

# STIGMA INDEX REPORT



JUNE 2011



**ASSESSMENT OF THE STIGMA INDEX AMONG PEOPLE LIVING WITH HIV AND  
AIDS IN SWAZILAND**

Final report

June 2011

## ACKNOWLEDGEMENTS

The Swaziland Network of People Living with HIV and AIDS (SWANNEPHA) would like to express appreciation to the UNFPA and IPPF for financial and technical support in the roll out of the stigma index in Swaziland. The organizations in Swaziland in both governmental and non governmental sector that supported initiatives to ensure that the stigma index is implemented are lauded for their efforts and support. These organizations include the Ministry of Health's National AIDS Programme, NERCHA, ICW, FLAS, UNFPA and UNAIDS.

The roll out of the stigma index would not have been possible without the willingness of People living with HIV and AIDS who worked as research assistants and as respondents who agreed to interviews and provided the data to describe issues related to stigma and discrimination in the country.

Appreciation is extended to the Consultant Ms Happiness Mkhathswa who led to roll out of the stigma index in Swaziland. Ms Lucy Stackpool-Moore from IPPF is also acknowledged for her technical support.

The stigma index was rolled out in Swaziland using the Userguide developed by the UNAIDS, IPPF, ICW and the Global Network of people living with HIV.

Appreciation is also extended to the Advisory Committee for providing guidance in the roll out of the Stigma Index. This committee comprised of representatives from the UNAIDS, Women and Law in Swaziland, SNAP and FLAS. The core team that supported the actual roll out of the stigma index is greatly appreciated and they were:

- i. Ms Lindiwe Simelane – SWANNEPHA
- ii. Mr Bheka Mziyako - FLAS
- iii. Ms Phelele Fakudze - FLAS
- iv. Ms Winnie Ncongwane – ICW
- v. Ms Renata Tallarico – UNFPA
- vi. Andile Nhleko – SWANNEPHA
- vii. Bernard Abingo - SWANNEPHA

## EXECUTIVE SUMMARY

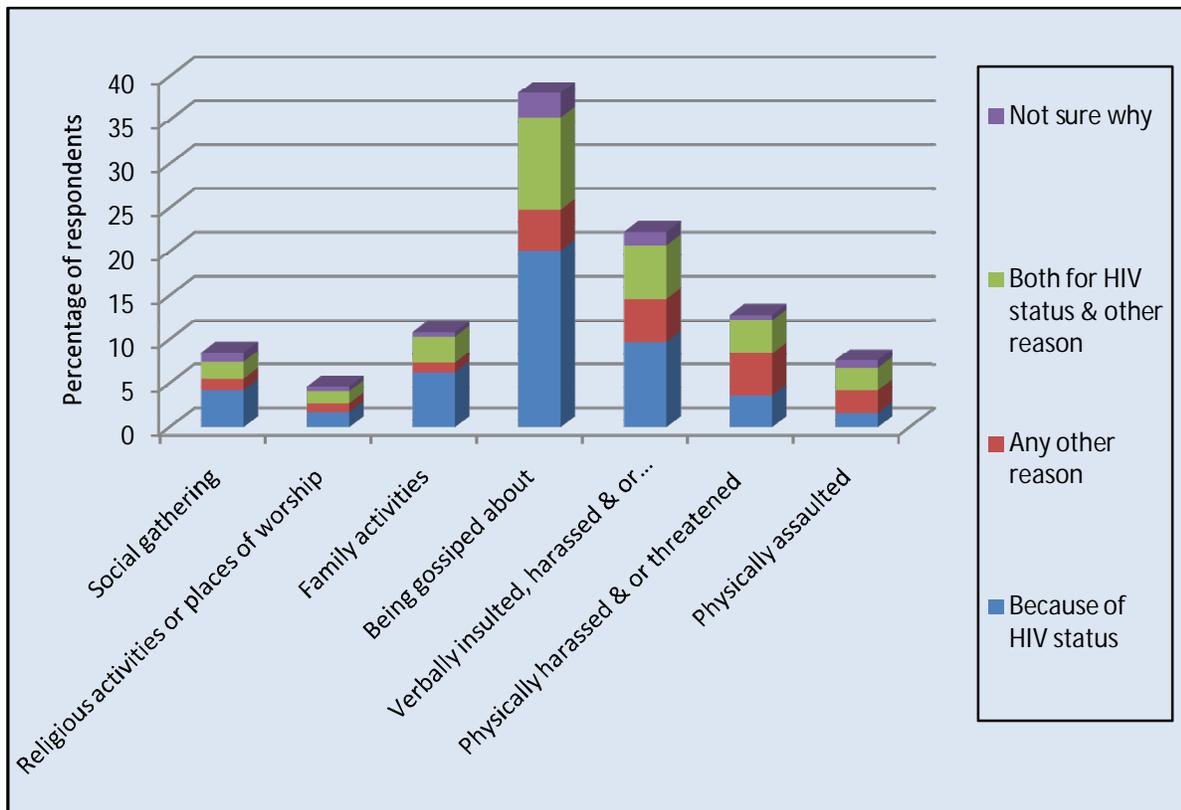
The purpose of this study was to increase capacity to assess and measure change related to stigma and discrimination in the context of the epidemic in Swaziland. The specific objectives were:

- To determine and document the experiences of stigma in the community, among PLHIV and in relation to health care using the stigma index;
- To measure the impact of stigma on programmes and interventions implemented in the country.

The Swazi roll out of the stigma index was based on the methodology developed by the People Living with HIV Stigma Index project. A total of 1233 People living with HIV were interviewed using an adapted questionnaire developed by the stigma index project and they comprised of 74.3% (916) females, 25.3% (312) males and 0.4% (5) who identified themselves as transgender. The highest percentage was those who had lived 1 to 4 years with HIV and they were 44.5% followed by those who had lived 5 to 9 years with HIV who were 33.2%. A majority of 75.8% interviewees lived in rural areas, 22.5% live in small towns and 1.7% lived in cities.

### Selected key findings were as follows:

- PLHIV experience stigma and discrimination from other people as shown in the following chart.



Fear of getting HIV and lack of knowledge regarding transmission of HIV were common reasons why PLHIV were stigmatized as indicated by 31.4% and 27.2% of the respondents respectively.

- ii. In relationships 8% of the respondents indicated that they had been subjected to psychological pressure or manipulation by their spouses or partners wherein their HIV status was used against them. There were 20% of the respondents who indicated that they experienced situations where their spouse or partner, members of their household was discriminated because of the respondent's positive HIV status. About 14.3% said they experienced this only once, 2.5% said few times and 3.2% said this happens often.
- iii. There were 5.5% of the respondents who stated that they had experienced discrimination by other PLHIV.
- iv. There were 2.8% of the respondents who alluded to having experienced being refused employment or a work opportunity because of their HIV status. There were also 2.3% of the respondents who had their job description or nature of their work changed or were refused promotion as a result of their HIV status.
- v. A total of 94.9% respondents said their children had never been dismissed, suspended or prevented from attending an educational institution because of their HIV status.
- vi. There were 4.6% who were denied dental care because of their HIV status, 1.1% were denied family planning services and 3.7% were denied sexual reproductive health services.
- vii. Internal stigma seemed to be the most common type of stigma experienced by respondents. There were 31.1% who stated they blame others, 26% alluded to blaming themselves, 24.7% who pointed they had low self esteem, 23.9% feel ashamed, 17.4% who felt guilty and even 7.1% who pointed out they felt like committing suicide.
- viii. There were 45.3% of the respondents who stated that they decided not to have more children because of their HIV status, 22% decided not to have sex and 17.5% decided not to get married. There were 13.8% who alluded to having isolated themselves from their families and friends, 8.8% decided not to attend social gatherings and 5.5% took a decision to stop working. There were also 5.4% who decided not to apply for a job or for a promotion, 4.1% withdrew from training or did not take up an opportunity for training, 4.1% avoided going to a local clinic when they needed to and 2.4% avoided going to a hospital when they needed to.

- ix. It appeared that people were still being forced to test for HIV as there were 3.7% of the respondents who had been forced to submit to a medical or health procedure including an HIV test. Furthermore there were 12.8% of the respondents who stated that their rights had been abused.
- x. The decision to test for HIV was voluntary for 83.7% while 11.4% pointed out that they took the decision to test under pressure from others, 4.2% were coerced and 0.7% pointed out that they were tested without their knowledge and only found out after the test had been done.
- xi. A majority of 75.8% of the respondents disclosed their HIV to their spouses or partners themselves, for 2.2% of the respondents they were told by someone else with the consent of the respondents, for 1.5% they were told without their consent and for 5.6% the spouses or partners did not know their HIV status.

In view of the findings the following recommendations were made:

- There is a need to improve the quantity and quality of counselling services and strengthening of positive living.
- Establish support centres for counselling of PLHIV who experience stigma and discrimination.
- Increase the scope and impact of HIV and AIDS awareness campaigns to reach all communities with information on rights of PLHIV as well as increased knowledge and understanding of transmission, treatment and support processes versus the importance of wellness of the PLHIV.
- Develop an intervention to support disclosure to children since they deal with parents' HIV status and frequently their own.
- Since there is high level of unemployment among PLHIV it is important to develop programmes for economic empowerment to enhance success in dealing with stigma and discrimination.
- Strengthen the curriculum of support groups to include life skills such as assertiveness to equip individual PLHIV to deal with stigma and discrimination and to enable them to support each other in support groups.
- A specific campaign on human rights of PLHIV should be implemented in both rural and urban areas.
- Evaluate the need for legislation to protect the rights of PLHIV.

- Put in place a call centre (toll free line) for PLHIV to call when denied essential services such as health services.
- Compile regional directories detailing where support services can be obtained to prevent suicide, depression and other negative feelings.
- Conduct a sensitization campaign on available legislation and guidelines.
- Package information on SRH and treatment options and distribute these widely throughout the country to enable people to obtain such information easily. (Development of IEC materials (pamphlets)).
- Develop a mass media programme targeting couples and families as well as males with messages of reducing stigma in relationships.
- Renew emphasis of provision of ongoing counselling
- Encourage VCT and community testing because individuals test because they want to know their HIV status
- Conduct a study among adolescents living with HIV to compares experiences of stigma and discrimination with adults

## ACRONYMS

HIV:	Human Immunodeficiency Virus
AIDS:	Acquired Immune Deficiency Syndrome
IPPF:	International Planned Parenthood Federation
NERCHA:	National Emergency Response Council on HIV and AIDS
ICW:	International Community of Women living with HIV and AIDS
FLAS:	Family Life Association of Swaziland
UNAIDS:	Joint United Nations Programme on HIV and AIDS
ANC:	Antenatal care
STI:	Sexually Transmitted Infections
TB:	Tuberculosis
DHS:	Demographic and Health Survey
PLHIV:	People Living with HIV
SWANNEPHA:	Swaziland National Network of people living with HIV and AIDS
GNP+:	Global Network of people living with HIV and AIDS
UNFPA:	United Nations Population Fund
SEC:	Swaziland Ethics Committee
MARPS:	Most at risk populations
CSW:	Commercial Sex Workers
MSM:	Men who have sex with men
ART:	Antiretroviral Therapy
GIPA:	Greater involvement of people living with HIV and AIDS
IDU:	Injecting drug users
NGO:	Non Governmental Organization
FBO:	Faith Based Organization
SASO:	Swaziland AIDS Support Organization
AMICAALL:	Alliance of Mayors' Initiative for Community Action on AIDS at the Local Level
SIPAA:	Support to International Partnership Against AIDS in Africa
SRH:	Sexual & Reproductive Health
IEC:	Information Education and Communication

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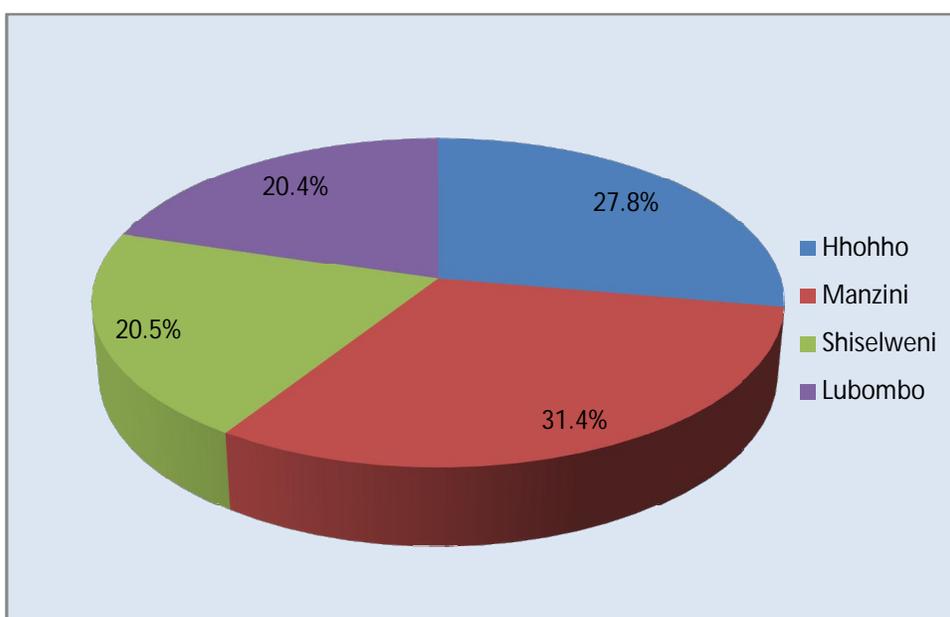
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## 1. BACKGROUND

### 1.1 The Swazi Population

The total population of Swaziland is 1,018,449 persons with 481,428 males and 536,021 females with more people living in the rural areas. Males form 47% of the population whilst females form 53% of the population. The rural population is 793,156 persons compared to 225,293 in the urban areas. The distribution of the population across the four regions varies slightly as shown below:

Figure1: Regional distribution of Swazi population



Source: 2007 Population and Housing Census (summary)

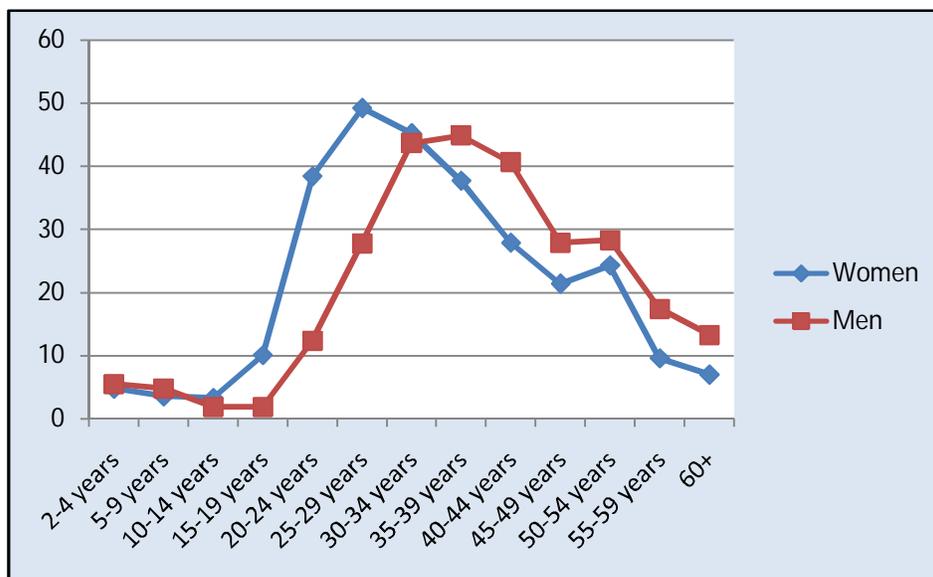
The country's population is said to be young because 39.6% is younger than 15 years of age and 52% is younger than 20 years of age.

### 1.2 HIV and AIDS in Swaziland

HIV prevalence in Swaziland has been increasing at very alarming rates over the years. The HIV prevalence has increased from 3.9% in 1992 to 42% in 2008 among women attending ANC. The country has been monitoring the HIV prevalence by conducting bi-annual HIV surveillance using selected population groups. Three sentinel populations were chosen; (1) antenatal clients, (2) STI (sexually transmitted infections) clients and (3) TB (tuberculosis) clients. Commercial Sex workers were included in 1994 as one of the sentinel populations from one sentinel site.

The Demographic and Health survey was conducted in 2007 and determined the prevalence of HIV in the general population as shown in the following figure.

Figure 2: HIV prevalence among population age 2 years and older



Source: Demographic and Health Survey 2007

The DHS showed that the country has a high HIV prevalence rate of 26% for the productive age group of 15-49 years and 19% for the population 2 and older. Of the 220,000 adults in Swaziland estimated to be HIV positive at the end of 2006, 120,000 (54.5%) were women. Unequal power relations and gender discriminations disadvantaging women are key factors underlying the higher prevalence of HIV in women in Swaziland (UNAIDS. 2008 The Road Towards Universal access to HIV/AIDS prevention, treatment, care & support).

### 1.3 Stigma and Discrimination

Discrimination occurs when a person is treated in a different, unjust, unfair or prejudicial manner, often on the basis of their belonging, or being perceived to belong, to a particular group. It is often viewed as the end result of the process of stigmatization. In other words, when stigma is acted upon (sometimes called “enacted stigma”), the result is discrimination. “Discrimination consists of actions or omissions that are derived from stigma and directed towards those individuals who are stigmatized.” Stigma is often described as a process of devaluation. In other words, if one is stigmatized one is discredited, seen as a disgrace and/or perceived to have less value. HIV-related stigma often builds upon and reinforces other existing prejudices, such as those related to gender, sexuality and race. For example, the stigma associated with HIV is often based upon the association of HIV and AIDS with already marginalized and stigmatized

behaviours, such as sex work, drug use and same-sex and transgender sexual practices (The People Living with HIV Stigma Index 2005).

HIV-related stigma affects those living with HIV and – through association – those who they are associated with, such as their partner or spouse, their children and the other members of their household. Efforts to address HIV and AIDS have been undermined by the stigma associated with the disease. Programmatic responses to HIV and AIDS are tremendously affected by the denial, silence, rejection and discrimination of people living or suspected to be living with HIV or AIDS. Fear of casual transmission and perceptions of people living with HIV or AIDS (PLHIV) being less productive and therefore potential threats to resources have exposed PLHIV to numerous social exclusions and oppressions. Living with HIV and AIDS is often seen as a deserving punishment for having engaged in some morally unacceptable behaviour. These negative social labels create a negative perception of self to those infected resulting in social withdrawal and self-exclusion as well as self-protective and survival mechanisms. Given the above, any person living with HIV or AIDS will find it hard to disclose their status. This does not only undermine preventative strategies, but affects health seeking behaviour, drives the epidemic underground and perpetuates the vicious and silent nature of the epidemic.

#### **1.4 SWANNEPHA**

The Swaziland National Network of People Living with HIV and AIDS (SWANNEPHA) was founded in 2004 by PLHIV with assistance of the Ministry of Health in collaboration with NERCHA, UNAIDS and SIPAA/ Action Aid after a situational analysis for people living with HIV and AIDS which showed poor coordination among the forty six associations that existed at the time. This network was formed to ensure efficacy in programme delivery among PLHIV as well as to mobilize and amplify the many voices of PLHIV in the national response to the country's socio economic development and health. SWANNEPHA's mission is to promote and uphold positive living for PLHIV by creating a bond among members for shared vision. Members of SWANNEPHA comprise of organizations of PLHIV and support groups of people infected and affected by HIV and AIDS. The SWANNEPHA goals include the following:

- Capacity building among member organization in programming and management of HIV and AIDS interventions;
- Coordinating and facilitating PLHIV interventions in the different communities;
- Information distribution;
- Monitoring and evaluation.

## **1.5 THE PLHIV STIGMA INDEX**

The stigma index was developed to collect information on stigma, discrimination and the rights of people living with HIV that will help in advocacy efforts. It is a project that has been developed and implemented by and for people living with HIV. It aims to collect information about the experiences of people living with HIV related to stigma, discrimination and their rights. The information obtained from PLHIV will enable documentation of various experiences of people living with HIV within a particular community or country regarding HIV-related stigma and discrimination; comparison in country and between countries, measure change over time and will inform programming and policy change. The People Living with HIV Stigma Index is the joint initiative of the Global Network of People Living with HIV/AIDS (GNP+); the International Community of Women Living with HIV/AIDS (ICW); the International Planned Parenthood Federation (IPPF); and the Joint United Nations Programme on HIV/AIDS (UNAIDS).

## **1.6 OBJECTIVES**

The purpose of this study was to increase capacity to assess and measure change related to stigma and discrimination in the context of the epidemic.

The specific objectives were:

- To determine and document the experiences of stigma in the community, among PLHIV and in relation to health care using the stigma index;
- To measure the impact of stigma on programmes and interventions implemented in the country.

## **2. Methodology**

### **2.1 Study design**

The Swazi roll out of the stigma index in Swaziland was based on the methodology developed by the People Living with HIV Stigma Index project, managed by the International Planned Parenthood Federation (IPPF) in partnership with UNAIDS, the Global Network of People Living with HIV (GNP+) and the International Community of Women Living with HIV (ICW). People living with HIV were at the centre of the process as interviewers and interviewees and as drivers of how the information was collected and analyzed. The SWANNEPHA partnered with FLAS, ICW, UNFPA, UNAIDS Swaziland and the Ministry of Health in implementing the index.

### **2.2 Ethical considerations**

Ethical approval was sought and obtained from the Swaziland Scientific and Ethics Committee (SEC). A protocol was submitted to the SEC for review followed by a presentation after which approval was granted for the stigma index to be implemented.

Informed consent was obtained from interviewees before interviews were conducted. This entailed provision of standard information explaining the index purpose and benefits through an information sheet which interviewers used to explain to interviewees before requesting their participation (annex 2). This sheet was provided in both English and Siswati and remained with interviewees to enable them to seek clarification even after interviews. Respondents were given the option to refuse to participate or to withdraw participation whenever they desired.

Confidentiality was ensured in the index by ensuring that all who came into contact with data signed a confidentiality agreement stating that they would not in any way disseminate respondents' identifying information in anyway. This agreement was signed by the leader of the study, the coordinator from SWANNEPHA, two data managers, interviewers and their supervisors. To secure confidentiality the index questionnaires and informed consent forms were identified by a unique identifying code (as opposed to the name of the interviewee). Each code included a country code of two digits; a region code of two digits; a site code, interviewer code of two digits; an interviewee code of two digits; and the location where the interview occurred. e.g. SD-HH-MG-HM-01 indicating Swaziland as the country, Hhohho as the region, Mbabane Government Hospital as the site and Happiness Mkhathswa as the interviewer and lastly interviewee number.

Interviewers ensured interviewees privacy during interviews by conducting interviews in places such that they could not be overheard by other people. Furthermore, filled questionnaires were kept in such a way that only interviewers, data

managers, the coordinator and the study leader were the only one that had access to them.

### 2.3 The sample

The study sample consisted of a mix of HIV positive people of different ages, sexuality, economic, social and educational backgrounds. The sample was not representative of the epidemiological profile of HIV infection in the country since most people infected with HIV are not necessarily aware of it and there is no guarantee that those who know they are HIV positive go on and disclose their HIV status. Efforts were therefore made to take a sample that is large enough to capture the main features of the population as well as the divergence from the main features. The known population of people living with HIV in Swaziland is 220 000 (UNAIDS 2008). There are over 150 support groups spread throughout the four regions of the country. These are located in both rural and urban areas.

The minimum number of participants of the stigma index was calculated using the cross sectional design formula. Thereafter available resources and population factors were considered and then the figure was proportionately distributed across the four regions. Inclusion of rural and urban populations was ensured as well as intentionally including both males and females and the different age groups. All PLHIV had an equal opportunity to be selected. It was anticipated that not all the participants would agree to participate thus a refusal rate of about 10% was added to the sample size. The minimum sample size therefore was calculated using the following formula:

$$n = (t^2pq)/d^2$$

Where:

n = first estimate of sample size (minimum sample size for large population)

t = confidence interval (if 95% use 1.96)

d = precision (0.05)

p = estimated prevalence (proportion) in target population (26%)

q = 1-p

Estimates of the sample size

Study population is estimated to be around 220 000

Desired Confidence Interval is 95%

Precision desired is 0.05

Estimated prevalence of HIV is 26% (proportion is 0.26)

Sample size estimate is "n"

$$n = (t^2pq)/d^2$$

t = confidence interval (95%) therefore use 1.96

p = estimated prevalence (use 26% is prevalence of reproductive population)

q = 1-p

d= precision (0.05)

$n = ((1.96 \times 1.96) \times 0.26 \times (1-0.26))/0.05 \times 0.05$

$n = (1 \times 0.74)/0.0025$

n= 296

Add 10% refusal rate n= 326

Applying the above formula based on the current confidence interval yielded a sample size of 330 having factored in the refusal rate. This provided the minimum number of participants. However with consideration of resources and the fact that the population is not necessarily all HIV positive individuals but those that have tested, a sample size of 1200 was then decided together with the core team.

## **2.4 Eligibility criteria**

All PLHIV 18 years and above were eligible to be included in the survey

Rural/ urban (50%/50%)

Sex (50% females/ 50% males)

Age groups: Efforts were to be made to interview about 60 per age group in the following age categories:

- 21 – 30years
- 31 – 40years
- 41 – 50 years
- 50+

MARPS: Among most at risk populations efforts were made to reach the following:

- CSW (10)
- MSM (10)
- Unemployed (10)

The locations of the sample are identified in annex 1. Please see annex 3 for the sampling frame.

## **2.5 Data collection**

A tool developed by the Global Network of PLHIV (GNP+) , the International Community of Women living with HIV/AIDS (ICW), the International Planned Parenthood Federation (IPPF) and UNAIDS was used with minor adjustments (Annex 1). The questionnaire was translated into SiSwati to enable interviews with participants who were not conversant with English language. Research assistants were identified among PLHIV in support groups and those working in ART sites as Expert Clients since this initiative embraces the GIPA principle whereby the index was developed by PLHIV and is conducted by PLHIV. This was important to ensure that interviewees had support and confidence in expressing themselves on sensitive issues of stigma and discrimination when being interviewed by other PLHIV. In addition the training ensured objectivity and good research skills. The interviewers were trained for three and half days in the required procedures for obtaining and conducting interviews as well as on the tool that

was to be used to collect data. The interviewers were supervised in the field by regional supervisors who checked completeness of tools and collected them.

## **2.6 Field Methods**

All organizations of PLHIV were sensitized regarding the surveillance. Interested participants were offered informed consent for participation (Annex 2). A questionnaire was administered to obtain data.

## **2.7 Pilot Testing of the Questionnaire**

Before the commencement of data collection interviewers practiced using the tool after the training through interviewing each other. This process enabled the study team to agree on content and flow of questions, management of interviews, data entry and recording.

## **2.8 Data analysis**

Data management and analysis used SPSS.

### 3. Findings

#### 3.1 Demographic information of respondents

A total of 1233 People living with HIV were interviewed in the assessment and they comprised of 74.3% (916) females, 25.3% (312) males and 0.4% (5) who identified themselves as transgender. Their age groups are shown below.

Table 1: Age and Sex of respondents

Age	Women		Men		Total number	Percentage
	Number	Percentage	Number	Percentage		
18-20	19	2.1	4	1.3	23	1.9
21-24	89	9.7	6	1.9	95	7.7
25-29	186	20.3	22	7.1	208	16.9
30-39	299	32.6	103	33.0	402	32.7
40-49	212	23.1	96	30.0	308	25.1
50+	111	12.1	81	26.0	192	15.6
<b>Total</b>	916	100	312	100	1228	100

Respondents also indicated the number of years they had lived with HIV. The highest percentage was of those who had lived 1 to 4 years with HIV and they were 44.5% followed by those who had lived 5 to 9 years with HIV who were 33.2% as shown in the following table.

Table 2: Number of years living with HIV by sex

No. of Years	Male		Female		Transgender		Total	
	No.	%	No.	%	No.	%	No.	%
0-1 year	53	17.0	136	14.9	0	0	189	15.4
1-4 years	149	47.8	395	43.3	3	60.0	547	44.5
5-9 years	93	29.8	314	34.4	1	20.0	408	33.2
10-14 years	16	5.1	53	5.8	0	0	69	5.6
15 years and above	1	0.3	15	1.6	1	20.0	17	1.4
<b>Total</b>	312	100	913	100	5	100	1230	100

\*3 did not respond to this question hence total of 1230

The marital status of the respondents was as shown in the following table:

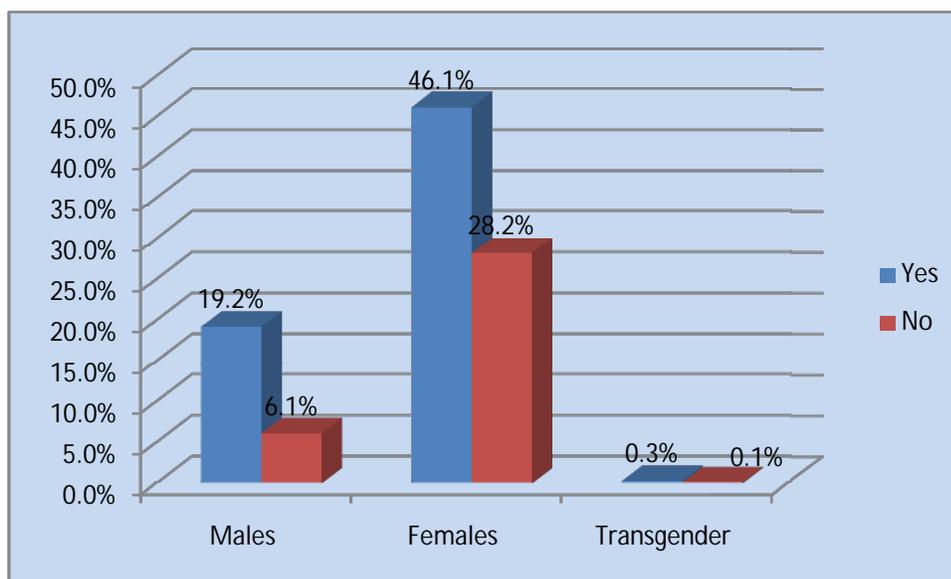
Table 3: Current relationship status by sex

Current relationship status	Male		Female		Transgender		Total	
	No.	%	No.	%	No	%	No.	%
Married partner living in household	150	48.1	271	29.6	1	20	422	34.2
Married partner temporary living/ working away from household	27	8.7	90	9.8	0	0	117	9.5
In a relationship, not living together	35	11.2	186	20.3	0	0	221	17.9
Single living alone	45	14.4	146	15.9	1	20	192	15.6
Single living with partner	29	9.3	51	5.6	3	60	83	6.7
Divorced/ separated	11	3.5	48	5.2	0	0	59	4.8
Widowed	15	4.8	124	13.5	0	0	139	11.3
<b>Total</b>	312	100	916	100	5	100	1233	100

The majority (68.7%) of respondents were in relationships with 34.2% married and living with their partners, 9.5% married but not living together temporarily, 17.9% were in a relationship but not living together and 6.7% were single and living with partner. Only 15.5% were single and living alone, 11.3% were widowed and 4.8% were divorced or separated. With regards to number of years in relationships with their spouses or partners 9.2% of the respondents had been in relationships for less than a year, 28.9% had been in relationships for over a year to four years, 22.6% had been in relationships for between four and nine years; and 39.3% had been in relationships for ten years and above.

A majority of 65.6% (809) pointed out that they were sexually active and 34.4% (424) said they were not as shown in the following chart.

Figure 3: Respondents who were sexually active by sex



Respondents were requested to indicate if they were gay or lesbian, transgender, sex workers, IDU or refugees. This was necessary because these groups are more vulnerable to stigma and discrimination in some communities. Their responses with regards to these categories were as shown in the following table:

Table 4: Sexual and behavior orientation

	Males		Females		Total	
	Number	Percent	number	Percent	Number	Percent
Gay or lesbian	0	0	1	0.1	1	0.1
Sex worker	3	1.0	24	2.6	27	2.2
Injecting drug user	2	0.6	0	0	2	0.2
Refugee/ asylum seeker	2	0.6	4	0.4	6	0.5
Don't belong to any of these categories	305	97.8	886	96.6	1193	96.8
<b>Total</b>	<b>312</b>	<b>100</b>	<b>916</b>	<b>100</b>	<b>1233</b>	<b>100</b>

Transgender is an umbrella term that includes transsexuals and transvestites. A transsexual is someone who may be born biologically male, yet has a female gender identity or be born a female and yet define themselves as a man. A transvestite is a

man who likes to wear female clothes and adopt traditionally female characteristics (PLHIV stigma index 2005).

Only 3% of the respondents had a physical disability. There were 1.5% who had disability in their limbs, 1.1% had visual impairment, 0.4% had hearing impairment.

The educational profile of respondents is shown in the following table.

Table 5: Respondents level of education by sex

Level completed	Males		Females		Transgender		Total	
	No.	%	No.	%	No.	%	No.	%
No formal education	56	17.9	139	15.2	0	0	195	15.8
primary school	106	34	341	37.2	1	20	448	36.3
High secondary school	128	41	394	43	0	0	522	42.3
Technical college / university	22	7.1	42	4.6	4	80	68	5.5
<b>Total</b>	<b>312</b>	<b>100</b>	<b>916</b>	<b>100</b>	<b>5</b>	<b>100</b>	<b>1233</b>	<b>100</b>

Only 5.5% had finished tertiary education, 42.3% had high school or secondary education, 36.3% had primary education and 15.8% had no formal education at all.

The following table shows the employment status of the respondents:

Table 6: Current employment status by sex

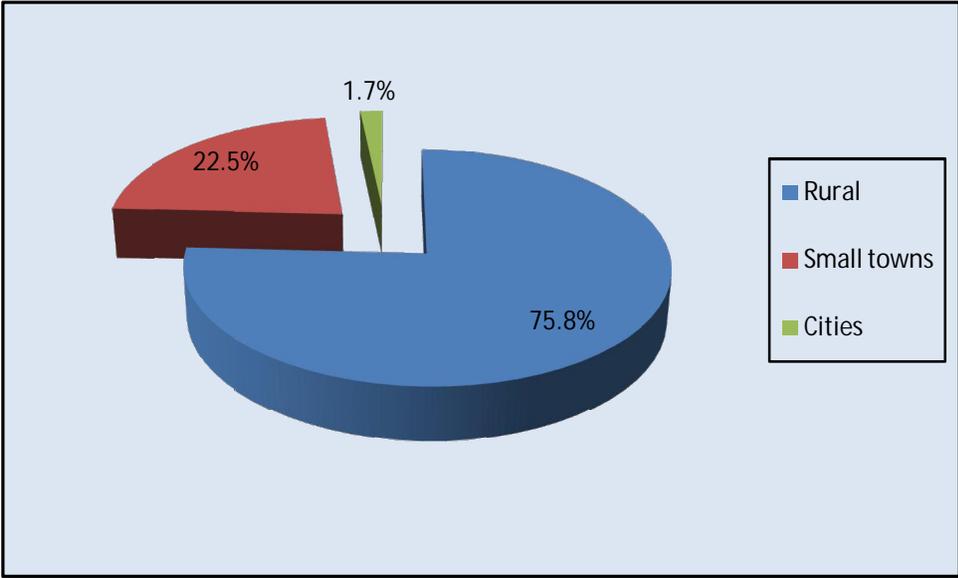
Current employment status	Male		Female		Transgender		Total	
	No.	%	No.	%	No.	%	No.	%
In full-time employment	84	26.9	127	13.9	3	60	214	17.4
In part -time employment	54	17.3	119	13	0	0	173	14
Working full time (self-employed)	12	3.8	48	5.2	1	20	61	4.9
Doing casual or part-time work (self-employed)	39	12.5	85	9.3	0	0	124	10.1
Unemployed and not working at all	123	39.4	537	58.6	1	20	661	53.6
<b>Total</b>	<b>312</b>	<b>100</b>	<b>916</b>	<b>100</b>	<b>5</b>	<b>100</b>	<b>1233</b>	<b>100</b>

There were 53.6% who were unemployed and not working at all and only 17.4% were in fulltime employment, 14% were in part time employment, 10.1% were doing casual work and 4.9% were self employed.

About 34.8% of the respondents had children who were AIDS orphans in their households

A majority of 75.8% interviewees lived in rural areas, 22.5% live in small towns and 1.7% lived in cities as shown in the following chart.

Figure 4: Distribution of respondents by where they live



37.3% of respondents had no income at all. Respondents who earned an income above E20 000 per month amounted to 0.2%, there were 1.4% who earned between E10 000 and E20 000 a month. The highest amount of income earned was E80 000 per month and the lowest was E16. The following table shows respondents and their income range.

Table 7: Respondents' income per month

<b>Amount</b>	<b>Number</b>	<b>Percentage (%)</b>
<b>Less than E100 a month</b>	17	1.4
E100 – E500	244	19.8
E501 – E1000	126	10.2
E1001 – E5 000	245	19.9
E5001 – E10 000	47	3.8
E10 001 – E20 000	17	1.4
E20 000 +	3	0.2
None	460	37.3
Not indicated	74	6
<b>Total</b>	<b>1233</b>	<b>100</b>

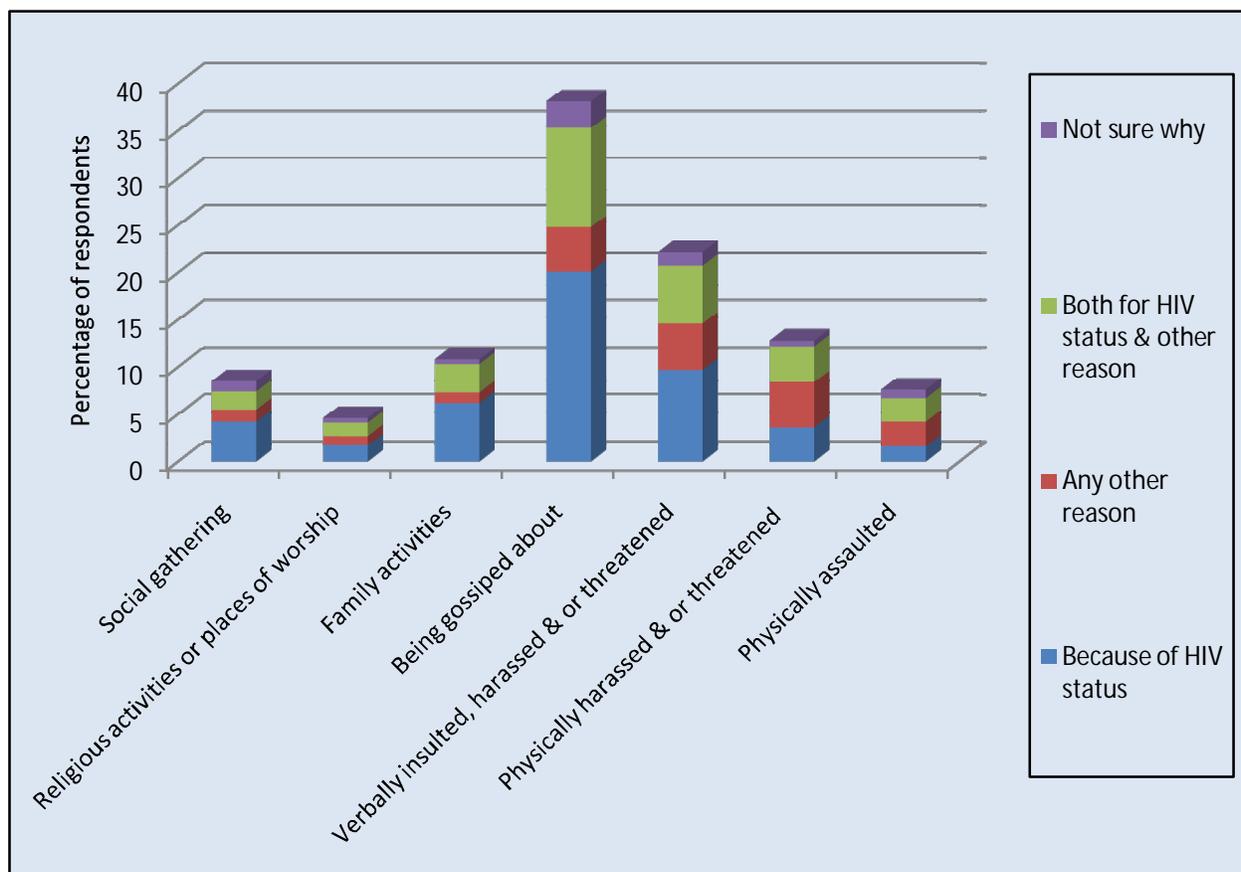
\*\$1 is equivalent to about seven Emalangeni (E7)

Respondents stated that in the past month for an average of 15 days there were members of their household that went without food because they did not have food or money to buy it.

### 3.2 Experiences of stigma and discrimination from other people

Respondents were requested to share their experiences of stigma that occurred in the year before the assessment. Their responses are shown in the following figure.

Figure 5: Respondents who experience stigma from other people



There were 8.6% who had experienced being excluded from social gatherings or activities such as weddings, funerals or parties. For 2.4% of the respondents this had occurred only once, for 3.6% this had occurred a few times and for 2.6% this had occurred often. There were 4.2% of the respondents who experienced exclusion from social gatherings who were certain that this was because of their HIV status. 1.3% said they were excluded for other reasons while 1.9% stated that it was for both their HIV status and other reasons and 1.1% were not sure why they were excluded. It is worth noting that the 68% of the respondents who experienced being excluded from social gatherings were from the rural areas, 29% from small towns and only 3% were from the cities.

Only 4.5% stated that they had an experience of being excluded from religious activities or places of worship. There were 1.3% who said this had happened often, 2.4% said few times and 0.7% said this happened only once. About 1.7% of the respondents explained that they were certain that this was because of their HIV status, 1.0% said this was for other reasons, 1.4% said it was because of their HIV status and other reasons and 0.5% were not sure why they were excluded.

There were 6.3% of the respondents who had often experienced being excluded from family activities, 3.2% had experienced this a few times and 1.4% had experienced this only once. Of these 6.2% were certain that this was because of their HIV status, 1.1% stated they were excluded for other reasons, 3.0% stated that they were excluded for both their HIV status and other reasons and 0.5% were not sure why they were excluded.

In as far as being aware of being gossiped about there were 13.7% of the respondents who stated this happened often, 18.1% said it happened a few times and 6.8% said it happened only once as shown below.

Table 8: Number of times being excluded from social activities

<b>How often have you been aware of being gossiped about?</b>	<b>Number of respondents</b>	<b>Percentage (%)</b>
Never	757	61.4
Once	84	6.8
A few times	223	18.1
Often	169	13.7
<b>Total</b>	<b>1233</b>	<b>100</b>

There were 20.1% respondents who were certain that they were gossiped about because of their HIV status, 4.7% said it was for other reasons, 10.5% said it was for both their HIV status and other reasons, 2.8% did not know why they were excluded.

While 77.9% of the respondents had never been verbally insulted, harassed and or threatened, there were 22.1% who had experience. About 8% of them had experienced this often, 9.2% had experienced this few times and 4.9% had experienced this only once. There were 9.7% of the respondents who were certain this was because of their HIV status, 4.9% said it was for other reasons, 6.1% said it was because of their HIV status and other reasons; 1.5% were not sure why they were treated this way.

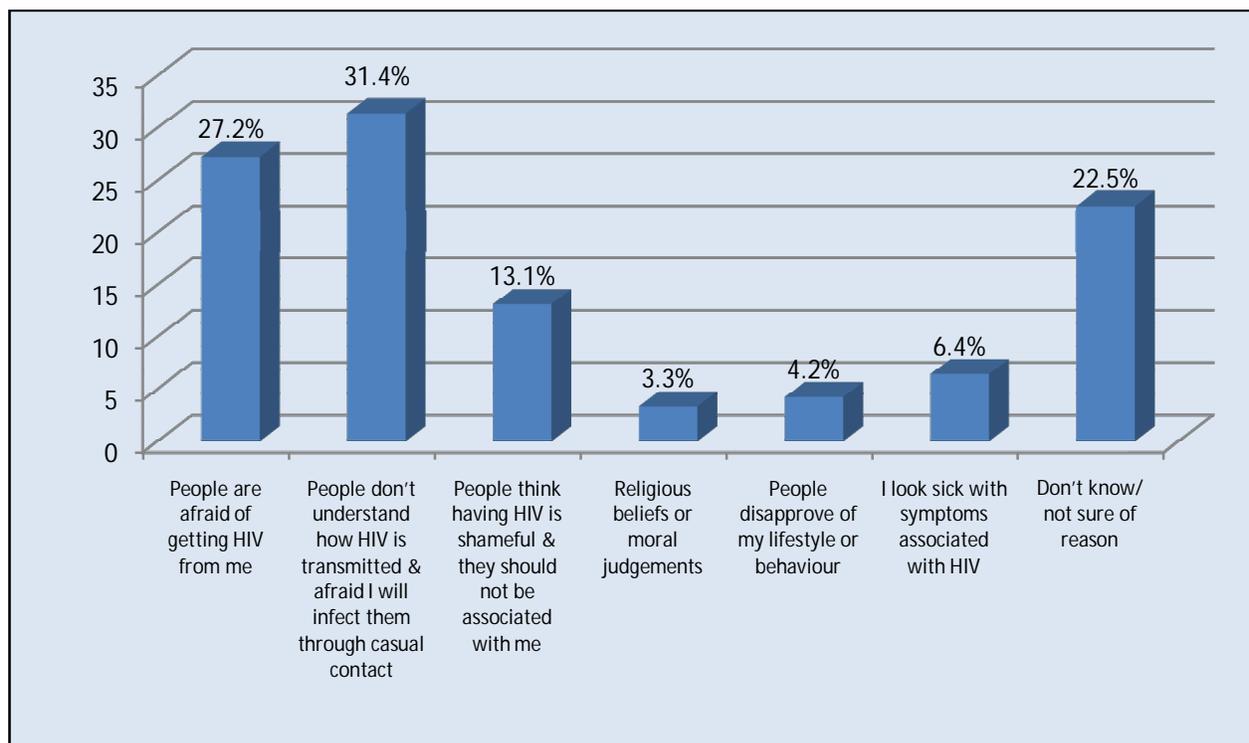
There were 12.8% of the respondents who had experienced being physically harassed and or threatened. There were 2.9% who experienced this often, 3.8% experienced this a few times and 6.1% experienced this only once. There were only 3.6% respondents who were certain this was because of their HIV status, 4.8% said this was for other reasons, 3.8% said they were physically harassed and or threatened because of both other reasons and their HIV status.

There were 7.7% of the respondents who had experienced being physically assaulted. About 1.1% said they experienced this often, 1.9% said they experienced this few times and 4.7% said this occurred only once. There were 1.6% of the respondents who had experienced physical assault who were certain that this was because of their HIV status, 2.6% said this was for other reasons, 2.5% said it was because of both their HIV status and other reasons, 0.9% were not sure why they were physically assaulted. With regards to who assaulted them 2.6% stated they were assaulted by their spouse or partner, 2.4% were assaulted by another member of the household, 1.5% stated that they were assaulted by persons outside the household know to them and 0.6% were assaulted by an unknown person.

It appeared that the stigma and discrimination by others was experienced by respondents from all age groups, gender, location, levels of education and marital status (see annex 5).

Respondents who had experienced some form of HIV related stigma and or discrimination in the last 12 months indicated reasons why they think it happened. These are shown in the following figure.

Figure 6: Reasons why respondents were stigmatized



Ignorance about transmission was the main cause of stigma and discrimination as 57.4% of the respondents indicated that they thought people were afraid they would get the infection from them as shown above. This was followed by 13.1% of the respondents who felt they were stigmatised because people think having HIV is shameful and so they should not associate with one infected with HIV, 6.4% felt that they were stigmatized because they look sick with symptoms and 4.2% stated that this was because people disapprove of their lifestyle. There were 22.5% who stated that they did not know nor were not sure why they were stigmatized and discriminated.

### 3.3 Stigma and discrimination in relationships

Respondents were requested to indicate their experiences of stigma and discrimination in relationships in the last twelve months.

About 8% of the respondents indicated that they had been subjected to psychological pressure or manipulation by their spouses or partners in which their HIV status was used against them. About 3.3% said this happened once, 2.8% said a few times and 1.9% said this happened often. There were 8.1% of the respondents who had experienced sexual rejection because of their HIV status, 1.6% experienced this once, 3.6% experienced this a few times and 2.9% often.

There were 20% of the respondents who indicated that they have the experience of their spouse or partner, members of their household who were discriminated because of the respondent's positive HIV status. About 14.3% said they experienced this only once, 2.5% said few times and 3.2% said this happens often.

### 3.4 Stigma and discrimination by other PLHIV

There were 5.5% of the respondents who stated that they had experienced discrimination by other PLHIV. About 2.6% said they experienced this once, 1.6% said few times and 1.3% said they often experienced this.

### 3.5 Access to Work, Health and Education services

A majority of respondents (91.8%) had never been forced to change their place of residence or been unable to rent accommodation. However there were 5.4% who had experienced this once, 1.6% who experienced this few times and 1.2% who experienced this often as shown in the following table.

Table 9: Change of residence or unable to rent accommodation

	Number of respondents	Percentage
Never	1132	91.8
Once	66	5.4
A few times	20	1.6
Often	15	1.2
<b>Total</b>	1233	100.0

About 2.6% of the respondents felt they were forced to change their residence or unable to rent accommodation because of their HIV status, 3.6% stated it was because of other reasons, 1.5% stated it was because of other reasons and their HIV status, 0.7% were not sure why it occurred.

There were 4.6% respondents who had experienced losing a job or another source of income. About 1.8% experienced this once, 2.2% few times and 0.6% experienced this often. Only 1.1% were certain that this happened because of their HIV status, for 2.5% of the respondents this was for other reasons, for 0.6% this was for both other reasons and their HIV status, and 1% were not sure why this happened. Among the respondents who lost their job or income because of HIV 0.6% stated that they were actually discriminated by their employer or coworkers, 1.3% said they felt obliged to stop working due to poor health, 0.3% said it was because of both the discrimination and poor health and 2.1% said it was because of another reason.

There were 2.8% of the respondents who alluded to having experienced being refused employment or a work opportunity because of their HIV status. There were also 2.3% of the respondents who had their job description or nature of their work changed or were refused promotion as a result of their job description. For 1.9% of the respondents this happened only once, for 0.3% it happened a few times and for 0.1% if happened often. About 0.8% of the respondents felt that this happened because of discrimination by their employer or co-workers, for 0.6% it was because of ill-health, for 0.4% this happened because of both their poor health and discrimination and for 0.4% said it was because of other reasons.

A majority of 89% respondents stated they had never been dismissed, suspended or prevented from attending an educational institution because of their HIV status, 1.1% said they were once refused such opportunities, 0.2% said it happened a few times, with 0.6% said it happened often as shown in the following table.

Table 10: Access to educational institution

	<b>Number of respondents</b>	<b>Percentage</b>
Never	1097	89.0
Once	13	1.1
A few times	3	.2
Often	8	.6
Not applicable	112	9.1
<b>Total</b>	<b>1233</b>	<b>100.0</b>

A total of 94.9% respondents said their children had never been dismissed, suspended or prevented from attending an educational institution because of their HIV status while 0.8% said it happened once, 0.1% said a few times, 0.6% said often. This is shown in the following table:

Table 11: Access to education by children

	<b>Number of respondents</b>	<b>Percentage (%)</b>
Never	1170	94.9
Once	10	0.8
A few times	1	0.1
Often	7	0.6
Not applicable	45	3.6
<b>Total</b>	<b>1233</b>	<b>100.0</b>

A few people were denied dental care because of their HIV status with 4.1% saying they were denied once, 0.2% saying a few times, 0.1% saying often as shown in the following table:

Table 12: Denied dental care services

	<b>Number of respondents</b>	<b>Percentage</b>
Never	1161	94.2
Once	51	4.1
A few times	3	0.2
Often	1	0.1
Not applicable	17	1.4
<b>Total</b>	<b>1233</b>	<b>100.0</b>

Family planning services were available and free in most health centres in the country including clinics but 1.1% of the respondents said they were denied those services because of their HIV status as shown below.

Table 13: Respondents who were denied access to health care services

	Family planning		SRH services	
	Number of respondents	Percentage	Number of respondents	Percentage
Yes	13	1.1	46	3.7
No	800	64.9	1186	96.2
Not applicable	420	34.1	1	0.1
<b>Total</b>	1233	100.0	1233	100

There were 3.7% of the respondents who stated they were denied SRH services because of their HIV status.

### 3.6 Internal Stigma and Fears

Respondents were requested to identify feelings they had experienced because of their HIV status and their responses are shown in the following table.

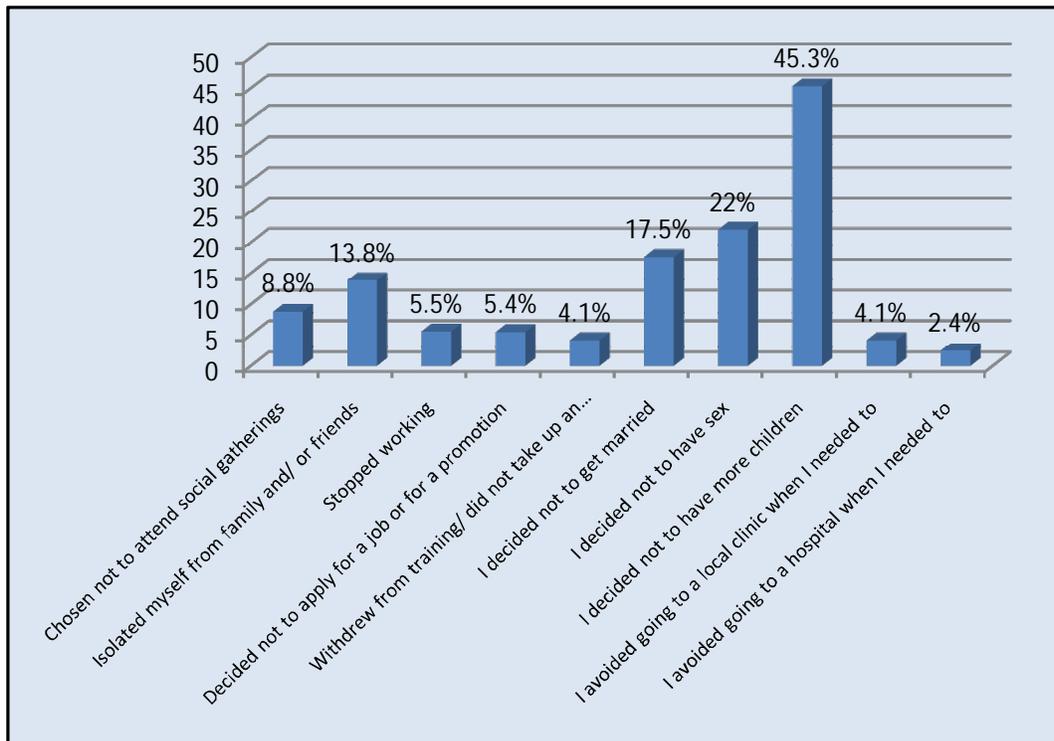
Table 14: Feelings because of HIV status

	Number		Percentage	
	Males	Females	Males	Females
I feel ashamed	76	219	6.2	17.8
I feel guilty	49	165	4	13.4
I blame myself	102	219	8.3	17.8
I blame others	84	299	6.8	24.2
I have low self-esteem	87	217	7.1	17.6
I feel I should be punished	24	47	1.9	3.8
I feel suicidal	29	59	2.4	4.8

Respondents had these feelings which showed they suffered internal stigma. There were 31.1% who stated they blame others, 26% alluded to blaming themselves, 24.7% who pointed they had low self esteem, 23.9% feel ashamed, 17.4% who felt guilty and even 7.1% who pointed out they felt like committing suicide.

Respondents were also requested to indicate things they had done because of their HIV status and their responses are shown in the following chart.

Figure 7: Things done because of HIV status

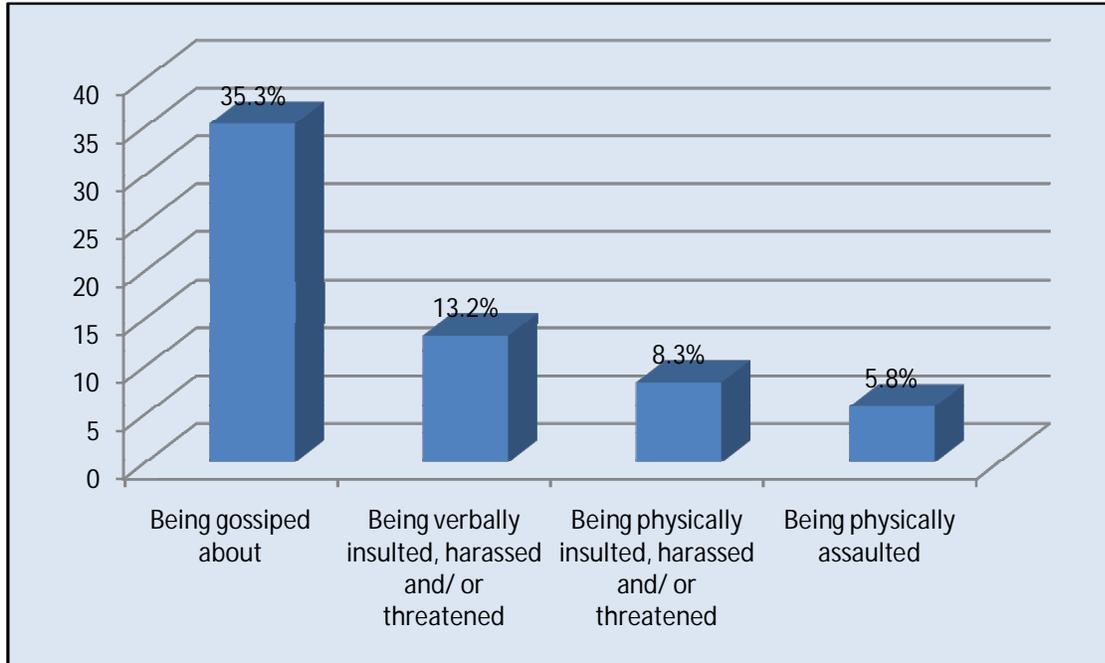


There were 45.3% of the respondents who stated that they decided not to have more children because of their HIV status, 22% decided not to have sex and 17.5% decided not to get married. There were 13.8% who alluded to having isolated themselves from their families and friends, 8.8% decided not to attend social gatherings and 5.5% took a decision to stop working. There were also 5.4% who decided not to apply for a job or for a promotion, 4.1% withdrew from training or did not take up an opportunity for training, 4.1% avoided going to a local clinic when they needed to and 2.4% avoided going to a hospital when they needed to.

### 3.7 Fears

Respondents also shared fears they had related to living with HIV as shown in the following chart:

Figure 8: Fear of things happening to you



There were 35.3% of the respondents who feared being gossiped about, 13.2% feared being verbally insulted, harassed or threatened, 8.3% feared being physically harassed or threatened and 5.8% feared being physically assaulted.

Over 20.3% of the respondents feared that because of their HIV status people would not want to be sexually intimate with them.

### 3.8 Rights, Laws and Policies

#### 3.8.1 Policies

There were more respondents who had not heard about the Act on HIV and AIDS than those who had heard about it as shown in the following table.

Table 15: Knowledge of the HIV and AIDS Act

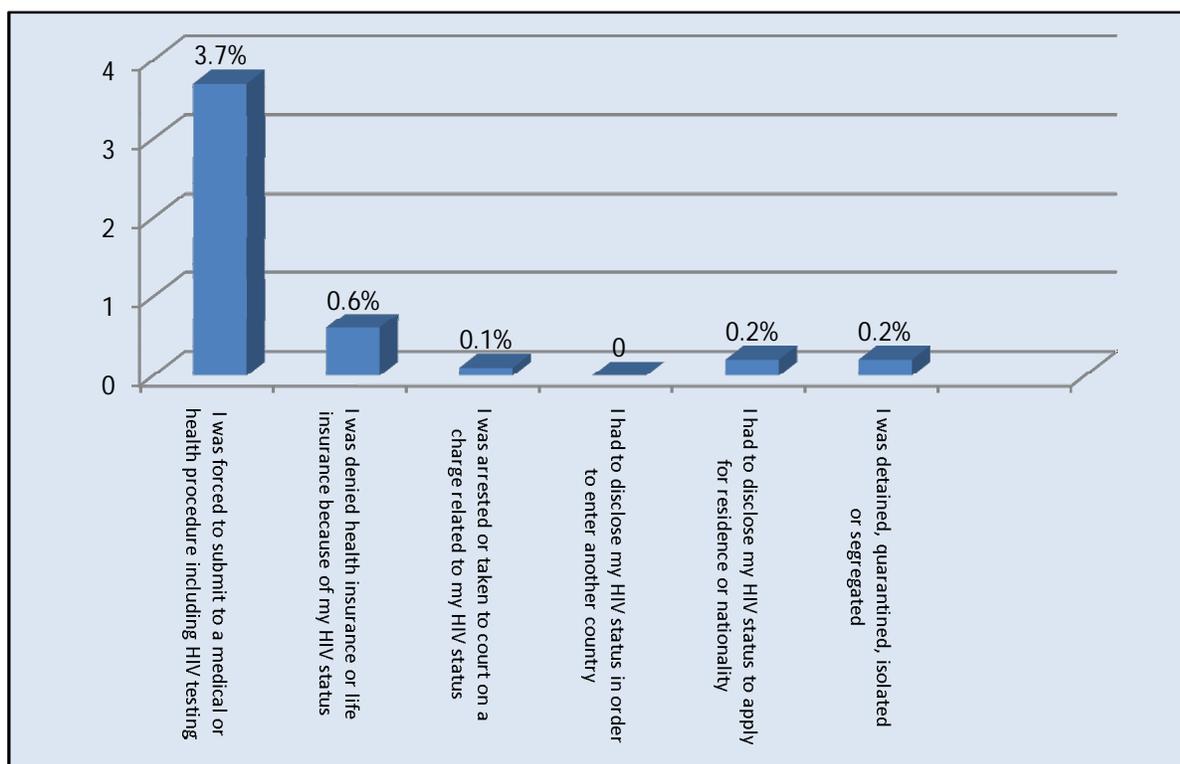
	Number of respondents	Percentage
Yes	509	41.3
No	724	58.7
Total	1233	100

There were 58.7% who had never heard about the Act on HIV and AIDS. Out of those who had heard about it 54.8% had read or discussed the content of the Act.

### 3.8.2 Rights

Respondents were requested to indicate if their rights had been compromised in the past twelve months because of their HIV status and their responses are shown in the following chart.

Figure 9: Percentage respondents who had their rights compromised



It appeared that people were still being forced to test for HIV as there were 3.7% of the respondents who had been forced to submit to a medical or health procedure including an HIV test. Furthermore there were 12.8% of the respondents who stated that their rights had been abused as shown in the following table.

Table 16: Percentage respondents who had their rights abused

	<b>Number</b>	<b>Percentage (%)</b>
Yes	158	12.8
No	834	67.6
Not sure	241	19.5
<b>Total</b>	<b>1233</b>	<b>100.0</b>

Only 3.9% said they tried legal redress for the abuse of their rights. The reasons given for not seeking legal redress were as shown below:

Table 17: Reasons for not trying to get legal redress

<b>Reasons</b>	<b>Frequency</b>	<b>Percentage (%)</b>
Insufficient financial resources to take action	19	1.5
Process of addressing problem appeared too bureaucratic	3	.2
Felt intimidated or scared to take action	20	1.6
Advised against taking action by someone	8	.6
No or little confidence that the outcome will be successful	14	1.1
None of the above	94	7.6
<b>Total</b>	<b>158</b>	<b>12.8</b>

Out of the 12.8% respondents who said their rights were abused 12.6% had tried to get a government employee to take action against the abuse of their rights as people living with HIV and 87.3% did nothing.

Only 1.8% of the respondents tried to get a local politician to take against an abuse of their rights as PLHIV in the last twelve months. The matter was then resolved for 0.6% of the respondents and it was still pending for 0.4% of the respondents. There were 1.1% who stated that nothing happened despite the fact that they tried to get a local politician to take action.

### 3.9 Effecting change

A total number of 28% respondents had confronted, challenged or educated someone who was stigmatizing and/ or discriminating against them.

Table 18: Percentage respondents who confronted, challenged or educated someone who was stigmatizing

	<b>Frequency</b>	<b>Percentage</b>
Yes	345	28.0
No	888	72.0
<b>Total</b>	1233	100.0

Over 56.7% of the respondents stated they knew of an organization or group that they could go to for help if they experienced stigma or discrimination. The organizations they knew were as follows:

Table 19: Known organizations of support

Organizations	Percentage (%)
People living with HIV support group	47.2
Network of people living with HIV	32.9
Local NGO	14.8
Faith based organization	7.2
A legal practice	2.5
A human rights organization	7.8
National NGO	4.7
National AIDS Council or committee	4.5
International NGO	1.8
UN organization	4.2
Other	3.2

Support groups were the mostly known organizations followed by the network of PLHIV, local NGO and FBO. The least known were international NGO and legal practices.

About 10.9% of the respondents alluded to have sought help from the above mentioned organizations.

### 3.10 Issues of stigma and discrimination that respondents experienced

There were numerous instances of stigma and discrimination that respondents faced and dealt with. They frequently had the help of others. The following were the the issues that some respondents faced:

- One stated that the issue was the perception that “she brought HIV to the family.”
- Abuse by a boyfriend

- A sick child with Herpes Zoster
- Being excluded from a funeral of a relative because of HIV status
- Family members tried to take my home after my husband died
- Neighbours took over fields since the woman was widowed and sick and as such unable to plough.
- "...I was looking malnourished and everyone suspected I was HIV positive."
- "...I was sickly and people started talking badly about me being HIV positive."
- A local clinic refused to give one a file in order to be transferred to another clinic.
- "...family refused to eat food I cooked because I am HIV positive."
- "...my wife used to told me I have AIDS and that I should die alone and so I left her."
- "...my status was disclosed in my presence without my consent."
- Suspecting that people were being told of my HIV status
- "...they insulted me about my HIV status."
- "...they said I'm gay and HIV came with me."

PLHIV received help from family, friends, community leaders, NGO, organizations of PLHIV and from the National AIDS Council. The following were identified by respondents:

- Husbands
- Wives
- Brothers and sisters
- Community leadership in chiefdoms
- SASO
- Red Cross councillors in the community
- SWANNEPHA
- Lawyer
- AMICAALL
- World Vision

One respondent actually got services of a lawyer to deal with stigma and discrimination whilst those assisted by family members stated that these family members facilitated

extended family members' meetings where clarification of what it means to be HIV positive. Still others facilitated community meetings where NGO conducted educational awareness campaigns, started support groups and community leaders mediated in restoration of property for PLHIV.

### 3.11 Supporting other PLHIV

There were 65.7% of respondents who said they have supported other PLHIV in the last 12 months. The following table shows the types of support respondents provided.

Table 20: Types of support provided to other PLHIV

Type of support	Percentage (%)
Emotional support	55.3
Physical support	14.4
Referral to other services	19.7

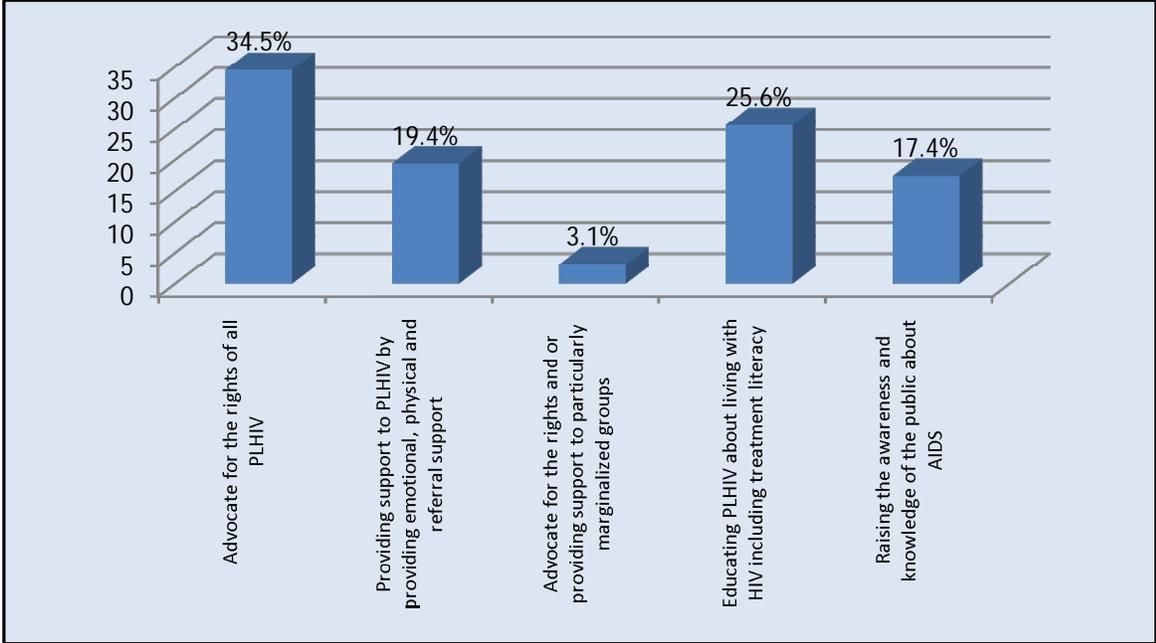
About 44% of the respondents were members of a PLHIV support group or network but only 19.9% had been involved either as a volunteer or an employee in a programme or project that provides assistance to PLHIV. Only 11.5% had been involved in efforts to develop legislation, policies or guidelines related to HIV. With regards to power to influence decisions the respondents responses were as follows:

Table 21: Power to influence decisions

	Percentage (%)
Legal/ rights matters affecting people living with HIV	37.1
Local government policies affecting PLHIV	20.2
Local projects intended to benefit PLHIV	33.4
National government policies affecting PLHIV	10.6
National programmes/ projects intended to benefit PLHIV	10.0
International agreements/ treaties	3.2
None of these things	38.4

Respondents were requested to identify one important thing that can be done to address stigma and discrimination by SWANNEPHA and the following were their responses.

Figure 10: Respondents choice of priority intervention



There were 34.5% of the respondents who identified advocating for the rights of all PLHIV as the important thing that needs to be done. This was followed by educating PLHIV about living with HIV including treatment literacy which was identified by 25.6% of the respondents, then provision of support to PLHIV by providing emotional, physical and referral support which was identified by 19.4% of the respondents.

**3.12 Testing/ Diagnosis**

Respondents were requested to indicate the reasons why they were tested for HIV. The following table shows their responses.

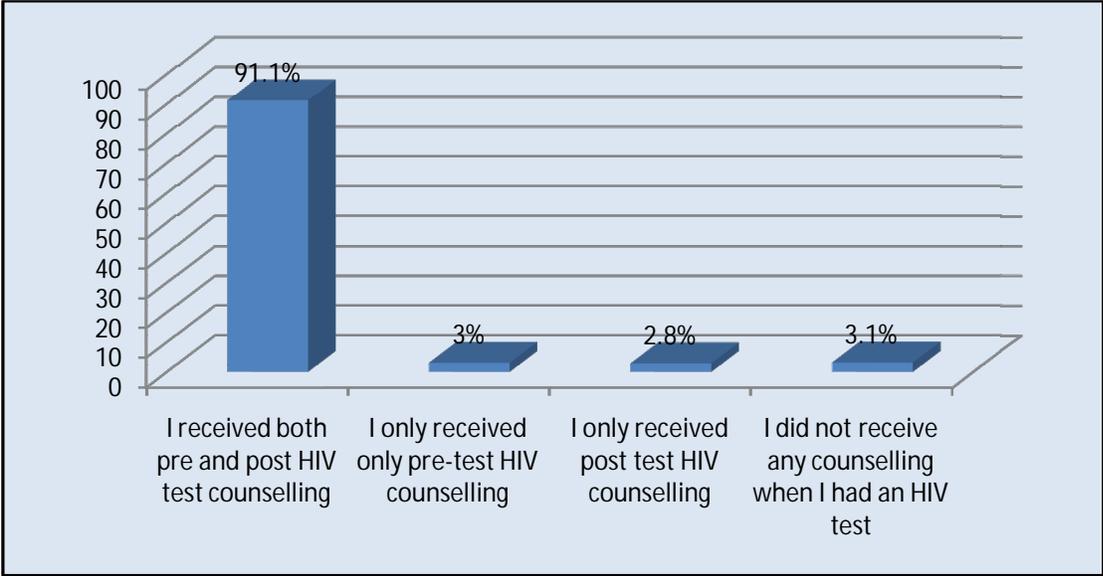
Table 22: Reasons respondents tested for HIV

Reasons	Percentage
Employment	1.8
Pregnancy	14.1
To prepare for a marriage/sexual relationship	0.8
Referred by a clinic for STI	2.8
Referred for suspected HIV related symptoms	13.5
Husband/ wife/ partner/ family member tested positive	4.5
Illness or the death of husband/ wife/ partner/ family member	24
I just wanted to know	41.3
Other	11.2

It appeared that the most common reason for testing among the respondents was a desire to know their HIV status followed by illness or the death of husband/ wife/ partner/ family member, pregnancy, then referral for suspected HIV related symptoms. The decision to test for HIV was voluntary for 83.7% while 11.4% pointed out that they took the decision to test under pressure from others, 4.2% were coerced and 0.7% pointed out that they were tested without their knowledge and only found out after the test had been done.

While a majority of respondents received both pretest and posttest counselling, there were respondents who did not receive counselling at all as shown in the following chart.

Figure 11: Counselling received by respondents



### 3.13 Disclosure and Confidentiality

Table 23: Disclosure of HIV status to these people or groups

Person/ group	I told them	Someone told them with my consent	Someone told them without my consent	They don't know my HIV status	Not applicable
Your husband/ wife/partner	75.8	2.2	1.5	5.6	14.9
Other adult family members	69.7	7.7	4.3	12.8	5.4
Children in your family	58.0	4.0	3.5	29.0	5.5
Your friends/ neighbours	53.9	2.3	8.1	29.9	5.8
Other people living with HIV	68.9	1.5	3.2	17.4	8.8
People who you work with (your co-workers)	20.0	1.2	1.5	18.2	59.0
Your employer/ boss/ your clients	16.0	1.1	1.1	15.7	66.2
Injecting drug partners	2.7	0.2	0.6	7.9	88.6
Religious leaders	20.4	5.3	1.5	34.5	38.4
Community leaders	22.4	1.9	2.0	38.5	35.2
Health care workers	71.8	1.4	2.1	12.7	12.0
Social workers/counsellors	59.7	1.4	2.3	16.6	20.0
Teachers	5.1	0.2	0.7	40.4	53.5
Government officials	3.4	0.2	0.2	35.2	60.9
The media	1.1	0.2	0.2	35.6	62.9

A majority of 75.8% of the respondents disclosed their HIV to their spouses or partners themselves, for 2.2% of the respondents they were told by someone else with the consent of the respondents, for 1.5% they were told without their consent and for 5.6%

the spouses or partners did not know their HIV status. Furthermore other adult family members were mainly told by the respondents themselves, for 7.7% of the respondents they were told with the consent of the respondent, for 4.3% they were told without consent and for 12.8% they did not know. Over 58% of the children in their families were told by the respondents themselves which was also the case for other PLHIV where a majority of 68.9% was told by the respondents themselves. A majority (71.8%) of respondents told the health care workers of their HIV status. There were instances where people were told the HIV status of respondents without consent. This was the case for 8.1% of the respondents who indicated that their friends and neighbours were told without their consent, 4.3% indicated that other adult family members were told without their consent.

Respondents indicated that they were sometimes pressured to disclose their HIV status as shown below.

Table 24: Whether respondents were pressured to disclose HIV status

	PLHIV and groups/ networks of PLHIV		Other people not living with HIV	
	Number of respondents	Percentage	Number of respondents	Percentage
Often	86	7	149	12.1
A few times	79	6.4	91	7.4
Once	41	3.3	48	3.9
Never	1027	83.3	945	76.6

There were 23.4% of the respondents who felt pressure to disclose their HIV status from other individuals not living with HIV such as family members, social workers, NGOs. About 12.1% stated that the pressure was often, 7.4% said it was a few times and 3.9% said it was only once. Respondents who felt pressure to disclose their HIV status from PLHIV, groups and networks of PLHIV were 16.7%.

Respondents were requested to indicate if a health care worker ever told other people about their HIV status without their consent. The following table shows their responses.

Table 25: Respondents where health worker told other people

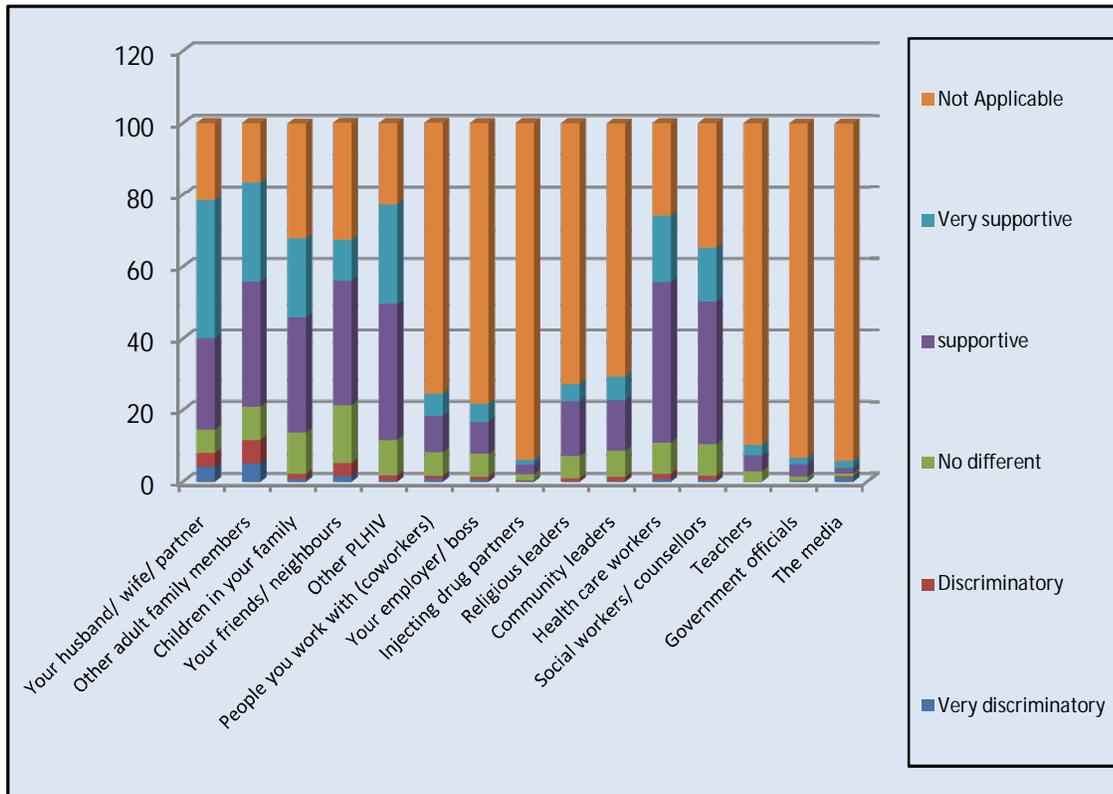
	<b>Number</b>	<b>Percentage (%)</b>
Yes	61	4.9
No	959	77.8
Not sure	213	17.3

There were 4.9% of the respondents who stated that a health care worker such as a doctor, nurse, counsellor, laboratory technician told other people about their HIV status without their consent.

There were 9.3% of the respondents who stated that their medical records relating to their HIV status were not being kept confidential, 26.6% said they did not know and 64.1% said they were sure their records were kept confidential.

Respondents were also requested to describe the reactions of different people when they first knew about their HIV status. The following chart shows their responses.

Figure 12: Reactions of different people on hearing respondents' HIV status



Other adult family members were identified by 4.8% of the respondents as very discriminatory in their reaction when they first knew about the respondents HIV status. They were followed by spouses or partners who were identified by 4% of the respondents as very discriminatory. Other adult family members were identified as discriminatory by 6.8% of the respondents, followed by spouse or partner who were identified by 4.1% as discriminatory, then friends and neighbours were identified by 3.5% as discriminatory.

A majority of 82.1% found the disclosure of their HIV status an empowering experience.

### 3.14 Treatment

The respondents of this study described their health status as shown in the following table.

Table 26: Respondents' health status

Health state	Number	Percentage (%)
Excellent	404	32.8
Very good	331	26.8
Good	306	24.8
Fair	159	12.9
Poor	33	2.7

Only 2.7% characterized their health as poor, 32.8% stated that it was excellent, 26.8% as very good, 24.8% as good and 12.9% as fair.

About 76.1% were on antiretroviral treatment. There were 92.5% who stated that they have access to ART which included even those who were not on treatment. Only 43% were taking medication to prevent or treat opportunistic infections and 66.3% said they have access to medication for opportunistic infections. There were 10.1% who said they did not know if medication for opportunistic infections was accessible and 23.5% said they did not have access to this medication.

In as far as having a constructive discussion with a health care professional on the subject of your HIV related treatment options, 59.3% stated they had these discussions while 40.7% did not. On having constructive discussion with health care professionals on other subjects such as your sexual and reproductive health, sexual relationships, emotional well being, drug use there were 55.6% who said they had these discussions and 44.4% did not.

### 3.15 Having children

Respondents were asked to give information about their reproductive health and activities and their responses are shown in the following table.

Table 27: Respondents' SRH information

	Yes (%)	No	Don't know	Not applicable
Do you have children	86.4	13.6	-	-
Are any of the children known to be HIV positive	15.3	84.7	-	-
Since being diagnosed as HIV positive, have you ever received counselling about your reproductive options	52.2	39.8	-	7.9
Has a health care professional ever advised you not to have a child since you were diagnosed as HIV positive	12.2	81.0	-	6.8
Has a health care professional ever coerced you into being sterilized since you were diagnosed as HIV positive	3.0	90.2	-	6.5
Is your ability to obtain antiretroviral treatment conditional on the use of certain forms of contraception	5.8	62.8	10.4	20.5
Have you been coerced by a health care professional to do termination of pregnancy because of your HIV status	1.0	75.3	-	23.4
Have you been coerced by a health care professional in relation to a method of giving birth because of you HIV status?	10.2	64.7	-	24.8
Have you been coerced by a health care professional in relation to infant feeding practices because of you HIV status?	17.3	57.9	-	24.6

There were 86.4% of the respondents who had children and 15.3% of the respondents stated that they have children who were known to be HIV positive. Only 52.2% of the respondents had received counselling about their reproductive options since being diagnosed as HIV positive, 39.8% said they did not receive such a service. About 12.2% were advised by a health care professional not to have a child since they were diagnosed as HIV positive and 3% were coerced into being sterilized. There were 5.8% who stated that their ability to obtain antiretroviral treatment was conditional on the use of certain forms of contraception, 1% of the respondents had an experience of being coerced by a health care professional to do termination of pregnancy because of your HIV status and 10.2% experienced being coerced by a health care professional in

relation to a method of giving birth because of their HIV status and 17.3% were also coerced with regards to infant feeding practices.

## **4. Discussions**

### **4.1 Demographics**

The majority (65.3%) of respondents was sexually active and this was the case for both males and females. This shows the importance of positive prevention and need for continuing with raising awareness on issues of SRH with regards to stigma and discrimination. Furthermore there were 15.8% of the respondents who did not have formal education. This important to note for effective targeting in developing programmes targeting PLHIV. Over 53% of the respondents were unemployed. This is indicative of poverty which in itself increases vulnerability to stigma and discrimination. In the DHS (2006) only 38.1% of the PLHIV were employed.

### **4.2 Experiences of stigma and discrimination from other people**

The leading experience of stigma and discrimination from other people that respondents experienced was being aware of being gossiped about which was followed by being verbally insulted, harassed and or threatened and then being physically harassed and threatened. There were significant percentages of respondents who experienced exclusion from families, exclusion from social gatherings and even being physically assaulted.

Stigma and discrimination happens in relationships whereby PLHIV are subjected to psychological pressures, sexual rejection and discrimination by spouses or partners and other members of their households.

Stigma still occurs because people think transmission will occur with casual contact which indicates that there is still need to increase awareness.

PLHIV are stigmatized in the workplace and because they do not know their rights this will keep happening.

There were indications that some PLHIV were denied dental, family planning and sexual reproductive health services. Everyone has a right to such services regardless of their HIV status.

There were respondents who were tested without receiving pretest and post test counselling. This is against HIV testing and counselling guidelines of the country which require that people receive both pretest and post test counselling. There were also instances in disclosure where PLHIV HIV status was disclosed without their consent.

Information on HIV treatment options was not readily available as well as discussions on sexual reproductive health and emotional wellbeing.

PLHIV experience stigma and discrimination from other PLHIV.

#### **4.3 Internal stigma and fears**

In addition to perceived stigma and discrimination where high percentages of respondents indicated they were gossiped about there were very high percentages who indicated they felt negative emotions including suicide. Respondents showed that they went on to make decisions such as not getting married and excluding themselves from social gatherings.

#### **4.4 Testing and diagnosis**

The most common reason for testing for HIV was self initiated because people wanted to know their HIV status. This important to note since it also gives a direction in terms of access to testing centres. Community testing seems to be needed as the majority is testing when they are still healthy.

#### **4.5 Disclosure**

It was very common for PLHIV to disclose to others and this included spouses, family members and children as well as employers. This important in terms of support required for disclosure especially for children as when their parents disclose to them they also face the fact that they may also be infected.

## **5. Conclusions**

The most commonly experienced stigma and discrimination among PLHIV was internal and perceived compared to stigma by others.

It appeared that there is stigma and discrimination by other people in the community and it affects PLHIV of all ages, sex, rural and urban locations.

Interventions are needed to empower PLHIV to deal with stigma and discrimination as individuals as well as groups.

There are still important gaps in knowledge on HIV and AIDS particularly on HIV transmission which makes it difficult for individuals to be supportive to PLHIV.

The policy on HIV and AIDS that protects the rights of people living with HIV needs to be provided or discussed with them as most of them did not know about it.

The importance of HIV testing while people are healthy should be encouraged as most people tested because they were sick.

## 6. Recommendations

- There is a need to improve the quantity and quality of counselling services and strengthening of positive living.
- Establish support centres for counselling of PLHIV who experience stigma and discrimination.
- Increase the scope and impact of HIV and AIDS awareness campaigns to reach all communities with information on rights of PLHIV as well as increased knowledge and understanding of transmission, treatment and support processes versus the importance of wellness of the PLHIV.
- Develop an intervention to support disclosure to children since they deal with parents' HIV status and frequently their own.
- Since there is high level of unemployment among PLHIV it is important to develop programmes for economic empowerment to enhance success in dealing with stigma and discrimination.
- Strengthen the curriculum of support groups to include life skills such as assertiveness to equip individual PLHIV to deal with stigma and discrimination and to enable them to support each other in support groups.
- A specific campaign on human rights of PLHIV should be implemented in both rural and urban areas.
- Evaluate the need for legislation to protect the rights of PLHIV.
- Put in place a call centre (toll free line) for PLHIV to call when denied essential services such as health services.
- Compile regional directories detailing where support services can be obtained to prevent suicide, depression and other negative feelings.
- Conduct a sensitization campaign on available legislation and guidelines.
- Package information on SRH and treatment options and distribute these widely throughout the country to enable people to obtain such information easily. (Development of IEC materials (pamphlets)).
- Develop a mass media programme targeting couples and families as well as males with messages of reducing stigma in relationships.
- Renew emphasis of provision of ongoing counselling

- Encourage VCT and community testing because individuals test because they want to know their HIV status
- Conduct a study among adolescents living with HIV to compares experiences of stigma and discrimination with adults

## Annex 1: Sampled Sites

No.	Hhohho region
1.	Dvokolwako Health centre
2.	Horo Clinic
3.	Lobamba Clinic
4.	Mbabane Government Hospital
5.	Piggs Peak Government Hospital
Manzini region	
6.	FLAS- Manzini
7.	King Sobhuza II Clinic
8.	Ludzeludze
9.	Luyengo Clinic
10.	Mankayane Government Hospital
11.	RFM Hospital
12.	Sigombeni Clinic
Lubomo region	
13.	Vuvulane Clinic
14.	Lubulini Clinic
15.	Good Shepherd Hospital
16.	Sithobel Health Centre
17.	Siphofaneni Clinic
18.	Mpolonjeni Clinic
19.	Tikhuba
Shiselweni region	
20.	Hlatikhulu Government Hospital
21.	Mtsanjeni Health Centre
22.	Nhlangano health Centre
23.	Somntongo
24.	NATTIC Clinic
25.	Gege Clinic

## **Annex 2: Information sheet**

### **THE PEOPLE LIVING WITH HIV STIGMA INDEX INFORMATION SHEET**

Note to interviewers: this information sheet is designed for the interviewees to take away as a summary of the project if they are interested. Take some spare copies with you to the interview. However it is best not to read through the whole information sheet in the interview itself, as much of this information is covered in other parts of the interview process (for example in the informed consent form).

The SWANNEPHA and partners is conducting a stigma index that will describe experiences of stigma and discrimination among PLHIV. To obtain information for this we request your participation by giving an interview on your experiences. Each questionnaire that is administered forms part of a larger survey conducted in a country that aims to document the extent of stigma and discrimination experienced by people living with HIV in Swaziland. The questionnaire, together with the idea of conducting such a survey, has been adapted from that which was developed by the Global Network of People Living with HIV (GNP+) and the International Community of Women Living with HIV/AIDS (ICW), with financial and management support from the International Planned Parenthood Federation (IPPF) and the Joint United Nations Programme on HIV/AIDS (UNAIDS).

### **THE PURPOSE AND NATURE OF THE PEOPLE LIVING WITH HIV STIGMA INDEX SURVEY**

The People Living with HIV Stigma Index survey was created to find out more about the experiences of people living with HIV, especially experiences of stigma or discrimination. There are a number of organizations campaigning against stigma and discrimination and fighting for the human rights of people living with HIV. It is hoped that this survey will one day provide information that will help these efforts. In order to collect such information (i.e. on what HIV-positive people are experiencing, specifically in relation to stigma and discrimination), the questionnaires and survey will be administered and managed by Organizations or networks of people living with HIV in a country. The information that is collected from the questionnaires will then be put together and presented in a way that presents a general picture of the experiences of people living with HIV in that country. It is not information about individual experiences of stigma and/or discrimination. For example, in documenting the results of the survey, information will be presented in the report on "What percentage of people living with HIV experienced discrimination last year", as opposed to presenting information on your own, personal experiences of stigma and discrimination. Ultimately, the main aim of this project is to broaden the understanding of stigma and discrimination faced by people living with HIV in different countries, and to be able to find out if there have been changes over a period of time. The organizations involved in this project intend to use the information as a national and global advocacy tool to fight for the human rights for people living with HIV.

### **PROCEDURES AND PROCESSES INVOLVED IN PARTICIPATING**

I would like to make clear that your participation in this project is entirely voluntary. It is your choice whether to participate or not. If you choose to participate, you are also free to not answer any of the questions, and you can also decide to stop participating in the interview at any time that you wish. In terms of process, if you choose to participate in the survey, we will complete a questionnaire that asks you questions about your social environment, work, access to health services, knowledge about your rights, HIV testing and treatment. Please feel free to ask to see the questionnaire at this stage if you would like to take a more detailed look at the questions. If you participate in the survey, we will fill in the questionnaire together. You can write down the answers and I will help explain anything that is not clear to you. Or, if you prefer, I can fill it in for you while you sit beside me checking that I am ticking the right boxes and recording your responses correctly. We believe that stories sometimes help people better understand what other people experience. If you participate in the survey and at some point in

the interview you describe an experience that I would like to include in the survey report, I will stop and ask for your permission to do so. I may also request an additional interview with you in order to record your story and your experience so it can then be written up as a case study. You should always feel free to say no. If you tell me that I have your permission to include a particular experience you have had in the report, I will not use your name, and I will not include any personal information that would allow someone to identify you. The story will be completely anonymous. Lastly, before we begin to conduct an interview and administer the questionnaire, we need to obtain informed, signed consent from all potential survey participants. This ensures that all those agreeing to participate in the survey are voluntarily willing to participate and that they have obtained all the information they needed in order to make an informed choice about their participation.

#### CONFIDENTIALITY AND POTENTIAL RISKS OF PARTICIPATING IN THE SURVEY

This project is taking every possible step to ensure confidentiality, i.e. to prevent any personal information from being known to people outside the research team. We know that breaches of confidentiality could lead to problems for interviewees, so we have put in place measures to avoid this from happening. For example, we do not write the name of the interviewee (i.e. the person being interviewed who is providing us with information about their experiences of living with HIV) on the questionnaire, and we do not write down anything that would allow someone to link the completed questionnaire to the interviewee. All questionnaires and other forms used in this project will be stored in a locked cabinet or cupboard. These data will be destroyed as soon as they are no longer needed (i.e. once they are stored electronically in a suitably secure place).

#### DISCOMFORT THAT YOU MIGHT EXPERIENCE AS A PARTICIPANT

The questionnaire asks personal questions that may make you feel uncomfortable at times, and it may bring up topics that are difficult to talk about. We do not wish for this to happen. We want you to know that you do not have to answer any question or take part in the interview if you feel the questions are too personal or if talking about them makes you uncomfortable. If you find you feel uncomfortable at any point during the interview, you can decide to pause or stop the interview at this time – it is completely up to you to decide this and to indicate to me, as the interviewer, that you wish to pause or stop the interview process. Sometimes people want to explore certain issues and experiences in more depth after the interview. In case you need psychological or physical support, such as counselling or legal assistance or advice concerning educational, health or social support, we have developed a list of professional support services in our community. I will be happy to share this information with you.

#### POTENTIAL BENEFITS FOR YOU AND THE COMMUNITY IN RELATION TO YOUR PARTICIPATION

We hope that the process of going through the questionnaire is an interesting one for you as it might cover some issues that you may not have thought about in detail. We also hope that you will learn from the interview process and from any discussions which may arise from it. However it is hoped that, through you and other people living with HIV participating in this project, we will be able to produce rich and valuable information that will assist both our national and global efforts to reduce HIV-related stigma and discrimination and ultimately improve the lives of all people living with HIV.

### **Annex 3: Confidentiality Agreement**

#### CONFIDENTIALITY AGREEMENT: PARTNERS

I \_\_\_\_\_, from \_\_\_\_\_ (name of organization) assisting with the People Living with HIV Stigma Index survey project in Swaziland, agree to the following:

- I will take all possible steps to protect the confidentiality of the information that I handle. This means that if personally identifying information is made known to me during the course of the project, I will not disclose it –either verbally or in writing to anyone. I will do nothing that discloses the identity of someone who is or has been associated with the project.

Signature: \_\_\_\_\_

Name (printed): \_\_\_\_\_

Date: \_\_\_\_\_

Place (town, country): \_\_\_\_\_

#### PROJECT LEADER OR ANOTHER WITNESS:

Signature: \_\_\_\_\_

Name (printed): \_\_\_\_\_

Date: \_\_\_\_\_

Place (town, country): \_\_\_\_\_

## Annex 4: Informed consent form

### INFORMED CONSENT FORM

To be completed by the interviewee and the interviewer. My name is \_\_\_\_\_  
[INSERT the name of the interviewer.] I am administering a questionnaire about the experiences of people living with HIV, particularly the experiences of stigma and discrimination they may have had. I have provided you with an information sheet that describes the purpose of this questionnaire and how the information collected from this questionnaire will form part of a larger survey that is being conducted in this country to document some of the experiences of people living with HIV. The information sheet also outlined what types of information you will be asked, how we will keep this information confidential and the potential risks involved in your participating in this survey. Before we begin the questionnaire, I would like to make sure that you are voluntarily willing to participate in this survey and that you have obtained all the information that you need in order to make an informed choice about your participation. This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. You do not have to decide today whether or not you will respond to this questionnaire. Before you make a decision, you can talk to anyone you feel comfortable with about the questionnaire and/or the survey. Please feel free to also contact the project team leader if you have any questions or concerns about this questionnaire or the survey. These are the contact details

for the team leader:

Name: Happiness Mkhathshwa

Contact details: Telephone 422 1698/ 76081780. P.O. Box 4130, Mbabane. Email: happiness@swaziplace.com.

If, however, you choose to respond to this questionnaire and thus participate in the survey, I will ask you some questions about some of your experiences as a person living with HIV, in particular those related to the experiences of stigma or discrimination you may have had. I expect that the interview will take between two and three hours. Before asking you whether or not you would like to be a participant, I would like you to know that:

1. Your participation in this survey is entirely voluntary. It is your choice whether to participate or not.
2. You are free to not answer any of the questions in the questionnaire.
3. You may stop participating in the interview at any time that you wish.

The information collected in this interview will be kept strictly confidential. To help ensure confidentiality, I will not write your name on the questionnaire or this form, and I will not write down particular details that would allow you to be identified. If you would like to know more about the measures that we are taking to protect confidentiality, please ask me to provide you with these details. Your participation will include my providing you with a list of services that are available in our community, including health care, social support and legal services. Do you consent to participating in the interview?

Yes 1

No 2

If NO: Thank you for your time.

If YES: Thank you for agreeing to take part in this project. By saying yes, that means that you have read the information on the information sheet, or it has been read to you. You have had the opportunity to ask questions related to the questionnaire and the People Living with HIV Stigma Index survey and any questions you have asked have been answered to your satisfaction. You consent voluntarily to be a participant in this project and you understand that you have the right to end the interview at any time.

If you agree, please sign here. I will also sign this form to confirm that your consent has been obtained.

I have read the information on the information sheet, or it has been read to me. I have had the opportunity to ask questions related to the questionnaire and the People Living with HIV Stigma Index survey, and any questions I have asked have been answered to my satisfaction. I consent voluntarily to be a participant in this project and understand that I have the right to end the interview at any time.

Signature of participant: \_\_\_\_\_

Signature/initials of interviewer: \_\_\_\_\_

Date of interview: \_\_\_\_\_

**Annex 5: Experiences of stigma and discrimination from others by age, gender, location of residence and level of education**

In the last 12 month, how often have you been excluded from social gatherings or activities	Age of respondents						Total
	18-20	21-24	25-29	30-39	40-49	50+	
once	2	0	5	9	9	4	29
a few times	4	2	5	14	7	13	45
often	1	0	7	11	10	3	32
Never							
Total	24	95	211	403	308	192	1233

In the last 12 months, how often have you been excluded from religious activities or places of worship?	Age of respondents						Total
	18-20	21-24	25-29	30-39	40-49	50+	
Never	19	93	203	385	292	186	1178
once	1	1	1	4	2	0	9
few times	3	1	3	9	8	6	30
often	1	0	4	5	6	0	16
Total	24	95	211	403	308	192	1233

In the last 12 months, how often have you been excluded from family activities?	Age of respondents						Total
	18-20	21-24	25-29	30-39	40-49	50+	
Never	17	86	178	358	281	177	1097
once	0	3	3	7	2	2	17
few times	3	1	12	12	9	3	40
often	4	5	18	26	15	10	78
Total	24	95	211	403	307	192	1232

In the last 12 months, how often have you been aware of being gossiped about?	Age of respondents						Total
	18-20	21-24	25-29	30-39	40-49	50+	
Never	10	66	128	234	189	130	757
once	1	7	10	29	28	9	84
few times	4	12	43	91	50	23	223
often	9	10	30	49	41	30	169
Total	24	95	211	403	308	192	1233

In the last 12 months, how often have you been verbally insulted, harassed and/ or threatened?	Age of respondents						Total
	18-20	21-24	25-29	30-39	40-49	50+	
Never	16	74	156	317	248	149	960
Once	0	5	9	15	16	15	60
few times	6	7	26	37	23	15	114
Often	2	9	20	34	21	13	99
Total	24	95	211	403	308	192	1233

In the last 12 months, how often have you been physically insulted, harassed and/or threatened?	Question 2 how old are you?						Total
	18-20	21-24	25-29	30-39	40-49	50+	
Never	18	89	184	350	275	159	1075
Once	0	3	11	26	19	16	75
few times	4	2	11	16	7	7	47
Often	2	1	5	11	7	10	36
Total	24	95	211	403	308	192	1233

In the last 12 months, how often have you been physically assaulted?	Age of respondents						Total
	18-20	21-24	25-29	30-39	40-49	50+	
Never	18	89	191	372	287	182	1139
Once	3	2	12	20	15	6	58
few times	0	3	6	9	5	0	23
Often	3	1	2	2	1	4	13
Total	24	95	211	403	308	192	1233

In the last 12 month, how often have you been excluded from social gatherings or activities	Sex of respondents			Total
	male	female	transgender	
Never	287	836	4	1127
Once	5	24	0	29
a few times	13	32	0	45
Often	7	24	1	32
Total	312	916	5	1233

In the last 12 months, how often have you been excluded from religious activities or places of worship?	Sex of respondents			Total
	male	female	transgender	
Never	298	876	4	1178
Once	4	5	0	9
few times	6	24	0	30
Often	4	11	1	16
Total	312	916	5	1233

In the last 12 months, how often have you been excluded from family activities?	Sex of respondents			Total
	male	female	transgender	
Never	276	817	4	1097
Once	1	16	0	17
few times	12	27	1	40
Often	23	55	0	78
Total	312	915	5	1232

In the last 12 months, how often have you been aware of being gossiped about?	Sex of the respondents			Total
	male	female	transgender	
Never	197	560	0	757
Once	26	58	0	84
few times	43	178	2	223
Often	46	120	3	169
Total	312	916	5	1233

In the last 12 months, how often have you been verbally insulted, harassed and/or threatened?	Sex of respondents			Total
	male	female	transgender	
Never	249	709	2	960
Once	13	47	0	60
few times	26	85	3	114
Often	24	75	0	99
Total	312	916	5	1233

In the last 12 months, how often have you been physically insulted, harassed and/or threatened?	Sex of respondents			Total
	male	female	transgender	
Never	267	805	3	1075
Once	26	48	1	75
few times	14	32	1	47
Often	5	31	0	36
Total	312	916	5	1233

In the last 12 months, how often have you been physically assaulted?	Sex of respondents			Total
	male	female	transgender	
Never	290	846	3	1139
Once	12	44	2	58
few times	7	16	0	23
Often	3	10	0	13
Total	312	916	5	1233

In the last 12 month, how often have you been excluded from social gatherings or activities	Location of household			Total
	rural area	small town or village	large town or city	
Never	862	247	18	1127
Once	23	6	0	29
a few times	26	18	1	45
Often	23	7	2	32
Total	934	278	21	1233

In the last 12 months, how often have you been excluded from religious activities or places of worship?	Location of household			Total
	rural area	small town or village	large town or city	
Never	902	257	19	1178
Once	6	3	0	9
few times	16	13	1	30
Often	10	5	1	16
Total	934	278	21	1233

In the last 12 months, how often have you been excluded from family activities?	Location of household			Total
	rural area	small town or village	large town or city	
Never	843	235	19	1097
Once	11	5	1	17
few times	31	8	1	40
Often	48	30	0	78
Total	933	278	21	1232

In the last 12 months, how often have you been aware of being gossiped about?	Location of household			Total
	rural area	small town or village	large town or city	
Never	583	160	14	757
Once	61	22	1	84
few times	168	51	4	223
Often	122	45	2	169
Total	934	278	21	1233

In the last 12 months, how often have you been verbally insulted, harassed and/or threatened?	Location of household			Total
	rural area	small town or village	large town or city	
Never	751	192	17	960
Once	48	12	0	60
few times	71	41	2	114
Often	64	33	2	99
Total	934	278	21	1233

In the last 12 months, how often have you been physically insulted, harassed and/or threatened?	Location of household			Total
	rural area	small town or village	large town or city	
Never	818	238	19	1075
Once	49	26	0	75
few times	34	11	2	47
Often	33	3	0	36
Total	934	278	21	1233

In the last 12 months, how often have you been physically assaulted?	Location of household			Total
	rural area	small town or village	large town or city	
Never	875	246	18	1139
Once	36	21	1	58
few times	13	8	2	23
Often	10	3	0	13
Total	934	278	21	1233



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