	6%	7%	6%	8%	9%	6%
Avoided going to hospital	7%	7%	7%	6%	9%	9%	6%

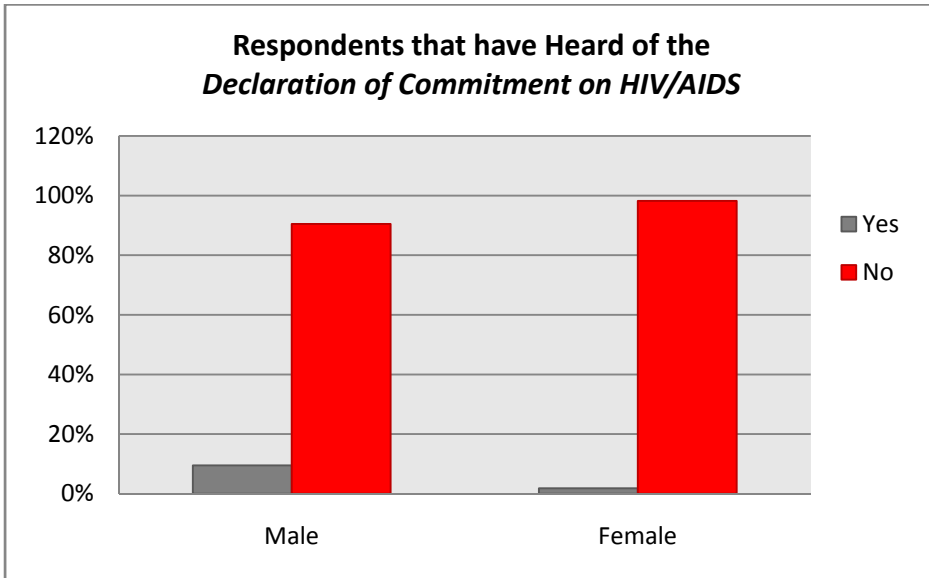
Figure 34 Fear that people “would not want to be sexually intimate with you as a result of HIV-positive status”



Nearly half of all respondents stated that they are “afraid that someone would not want to be sexually intimate with [them] because of their HIV-positive status” in the past 12 months.

7. Rights, Laws and Policies

Figure 35 "Have you heard of the Declaration of Commitment on HIV/AIDS, which protects the rights of people living with HIV?"



Only **2%** of HIV-positive female respondents stated they had heard of the Declaration of Commitment on HIV/AIDS, with only 9% of male respondents stated having heard of it.

In total only 8 respondents answered yes to having read or discussed the Declaration.

Only 1% stated they were aware of national law or policy in Myanmar that protects the rights of people living with HIV.

**10%** of respondents stated they had been detained, quarantined, isolated, or segregated in the past 12 months as a result of their HIV-positive status, while a smaller percentage stated they had been forced to submit to a medical or health procedure or disclose their HIV status to enter another country.

Figure 36 Things that have happened as a result of HIV-positive status in the past 12 Months

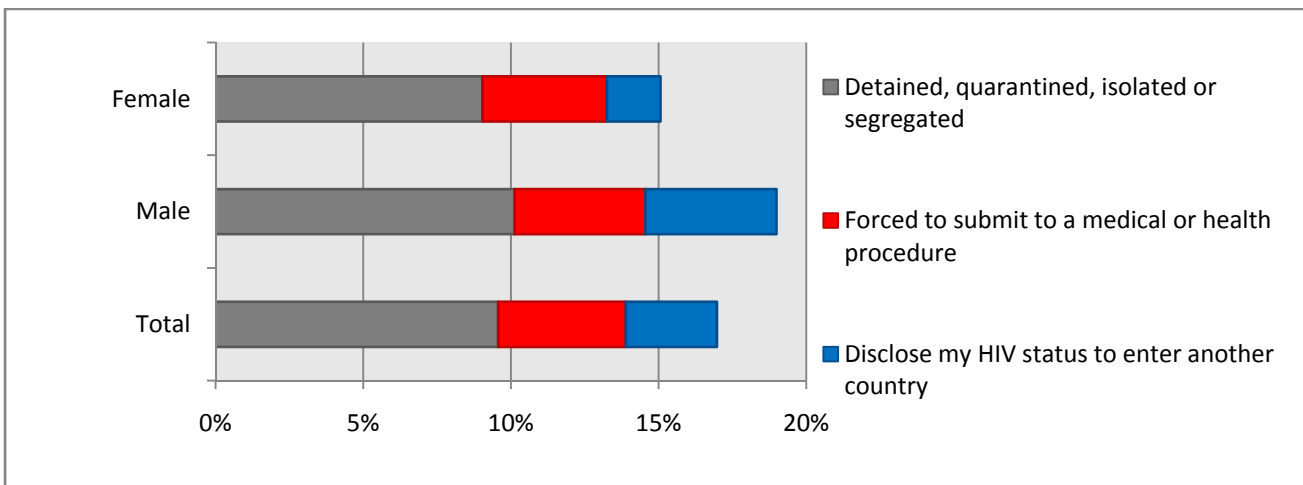
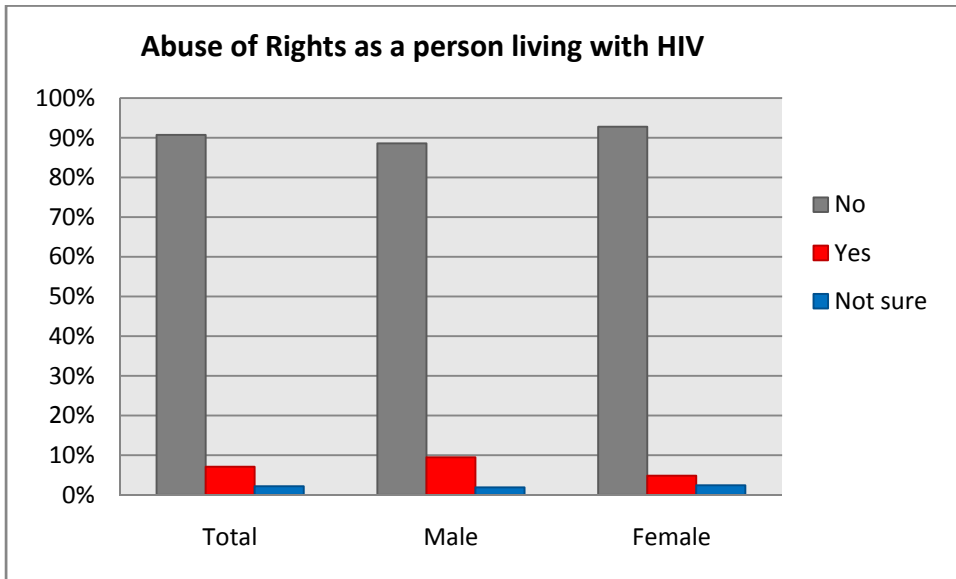


Figure 37 Abuse of rights as person Living with HIV in the past 12 Months



Of the small amount of respondents that felt their rights had been abused, a few had taking legal redress in response.

Of those that had not taken legal redress in response, respondents demonstrated little confidence in the outcome or stated they felt intimidated by the process.

## 8. Effecting Change, Challenges and problems, Having Children excerpts from interviews

If you have tried to resolve an issue of stigma and discrimination either on your own or with the assistance of others, describe what the issue was about, who – if anyone – helped you, and how you and/or others tried to resolve the matter.

*What was the issue of stigma and discrimination about?*

### Exclusion

“My in-laws don’t want to eat with me and refuse to share the same soap”. Tanintharyi Division

“I often cry because my mother makes me sit and eat by myself at a separate table”. Mandalay Division

“Because I have AIDS, I was treated differently by my boss and I drifted away from my colleagues. I ended up quitting my job and now I stay home and do not go out”. Mandalay Division

“I am not allowed to approach houses in the neighborhood. When people meet me, their face is hard. Some even close their nose”. Shan State

“Because I do not want to have sex anymore I became isolated from my husband, who ended up leaving with another woman”. Mandalay Division

“It is hard to borrow money for my business as I am HIV positive”. Shan State

“Since 2004, apart from one nurse, everyone at the public hospital refuses to put on IV drip to me and my son”. Magway Division

“My husband left me. If people learnt that I have AIDS, he would have to leave the military”. Shan State

### Prejudices

“I work as a midwife in a traditional clinic. Once I helped delivering the child of an officer. I was very careful not to touch the baby as I did not want to transmit my disease. But when the child became sick, the father started to ask strange questions to my coworkers”. Mon State

“I am not allowed anymore to bath in at public well. I have to fetch water and bath at home”. Sagaing Division

“The uncle of my husband refuses to drink the water I pour”. Shan State

“I am asked why I am not dead yet though I am infected”. Shan State

“Because they are afraid of getting infected, people do not want to share their clothes with me anymore”. Mandalay Division

“People believe I am a bad woman, a prostitute”. Tanintharyi Division

### Disclosure of HIV status

“My girlfriend told the neighborhood that I am HIV positive and the number of people visiting my beauty salon became very little”. Mon State

“Some colleagues and friends told people that I am HIV positive”. Magway Division “I have been refused jobs because of my situation”. Mon State

“A religious organization revealed the result of my HIV test. The leader of this organization forbade members to visit my home”. Sagaing Division

*If others helped you resolve the matter, who helped you?*

**Self-help**

“Nobody helped me”. Multiple

“I have to help myself, I am on my own”. Multiple

“I did not ask anyone for help, no one is willing to help”. Shan State

**Family**

“All my family members gave me support”. Mon State

**Organizations**

“SHG members helped me”. Mon State

“MRCS helped me”. Mon State

“I received advice from someone of the Red Cross”. Mon State

“I was helped by Pandomar organization”. Mandalay Division

“PC and Paradise gave classes on how to live with HIV”. Magway Division

“PE Peer Education helped me”. Mandalay Division

“I asked help at the Pyi Gyi Khin office”. Tanintharyi Division

“I got help from AZG Thezin hospital”. Shan State

“Lashio church gave me a shelter and Care Myanmar gave me food”. Shan State

“Someone from PLHA helped me”. Yangon Division

“The team leader from The Help gave me support”. Mandalay Division

**Other persons living with HIV**

“HIV positive people help one another”. Mandalay Division

How did you (and, if appropriate, others) try to resolve the matter? (i.e. what specifically did you and/or others do)?

### **Moving**

“I try to deny the fact that I have AIDS. I am thinking about changing my work to avoid people’s comments”. Mandalay Division

“I moved away from my hometown to Mawlamyine”. Mon State

“I try to stay away from the community”. Mon State

“No solution could be found”. Multiple

“I moved back to my native town”. Yangon Division

“I did not try to solve the problem but I just ran away”. Multiple

### **Learning**

“I learnt by myself how people get HIV/AIDS, how do patients need to behave and that if you take ART properly you may live long with HIV”. Multiple

“MRCS taught me how to make embroidery”. Mon State

“PE volunteers gave me health education and counseling”. Mandalay Division

“I tried to educate those who discriminate people who are HIV positive”. Mandalay Division

“U Sein Win from Care told me how people get HIV and he distributed IEC reading material”. Sagaing Division

### **Receiving help**

“A nurse took care of us HIV patients at the public hospital”. Mon State

“My sister slapped the faces and pulled the hair of people who said things about me”. Magwe Division

“I try to console myself with religion”. Yangon Division

## **SECTION 3E Problems and Challenges**

What do you see as the main problems and challenges in relation to:

### 1. Testing and diagnosis

#### **Lack of counseling**

“I did not receive any counseling when taking my blood test, I was simply told the result”. Mon State



### **Cost**

“Taking a CD4 testing is a bit costly”. Mon State

“I need to travel to Yangon to take a blood test. This is costly in terms of transportation, time, accommodation and food”.  
Tanintharyi Division

“I can’t spare time from my job to do the blood test”. Mandalay Division

### **Privacy**

“I am afraid I’ll be seen by people who know me when I go take the blood test”. Mandalay Division

“The doctor told other people about the result of my test without asking for my permission”. Tanintharyi Division

### 2. Disclosure and confidentiality

#### **Reduced livelihood opportunities**

“My girlfriend told the neighborhood that I am HIV positive and the number of people visiting my beauty salon became very little”.  
Mon State

“I am scared of losing my job”. Sagaing Division

“If I disclose the truth, I will have less job opportunities. But if I don’t reveal it, I won’t get any help from specialized organizations”.  
Magway Division

“As a sex worker, I have to keep my situation secret to retain my clients”. Shan State

#### **Exclusion**

“My husband might want to divorce me if he finds out I am HIV positive”. Mon State

“I don’t want my family and the community to know by fear of being discriminated and excluded”. Tanintharyi Division

“I don’t want my family to be disappointed”. Magway Division

“Now that people know, they don’t respect me anymore. I had to leave my place and I am now living in a friend’s house”. Mandalay  
Division

“I am afraid to tell my daughter that I am HIV positive”. Shan State

#### **Breach of confidentiality**

“I showed the test result from Baho Women’s Hospital to AMI. People in my community were informed because the Myanmar  
Women’s Welfare Association gave the result to the Dalat Health Department”. Yangon Division

### Antiretroviral treatment

#### **Cost**

“It is difficult for me to get the medicine. Because transportation costs are high, I have to pawn things first”. Mandalay Division

“I can’t buy ART, it is too expensive”. Mon State

#### **Availability**

“I can’t obtain medicine in the area where I had to move to. Treatment is available only in designated areas”. Mon State

“People who accept to sign for me to get ART treatment are rare. My parents are dead, and my siblings refuse to come with me to the hospital. I had to get married to a man who accepts to give his signature”. Yangon Division

“It is difficult for me to get the treatment as I don’t have a census registration card or an ID card”. Mandalay Division

“There is no place that distributes free ART in my city. I have to travel to the Indian border to get some”. Sagaing Division

“There is no place that distributes ART for free, there is no place where I can buy it. I don’t know what to do”. Mon State

#### **Sustainability**

“I am afraid about the side effects and that the organization providing the medicine will lose interest”. Yangon Division

“I have to do this treatment all my life but no organization can support me all this time”. Sagaing Division

#### **Lack of understanding and reserves**

“I am a bit scared of the side effects of ART”. Tanintharyi Division

“I don’t understand what this treatment is”. Magaway Division

“The counselor did not speak clearly to us patients. I did not understand what was being said and I did not get the ART on time”. Tanintharyi Division

“I am afraid I won’t be able to drink alcohol as usual if I take ART”. Rakhine State

“I am not sure whether I should take it”. Tanintharyi Division

#### **Organizations**

“I can easily get the ART from MSF Swiss if I need it”. Tanintharyi Division

“I am getting it for free from MDM now. But it will be bad if they stop their support”. Yangon Division

Having children when you are HIV positive

**Don't want**

"I don't want a child". Multiple

"I already decided not to marry again, so I won't have any child". Mon State

"I don't want a child, I can't afford financially to have one". Tanintharyi Division

"I already have a child and I won't get another one, not because I am HIV positive, but because I don't have enough money".  
Tanintharyi Division

**Want but have reserves**

"I am worried my child will be infected and I won't be able to take care of him/her". Rakhine State

"I would like to have a child but I am worried of infecting my wife and the child while trying to have a baby". Rakhine State

"Doctors told me there is a risk of mother to child infection and told me to get counseling before I plan to have a baby". Yangon  
Division

"I want a child but nurses prohibit me from having one". Sagaing Division

"I want to have another child, but because I have AIDS, I am afraid of having another one". Yangon Division

**Do want**

"I don't have a child yet, and I want one". Yangon Division

"I still want a child but not while working as a sex worker. I still want to build a family". Mon State

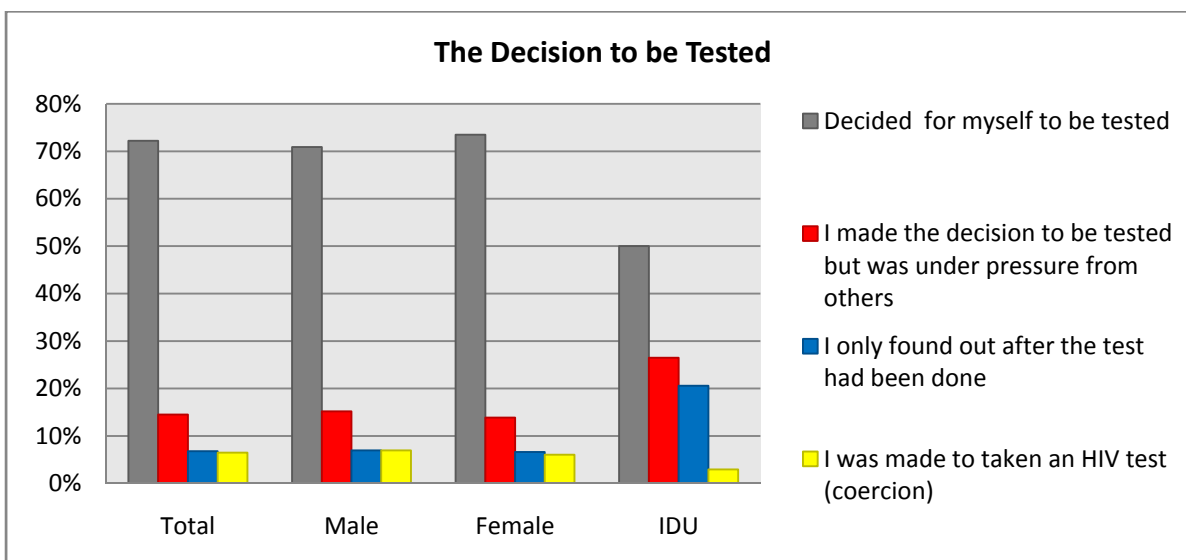
## 9. Testing/Diagnosis

Table 4 "Why were you tested for HIV"

Reasons for being tested for HIV (multiple answers allowed)	Male	Female
I just wanted to know	70%	68%
Referred due to suspected HIV related symptoms	60%	32%
Husband/wife/partner/family member tested positive	11%	36%
Death of husband/wife/partner/family member	6%	15%
Referred by a clinic for sexually transmitted infections	6%	7%
To prepare for sexual relationship	6%	4%
Pregnancy	1%	8%
Because the doctor has asked to take medical check up	5%	2%
Employment	4%	2%
Poor health condition	1%	3%
While giving birth		2%
Do the testing for authority person	1%	1%
His/her relative/friend ask for medical check up	1%	1%
Because he/she had herpes or pruritus	1%	1%
Needs to do blood testing when jailing	1%	
Her husband was involved in sexual work and he look thinner		1%
Got instructions from OPD		1%

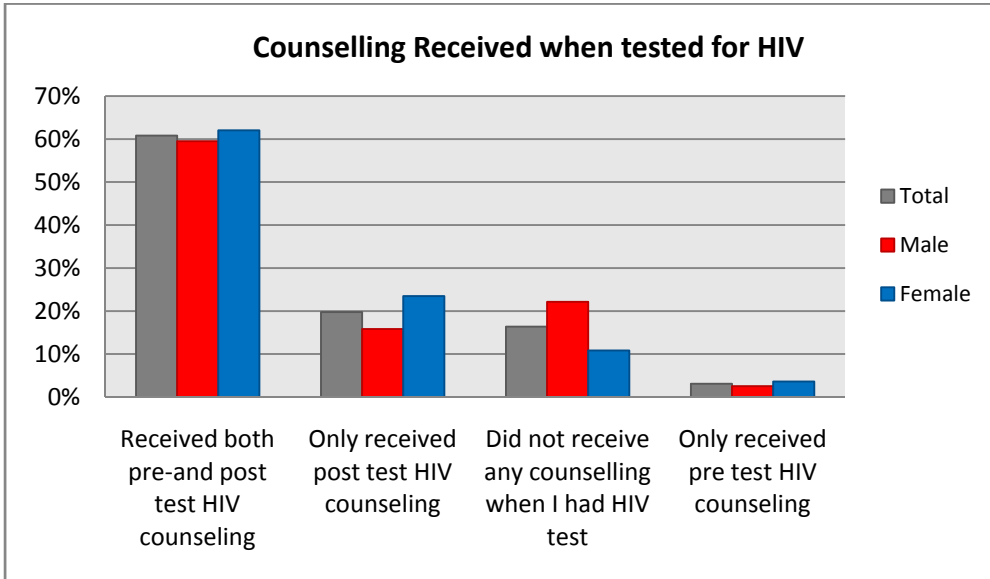
The majority of total respondents were tested for HIV out of curiosity because they "just wanted to know," while a large number of male respondents were referred for testing due to suspected HIV-related symptoms. Over 1/3 of female respondents had an HIV test performed because their husband/partner/family member had tested positive.

Figure 38 "Was the Decision to be Tested up to You?"



The majority of respondents stated that the decision to be tested was made on their own. A smaller percentage stated they made the decision to be tested but were under pressure from other persons. Only a small number of respondents reported that they were coerced into taking an HIV test. However, a larger number of respondents who belonged to the category of IDU reported that they were only aware of the HIV test being performed after it had been performed on them.

Figure 39 "Did you receive Counseling when you were Tested for HIV?"



The majority of respondents stated that when they were tested for HIV, they received both pre and post-test HIV counseling. However, 16% of respondents reported not receiving any HIV counseling when tested.

10. Disclosure and Confidentiality

Table 5 How Husband/Wife/Partner were told of respondent's HIV-positive status

How Husband/Wife/Partner were told of my HIV-positive status	Male	Female
I told them	47%	52%
Someone else told them with my consent	4%	5%
Someone else told them without my consent	4%	4%
They don't know my HIV status	18%	14%
Not applicable (those without permanent partners)	28%	24%

Table 6 How friends were told of the respondent's HIV-positive status

How Friends were told of my HIV positive status	Male	Female
I told them	51%	49%
Someone else told them with my consent	2%	
Someone else told them without my consent	10%	8%
They don't know my HIV status	32%	35%
Not applicable	4%	7%

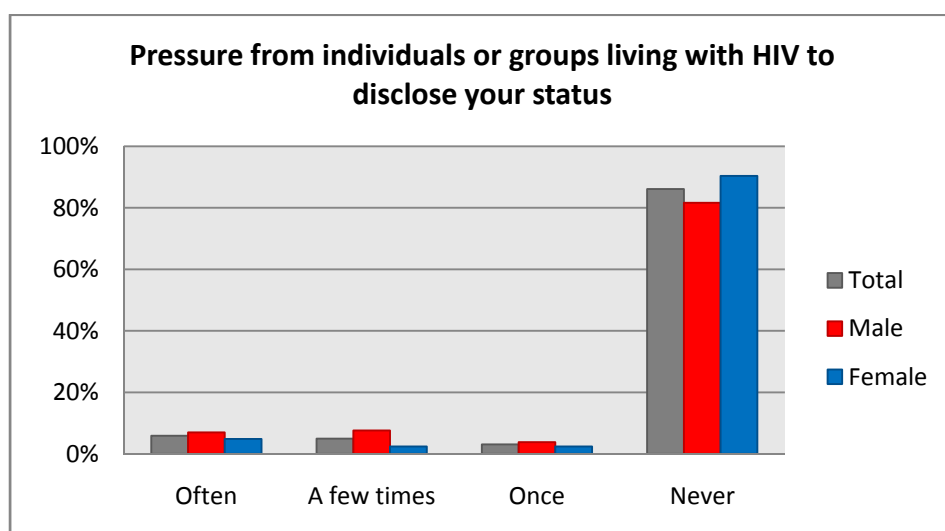
Respondents were asked how various persons in their lives were told about their HIV positive status, the respondents demonstrated much higher level of openness towards other people living with HIV than with non HIV positive people. In these tables three cross sections are shown for the difference in disclosing HIV positive status to Husband/Wife/Partner and Friends compared with disclosure to other people living with HIV.

**Table 7 How other people living with HIV were told of the respondents HIV-positive status**

How Other people living with HIV were told of my HIV-positive status	Male	Female
I told them	85%	90%
Someone else told them with my consent	6%	4%
Someone else told them without my consent	3%	2%
They don't know my HIV status	5%	4%
Not applicable	1%	



**Figure 40 Pressure felt from other HIV-positive persons for respondent to disclose their status**



Over 85% of all respondents reported that they never face pressure from individuals or groups/networks living with HIV to disclose their own status of being HIV-positive.

10% of respondents reported that a healthcare professional had disclosed their HIV-positive status to other people without their consent.

However, the majority of respondents, over 70%, stated that they believed their medical records related to their HIV status are kept completely confidential, while over 20% stated they don't know if their medical records are confidential.

**Table 8 "Has a health care professional disclosed your HIV status without your consent?"**

Health care professional disclosed status to other people without consent	Total	Male	Female
Yes	10%	8%	13%
No	80%	82%	79%
Not sure	9%	11%	8%

Figure 41 "How confidential do you think the medical records relating to your HIV status are?"

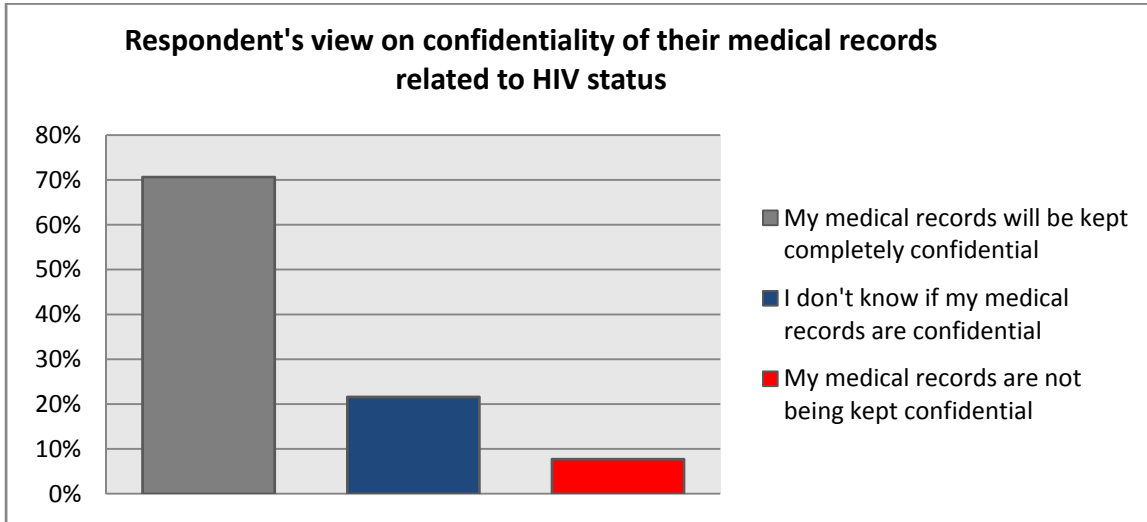
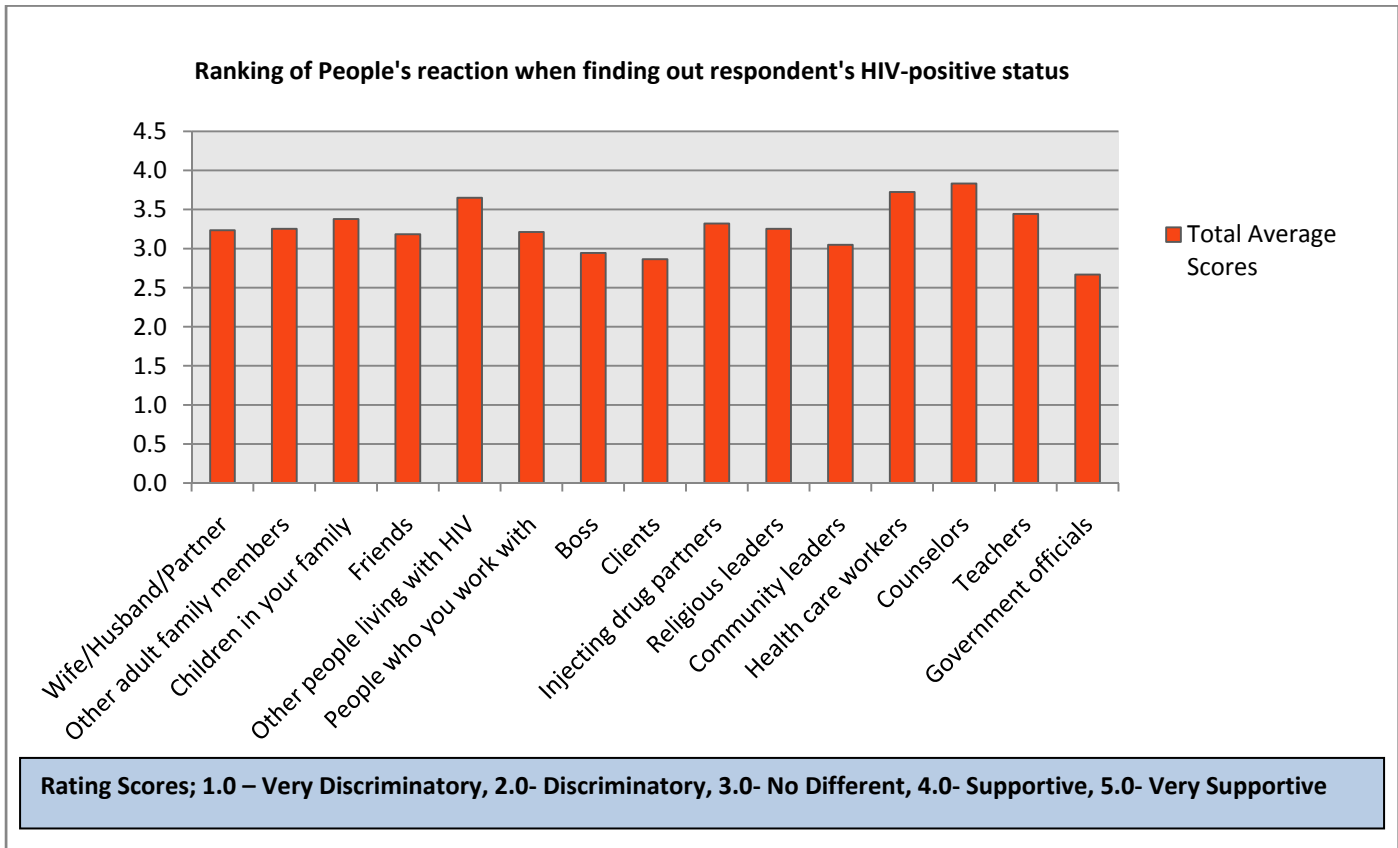


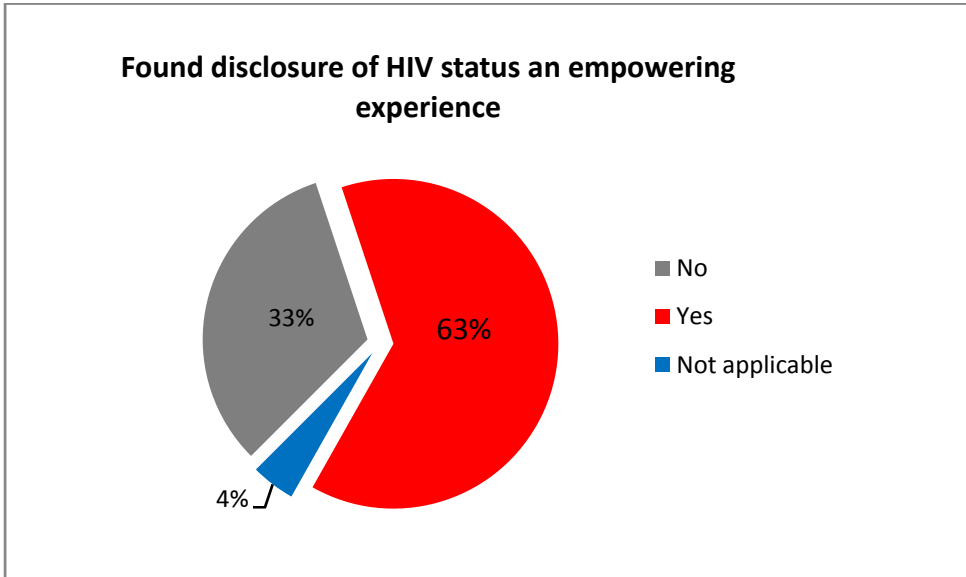
Figure 42 Rating of the reactions of various people when they first knew of the respondent's HIV-positive status



When respondents were asked to rate the initial reaction of various people from their community including wife/husband/partner, friends, religious and community leaders, healthcare workers and the government officials, the majority of respondents rated these various peoples' reactions as ranging from no difference to supportive. The respondents were asked to score the various peoples' reactions on a scale from 1-5, 1 being very discriminatory, and 5 being very supportive, with the majority of scores averaging above 3.



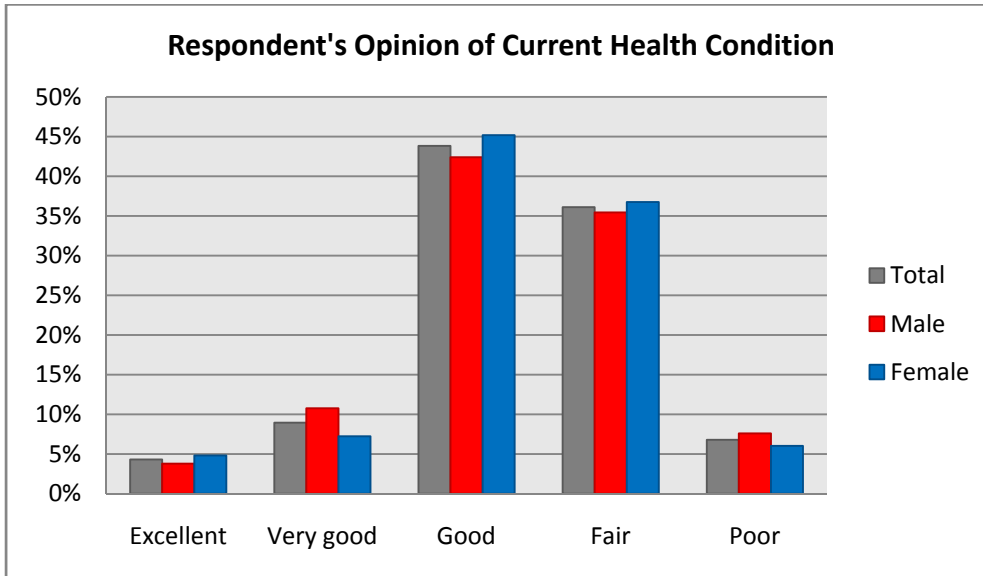
Figure 43 "Did you find the disclosure of your HIV status an empowering experience?"



Over 60% of all respondents found disclosure of their HIV status as an “empowering experience.”

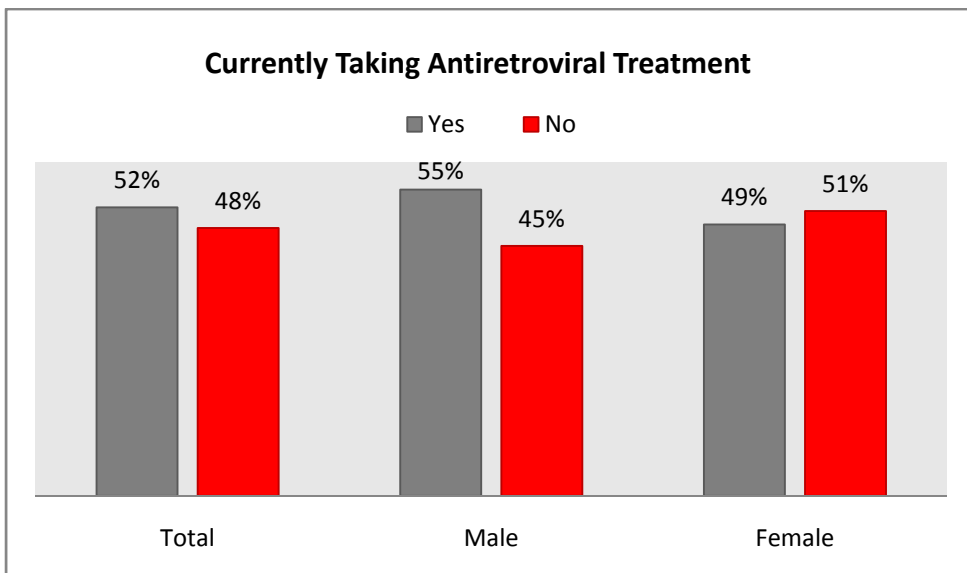
## 11. Treatment

Figure 44 Respondent's description of health at the moment



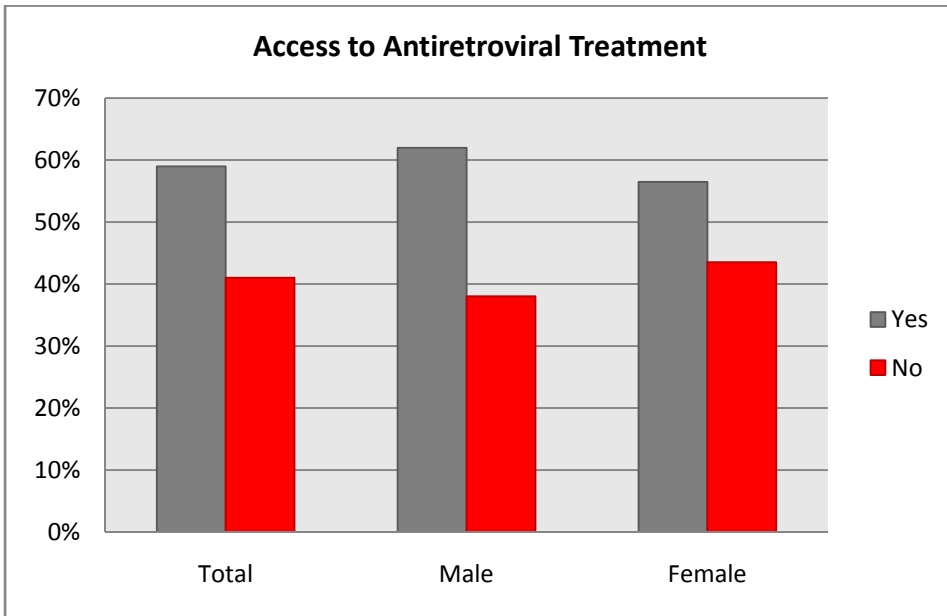
The majority of respondent's opinion of their current health condition was stated as being good, while several respondents rated their current health condition as being fair to poor. Fewer than 5% of all respondents rated their current health condition as being excellent.

Figure 45 Respondent's currently taking Antiretroviral Treatment



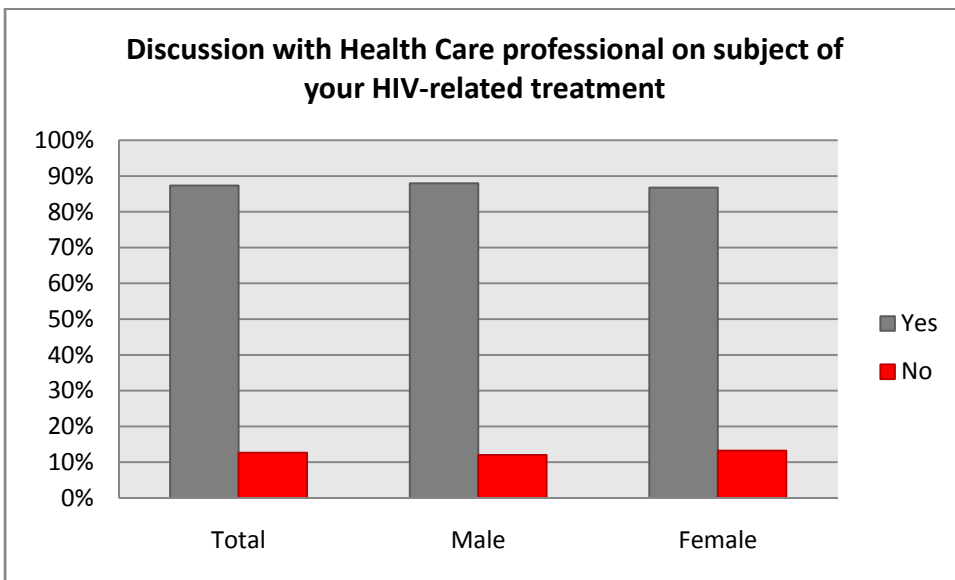
48% of total respondents and 51% of female respondents reported that they are currently not taking anti-retroviral treatment.

Figure 46 Access to antiretroviral treatment, even if not currently taking it



**41%**  
of all HIV-positive respondents reported that they currently do not have access to anti-retroviral treatment.

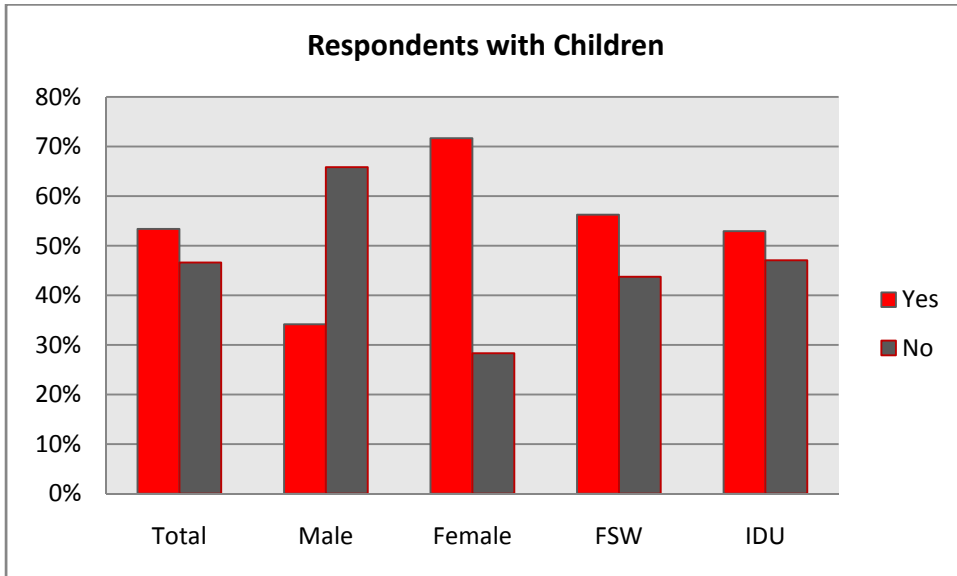
Figure 47 Discussion in the Past 12 months on HIV-related treatment



The majority of respondents reported they have had HIV-related treatment discussions with a health care professional in the last 12 months.  
However over 10% stated they have not had any HIV-related treatment discussions in the last 12 months.

## 12. Having Children

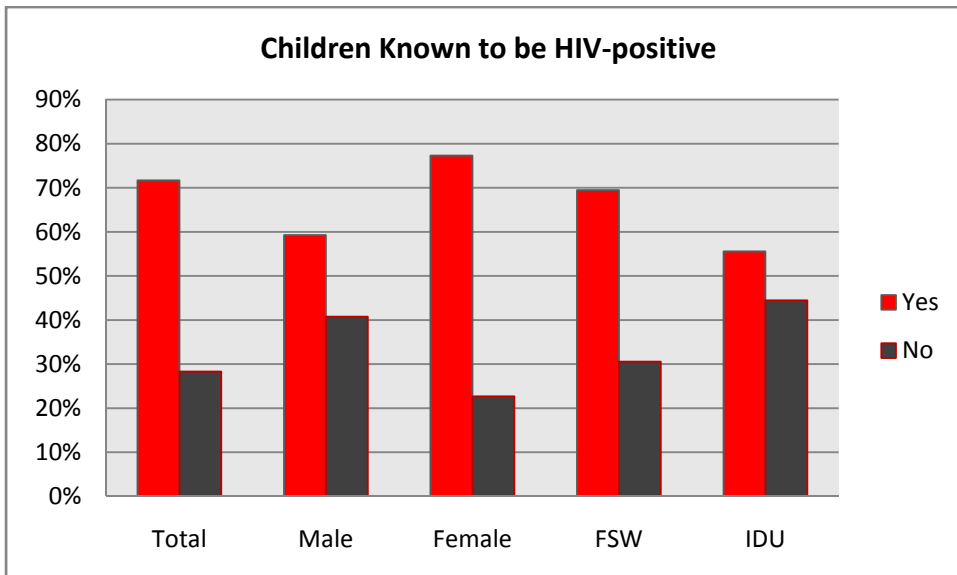
Figure 48 "Do you have a Child/Children?"



# 53%

of all respondents reported having a child or children. Over half of respondents categorized as FSW and IDU also reported having children.

Figure 49 Respondent's children known to be HIV-positive



# 72%

of all respondents that have children reported that at least one of their children is known to be HIV-positive.

77% of all female, 69% of all FSW and 56% of all IDU respondents that have a child, have at least one child known to be HIV-positive.