UNAIDS

THE PEOPLE LIVING WITH HIV STIGMA INDEX

An Analytical Report Based on Research Findings

October 2013

JN+

Jamaican Network
of Seropositives

ACKNOWLEDGEMENTS

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KEY PARTNERS

Jamaican Network of Seropositives (JN+)

Jamaican Network for Seropositives (JN+) is a national network of self-support groups which was started in 1997 and is recognized as the face and voice of people living with HIV and AIDS in Jamaica. It is part of the wider Caribbean Regional Network of Persons Living with HIV and AIDS. The organization's vision is "persons living with HIV and AIDS accepted and recognized as full members of society", while the mission is "to advocate for the rights and concerns of people living with and affected by HIV and AIDS, through empowerment, partnership and resource mobilization".

JN + serves as the hub to record complaints of stigma and discrimination, conduct interviews with the complainants and refer cases to the interim investigative team as well as maintain the database of the National HIV-related Discrimination Reporting and Redress System and to train report and redress investigators. It also collaborates with the Jamaica Community of Positive Women to reach and provide relevant support for women and children made more vulnerable to HIV and discrimination.

National HIV/STI Programme (NHP), Ministry of Health (MOH)

The National HIV/STI Programme (NHP) located within the Ministry of Health (MoH) was mandated by the Government of Jamaica to coordinate and lead the implementation of the national HIV/AIDS response. Since the inception of the NHP in 1986, its implementation arm has been expanded to involve the health sector's four Regional Health Authorities and five sector ministries – Labor and Social Security, National Security, Local Government, Education, and Tourism. The NHP also provides technical and financial support for the National AIDS Committee (NAC) created in 1988 and strengthened since then to expand the multisectoral support.

Global Network of People Living with HIV (GNP+)

GNP+ is the Global Network for and by People Living with HIV. GNP+ advocates improving the quality of life of people living with HIV. As the only Global Network working with all PLHIV regardless of how they choose to network, GNP+ works with independent and autonomous regional and national networks of people living with HIV in all continents, as well as networks that include people living with HIV, including key populations and treatment access networks.

IPPF

IPPF aims to improve the quality of life of individuals by providing and campaigning for sexual and reproductive health and rights (SRHR) through advocacy and services, especially for poor and vulnerable people. The Federation defends the right of all people to enjoy sexual lives free from ill health, unwanted pregnancy, violence and discrimination.

UNAIDS

The Joint United Nations Programme on HIV/AIDS (UNAIDS) leads and inspires the world to achieve its shared vision of zero new HIV infections, zero discrimination and zero AIDS-related deaths. UNAIDS unites the efforts of 11 UN organizations—UNHCR, UNICEF, WFP, UNDP, UNFPA, UNODC, UN Females, ILO, UNESCO, WHO and the World Bank—and works closely with global and national partners to maximize results for the AIDS response.

DISCLAIMER

The People Living with HIV Stigma Index is designed as a research tool by which people living with HIV capture data on their experiences and perceptions regarding stigma and discrimination.

In this regard, the results can be said to comprise a snapshot of the level of HIV related stigma and discrimination in a particular place and time. Through its implementation, the tools also serve to educate and empower on human rights related to HIV. Survey questions, therefore, focus on experiences and perceptions and do not represent factual investigations, with follow up questions, into particular allegations, incidents or events, nor are the answers to the questions subject to independent verification. As research participants interviewees have a right to anonymity and to confidentiality regarding their responses.

In addition to the empowerment function, appropriate uses of the data are for advocacy and in order to inform stigma/discrimination reduction programming in the national response to HIV.

ACRONYMS

Anti-retroviral Therapy	ART
Female Sex Worker	FSW
Global Network of People Living with HIV	GNP+
Health Policy Project	HPP
International Planned Parenthood Federation	IPPF
International Community of Women living with HIV and AIDS	ICW
Jamaican Network of Seropositives	JN+
Joint United Nations Programme on HIV/ AIDS	UNAIDS
Men Who Have Sex with Men	MSM
National Strategic Plan	NSP
Opportunistic Infections	OI
People Living with HIV	PLHIV
Statistical Institute of Jamaica	STATIN
United Nations General Assembly	UNGASS

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EXECUTIVE SUMMARY

In Jamaica, HIV-related stigma and discrimination have accompanied the epidemic from the reporting of the first HIV case. In the literature, it has been noted that fear of and actual experience with stigma and discrimination can reduce an individual's willingness to practice prevention, seek HIV testing, disclose his or her HIV status to others, get care and support, and begin and adhere to HIV treatment.

In August and September 2010, JN+ with support from UNAIDS, and with guidance from a local Steering Committee composed of PLHIV, Government, Academia and International Development Partners, conducted a study entitled, the People Living with HIV Stigma Index. The Index was designed as an international research tool to capture data on the experiences and perceptions of PLHIV regarding stigma and discrimination. This research was initiated by the international 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).

The objectives of this study were to document the experiences of people living with HIV regarding stigma and discrimination; provide the foundation for evidence-based programmatic interventions, provide a mechanism for measuring changes in stigma and discrimination, and gather information that will inform the development and implementation of national policies that protect the rights of people living with HIV. Jamaica is the only English speaking Caribbean country to conduct this study, and it serves as a baseline for measuring the level of stigma and discrimination of people living with HIV in Jamaica.

The research study used an uniform methodology so that the data captured can be compared with data from other countries. Qualitative and quantitative data was collected by persons living with HIV. Participants were recruited from all four health regions at HIV treatment sites. The results of the study are summarized below.

The study sample was comprised of 509 persons living with HIV (191 males and 315 females, 3 transgender). Few persons identified themselves as a member of a key population group.

The study findings provide evidence of the experience of stigma and discrimination among persons living with HIV in Jamaica. Psychosocial support, sexual and reproductive health services need to be strengthened to improve the quality of service delivery offered to persons living with HIV. In addition, more work needs to be done to increase knowledge of rights and laws that protect against discrimination and encourage disclosure. Overall, the research findings reinforce the need for anti-stigma and discrimination legislation which support and strengthen HIV programming efforts, as well as inform the development and implementation of national policies that protect the rights of people living with HIV.

In the 12 months preceding the study, the following was experienced by persons living with HIV:

<u>Experience with and Fear of Stigma and Discrimination(S&D)</u>

- Thirty-eight percent (38%) of persons living with HIV reported experiencing some form of stigma and discrimination because of their HIV status.
    - Fifty-four percent (54%) of respondents reported being gossiped about, 30% reported verbal harassment, 12% physical harassment, and 8% reported physical assault
    - Discrimination amongst persons living with HIV differed slightly between males and females; Females reported being gossiped about and being more physically harmed than males
    - The most common forms of discrimination experienced were gossip and verbal abuse
    - Respondents reported several types of family exclusion, including family members not eating from the same utensils, and being restricted from social and religious activities
- Persons living with HIV feared being subjected to stigma and discrimination
    - Fifty-two percent (52%) were fearful of gossip, 47% feared verbal assault, 41% feared physical harassment, and 41% were fearful of physical assault
    - The fear of stigma and discrimination doesn't change over time; persons living with HIV for 10 years or more continue to live in fear
    - Respondents reported restricting themselves from social and other activities because of their HIV status. The greatest restrictions related to their personal lives; 26% of respondents reported that they decided not to get married, 33% decided not to have sex and 61% decided not to have children
    - The greatest fear for persons living with HIV fear were being neglected and isolated

- Persons living with HIV have high levels of internalized stigma or self-stigmatization because of their status
    - Males are more likely to blame themselves and have feelings of guilt because of their status; Females are more likely to report feelings of shame, guilt and have low self-esteem
    - Twenty percent (20%) of females and 40% of persons aged 20-24 years reported feeling suicidal
    - Feelings of internalized stigma remain regardless of age, however length of time living with HIV reduced these negative feelings
    - Persons living with HIV are suffering from anxiety and depression regardless of location of residence, age, sex and length of time living with HIV.
- Discrimination was also reportedly committed by other persons living with HIV
- Respondents perceived that gays, lesbians, and bisexuals were most likely to experience the worst forms of discrimination

Access to health services

- Almost all respondents reported having access to health services, however persons living with HIV encounter discriminatory practices in health care settings and had privacy concerns
    - Forty percent (40%) of persons tested for HIV did not receive any pre or post test counseling
    - Over half of the respondents felt that they were not sure if their medical records were kept private
- Discrimination was reported in accessing sexual and reproductive health services
    - Less than half of the respondents ever received reproductive health counseling
    - Female respondents reported being advised not to have children, being coerced into getting tubal ligations, and being forced to end their pregnancies
    - Persons that live in both rural areas and small towns were more likely to be denied family planning and sexual and reproductive health services
    - Over 15% of respondents reported that their ability to obtain ART was conditional on the use of certain forms of contraception

- Eighty-nine (89%) of study participants reported currently taking anti-retroviral medication; Nineteen (19%) reported currently treating an opportunistic infection

Knowledge of Rights, Laws and Policies

- The majority of study respondents reported that they were unaware of HIV policies that protect the rights of persons living with HIV or knew of a group that can help persons living with HIV with stigma and discrimination
    - Less than half of study respondents reported that they were aware of the Declaration of Commitment on HIV /AIDS or the National HIV Policy
    - Eleven percent (11%) reported their rights as a person living with HIV were abused
    - Only nine percent (9%) of respondents reported being involved in any efforts to develop HIV legislation, policies or guidelines; less than 50% felt that they can affect any decision related to legal rights or policies
    - Most respondents surveyed knew of a support group for persons living with HIV; however only 40% of persons knew of a group that can help persons living with HIV with stigma and discrimination

Disclosure and Confidentiality

- Even though most respondents never feel pressure to disclose their status, most persons living with HIV are reluctant to disclose for of fear of discrimination
    - Persons living with HIV are less likely to disclose their HIV status to a spouse or partner, adult family member, someone they are dating or other persons living with HIV. Reactions from these persons tend to be supportive. Persons living with HIV were least likely to disclose to friends, neighbors whose reactions tended to be discriminatory.
    - Sixty-five percent (65%) of those that disclosed their status to others felt it was an empowering experience

Summary of Recommendations

The study findings provide evidence of the experience of stigma and discrimination among persons living with HIV in Jamaica. Psychosocial support, sexual and reproductive health services need to be strengthened to improve the quality of service delivery offered to persons living with HIV. In addition, more work needs to be done to increase knowledge of rights and laws that protect against discrimination and encourage disclosure. Overall, the research findings reinforce the need for anti-stigma and discrimination legislation which support and strengthen HIV programming efforts, as well as inform the development and implementation of national policies that protect the rights of people living with HIV.

The following is a summary of the key recommendations based on the study findings and are discussed in more detail in the Programme and Policy Recommendations section of the report.

- Advocate for the development of anti-discrimination legislation for vulnerable populations
- Support the amendment or repeal of laws which discriminate on particular grounds or against specific groups
- Continue to develop anti-stigma and discrimination campaigns as part of HIV programming at the national level in rural areas and small towns
- Engage persons living with HIV in the design, planning and advocacy process
- Develop and implement a comprehensive case management framework for the care, treatment and support of persons living with HIV
- Review and improve HIV testing and counseling procedures
- Increase psychosocial support
- Develop a comprehensive sexual and reproductive health policy
- Enforce existing codes of conduct with health care providers that violate the rights of the patient
- Review policies as it relates to confidentiality
- Develop a patient rights document that identifies the rights and responsibilities of patients
- Develop and implement support group sessions on appropriate care and treatment services
- Improve referral systems at treatment sites for enrollment in HIV support organizations
- Offer and publicize services of HIV support organizations
- Engage and encourage persons living with HIV to join HIV support organizations

SECTION I: BACKGROUND

According to the Jamaica National HIV Strategic Plan (NSP) 2012-2017 (draft of August 2011) information on the nation's HIV status, approximately 2.7 million persons reside in Jamaica; of these, 53% of the population is between 15 and 49 years. In 2011, the adult HIV prevalence in Jamaica was 1.7%, or approximately 32,000 persons. It is estimated though that half of these persons are unaware of their status.

In Jamaica, the HIV epidemic is both generalized in the population and concentrated among key populations. Rates of HIV infection among key sub-populations remain high despite the prevalence rate within the general population has been less than 2% for many years. Data from the Ministry of Health show the following prevalence rates:

Table 1: HIV Prevalence among key populations in Jamaica, 2011

Group[1]	**HIV Prevalence**
Adults 15-49	1.7%
Men who have sex with men (MSM)	32%
Female sex workers (FSW)	4.1%
Homeless/Drug users	8.2%
Prison inmates	2.5%

The key factors underlying the epidemic as described by the 2010 UNGASS Report are high risk behaviours such as multiple sex partners, high levels of transactional sex, and decreasing age of sexual debut. These factors combined with poverty, gender disparities and homophobia continue to fuel the transmission of HIV in Jamaica[2].

As part of its national response, the Government of Jamaica has been working with stakeholders from the private sector, non-governmental organizations, international partners and line ministries to implement the five priority actions that are defined under the country's 2007-2012 National Strategic Plan. The priority action areas are:

- Prevention
- Treatment, care and support
- Enabling environment
- Monitoring and evaluation
- Empowerment and governance

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[1] UNAIDS Country Progress Report (Jamaica), 2010

[2] ibid

The Strategic plan recognizes the need to focus equally on preventing the further spread of the epidemic, supporting better care for those infected and affected by HIV, and building capacity and resilience to withstand the impact of AIDS. In addition, the NSP emphasizes leadership development and governance to facilitate the integration of HIV and AIDS into the development programmes of government and civil society institutions as well as the private sector[3].

The People Living with HIV Stigma Index

The People Living with HIV Stigma Index is designed to measure the levels of stigma experienced by people living with HIV. Developed by the Global Network of People Living with HIV (GNP+), the International Community of living with HIV and AIDS (ICW), the International Planned Parenthood Federation (IPPF), in partnership with UNAIDS, the Index is intended to provide the basis for evidence based policy and programmatic interventions to combat stigma and discrimination. This is necessary since stigma and discrimination have been recognized as among the root causes of high HIV prevalence rates as well as low testing, low access to treatment, and poor health seeking behaviours. Further, the Stigma Index gathers perspectives on how stigma and discrimination affect each of the priority areas identified in the National Strategic Plan. It, therefore, helps policymakers and programmers to reflect on the effectiveness of the plan.

The People Living with HIV Stigma Index is being applied in a number of countries throughout the world. In Jamaica, UNAIDS and HPP provided technical and financial support to the study and the Jamaica Network of Seropositives spearheaded the process, with guidance from an appointed steering committee. The Stigma Index Steering Committee included representatives from the Jamaica Network of Seropositives, Ministry of Health, Caribbean Vulnerable Communities Coalition, Jamaica AIDS Support for Life, Jamaica Community of Positive Women, the University of the West Indies HIV and AIDS Response Programme, Caribbean HIV/AIDS Regional Training Network, UNAIDS, USAID and Health Policy Project.

The Stigma Index complements other studies, including the 2008 *HIV/AIDS Knowledge Attitudes* and *Behavior* Survey and the 2011 *National Survey of Attitudes and Perceptions of Jamaicans towards Same Sex Relationships*. There is also a range of related publications on subjects such as the problem of homophobia, HIV/AIDS risk mapping and HIV/AIDS prevention (King, 2006; Luton, 2009; Royes, 2003; White and Carr, 2005; Williams, 2000).

The present report is structured as follows: The first section of the report outlines the study objective and the methods of data collection and analyses used for the study. Section two outlines the limitations in the study methodology and analysis. Section three provides a description of the socio-demographic characteristics of the respondents. Section four describes the levels of internalized stigma, social fears and experience of stigma and discrimination. This section also describes issues

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[3] NSP 2012-2017

related to access, housing, health and educational services. Section five provides information on awareness of rights, laws and policies that affect persons living with HIV and recommendations for support group organizations. Section seven gives an overview of HIV testing, diagnosis and treatment. Section eight provides conclusions on the overall findings of the report. Section nine presents the policy and programme recommendations based on the findings of the report and Section ten outlines the strategies for dissemination of the findings.

1.1 Study Objectives

The objectives of the Stigma Index study are to:

1) Document the experiences of people living with HIV in Jamaica regarding stigma and discrimination;

2) Gather information that will inform the development and implementation of national policies that protect the rights of people living with HIV;

3) Provide the foundation for evidence based programmatic interventions;

4) Provide a baseline for measuring changes in stigma and discrimination over time;

5) Provide information that will allow comparison of the levels of stigma and discrimination across countries.

1.2 Ethical Considerations

Ethical approval was received from the Institutional Review Board (IRB) of the Ministry of Health in Jamaica. Voluntary informed consent was obtained by the interviewers to protect the respondents. The consent and confidentiality forms used for the study were the standard forms provided by the Stigma Index. Survey codes rather than names were used on the survey forms. In addition, confidentiality agreements were signed by interviewers, supervisors and data clerks. Respondents were remunerated for their participation to offset expenses related to travel to study sites. A referral sheet with contacts of trained persons at the Ministry of Health was also given to participants in case study participants wanted to discuss emotional or other issues that were disclosed during the interview process. All data collected were stored in locked file cabinets at the local UNAIDS office.

1.3 Methodology

Persons living with HIV were surveyed with the purpose of collecting and analyzing data on the problems and challenges experienced by people living with HIV. The study was conducted using a mix of quantitative and qualitative methods. A face to face paper based questionnaire was used to collect data by persons living with HIV as the primary interviewers. The survey data were complemented by focus group discussions and case studies conducted by the project manager.

In Jamaica key populations comprise: MSMs (particularly those who are homeless); crack/cocaine users; sex workers; young people (especially young females and out of school youth); persons who have been in prison and STI clinic attendees.

Invitations were sent to HIV support organizations (e.g., JN Plus, Eve for Life, Jamaican Community for Positives (JCW), Jamaica AIDS Support for Life) for their members in every parish to join the study. In addition, sensitisation sessions were held with Regional Health Authorities where clinic/hospital staff was informed about the study. Specifically, nurses, social workers, adherence counselors and physicians were asked to inform HIV patients about the study. Participants were predominately recruited from HIV treatment sites. Interviews took place at health centres or hospital conference rooms, community health centres, churches, and schools.

Even though invitations were sent to various HIV support organizations that assist persons living with HIV, including those that comprise the key population groups, the recruitment strategy did not have a specific approach to include members of these key groups.

1.4 Study Locations

The study was conducted in all four health regions in Jamaica, which included a mix of urban and rural parishes. The four health regions and corresponding parishes were: Western (St. James, Trelawny, Hanover, Westmoreland); Southern (St. Elizabeth, Manchester, Clarendon); North Eastern (Portland, St. Mary, St. Ann) and South Eastern (Kingston & St. Andrew, St. Thomas, and St. Catherine).

1.5 Sample Size

In tandem with the guidelines specified by the global steering committee, the research team aimed for a sample size that was, at minimum, 3.5% of the reporting population of persons living with HIV on anti-retroviral treatment. Based on the available figures, the original sample size was estimated at 350 respondents. Jamaica, however, opted for a population-based study, with the potential to make valid assessments across the regions. Correspondingly, the estimated sample size was therefore increased to 540.

Table 2 compares the study sample with the proportion of known national HIV cases reported in 2011 by region[4]. The table shows that there was an unequal distribution of participants by parish. Based on national estimates, the Western and

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[4] Jamaica HIV/AIDS Epidemic Update, January to December 2011. National HIV/STI Program, Ministry of Health

Southeast region has the greatest number of known HIV cases. The study sample was not proportionate to the number of cases per region; however, over 15% of the cases were reached. The study was able to capture 46% of the known HIV cases in the Western region; however, only 17% of the cases were interviewed in the Southeast region. Reasons for this were predominately due to the low participant turnout in Kingston and St. Andrew. In addition, the Southeast region was the last region arranged for data collection, and there was insufficient time to fully access this population as needed. Forty-nine percent (49%) of known HIV cases were captured in the Northeast region and 23% of the Southern region. Tables 3 and 4 provide a breakdown of how the sample was allocated.

Table 2: Comparison of proportion of national HIV cases in 2011 and study sample by region[5]

Regions*	**Sample N**	**National HIV Cases N (%)**	**Proportion of HIV cases in sample**
Western (St James, Trelawny, Hanover, Westmoreland)	224	488 (27)	46%
Southern (St Elizabeth, Manchester, Clarendon)	65	280 (16)	23%
North Eastern (Portland, St Mary, St Ann)	121	244 (14)	49%
South Eastern (Kingston & St Andrew, St Thomas, St. Catherine)	130	773 (43)	17%
Total	540	1785	30%

*The number of national HIV cases in unknown parishes and those with an overseas address were excluded

Table 3 shows the estimated sample by sex. An almost 50/50 split was estimated for the sample for sex by region. Table 3 shows the anticipated versus the actual sample of respondents by sex, age and region. Across the regions, care should be taken with gender and regional level analyses, as the sample sizes are not adequate for conclusive statements. As can be seen in Table 3, the actual numbers of participants differed greatly especially among males in the northeast, western, and southeast parishes.

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[5] Number of national HIV cases taken from Jamaica HIV/AIDS Epidemic Update, January to December 2011. National HIV/STI Program, Ministry of Health.

Table 3: Estimated sample breakdown by region and sex

Regions	Sample N (%)	Male N (%)	Female N (%)
Western (St James, Trelawny, Hanover, Westmoreland)	224 (41)	106 (41)	118 (41)
Southern (St Elizabeth, Manchester, Clarendon)	65 (12)	31 (12)	34 (12)
North Eastern (Portland, St Mary, St Ann)	121 (22)	57 (22)	64 (22)
South Eastern (Kingston & St Andrew, St Thomas, St. Catherine)	130 (24)	62 (24)	69 (24)
Total	540 (100)	255 (47)	285 (53)

Table 4: Number of Anticipated versus Actual Sample Respondents, by sex, age and region

	Region				
	Southern	Northeast	Western	Southeast	Total
Sex :					
Male	33	44	65	49	191
Female	38	61	121	95	315
TG	1	0	2	0	3
Age:					
16-19	0	1	3	2	6
20-29	16	11	35	21	83
30-39	20	38	59	58	175
40-49	19	32	59	37	147
50+	17	23	32	26	98
Total	**72**	**105**	**188**	**144**	**509**

TG= Transgender

1.6 Interviewer Selection and Training

Interviewer selection:

Consistent with the process in other parts of the world, interviewers were chosen from among persons who are living with HIV. Notices of vacancies were sent to agencies that are working with people living with HIV, and shortlisted candidates were invited to a three-day workshop. In order to ensure that the final complement of interviewers comprised the best available candidates, the final list of interviewers was selected at the end of the training period, using the following criteria:

1. Presence

A. Attended all days of the workshop

B. Demonstrated interest in topic area

2. Interaction

A. Related well with other members of the team

B. Opened to being challenged/corrected
C. Willingness to resolve issues
D. Level of participation in workshop (asked questions, made comments, participated in group work, role plays)
E. Open to the process of understanding issues related to stigma and discrimination, including emotional issues

3. Attitude
A. Demonstrated sensitivity
B. Demonstrated awareness of importance of confidentiality

4. Tests
A. Scored 80% or above on the post test
B. Demonstrated learnt interview skills
C. Demonstrated knowledge of core concepts

Notably, the criteria did not include literacy assessments, as the initial list of candidates had been selected based on the qualifications submitted. The application forms indicated that all candidates had achieved the minimum qualification of a high school level education.

This, combined with the other criteria, meant that while 17 potential interviewers attended the workshop, only 8 were selected as interviewers. This resulted in higher than desired workload; each interviewer was responsible for approximately 68 interviews. Further, selected interviewers were trained to conduct the focus groups. The team was supported by two team leaders, also persons living with HIV, who were members of the steering committee. The initial consultant/project manager conducted the case studies and provided oversight throughout the fieldwork, data entry and analysis.

1.7 Data Collection

Data for the study was collected between August and September 2011. Questionnaires were used to collect quantitative information and focus groups, and case studies were used to ascertain more in-depth information from persons living with HIV.

1. Questionnaire
    a. *Development/construction*

The questionnaire was pre-designed by the Global Network of People Living with HIV (GNP+), International Community of Women Living with HIV and AIDS (ICW), International Planned Parenthood Federation (IPPF) and UNAIDS. While only limited changes to this instrument were permitted, the country team was allowed to include specific country relevant questions in order to explore selected themes, which the Steering Committee considered critical for policy analysis and programming in Jamaica. Jamaica specific questions (n=21) or response categories (n=6) were added to the questionnaire and can be identified by the marker: JM*. The additional selected themes explored in the Jamaica study were:

- Deep rural/rural dynamics
- The dynamics of discrimination across urban spaces
- Internalized stigma (how persons feel about themselves) and outcomes
- Community stigma (within the community of persons living with HIV)
- Experiences of persons who have lived with the diagnosis for many years (these persons were encouraged to reflect on changes in types and levels of stigma and to make policy and programme recommendations)
- The differential nature of stigma across state and non-state agencies

b. Survey Administration

Surveys were completed through private interviews. Team leaders were available throughout all of these sessions in order to monitor the interview process, check the quality of the questionnaire at the site and facilitate immediate follow up action where needed.

2. Focus groups

The additional identified themes were incorporated in the focus group discussions. Specifically, the topics explored in the focus groups were:

- The dynamics of discrimination within rural and deep rural areas
- The relationship between HIV and poverty, particularly among the elderly
- Experiences of young people who are living with HIV
- Experiences of MSMs who are living with HIV

3. Case Studies

There were several questions in the survey in which certain responses signaled a possible case study. These questions were:

- Do you experience stigma and discrimination in your community by community members? (JM)
- What forms of discrimination are you more fearful of? (JM)
- Do you think there are some groups of persons living with HIV that experience more severe forms of discrimination than others? (JM)
- If yes, which group of persons living with HIV do you think experience the worst forms of discrimination? (JM)
- Do you think that discrimination against persons living with HIV has gotten worse over the last 5 years? (JM)
- Do you think that persons living with HIV have been experiencing less discrimination over the last 5 years? (JM)

- In the last 12 months have you been discriminated against by other people living with HIV?
- In the last 12 months has your wife/husband or partner or any members of your household experienced discrimination as a result of your HIV positive status?

In addition, focus group sessions were planned to include various subpopulation groups including sex workers, persons living with HIV with disabilities and persons living with HIV, who are/were prison inmates. However, the organization of these sessions with these key groups was not feasible. Information recorded in the focus group sessions and case studies was lost due to theft, and no transcripts were available for review (other than the notes from the programme manager).

1.8 Data Entry, Cleaning and Analysis

The data were entered and analyzed using the statistical software package SPSS version 20. Data were entered the data by persons living with HIV who were trained by the project manager. Univariate analysis of frequencies for each variable was conducted. Missing data and errors in data entry were identified. Data entry errors were corrected and missing data were evaluated to determine whether the responses were random or if there was a pattern in the missing data. A summary of the data cleaning efforts can be found in the document titled, "Stigma Index Data Cleaning" located in the HPP and UNAIDS office. Descriptive data analyses were conducted using basic summary statistics such as cross tabulations of the characteristics of the sample. Bivariate distributions were analyzed by the following main factors:

- Demographic characteristics (sex, age)
- Length of time living with HIV
- Place of residence (large town/city, small town/village, rural area) and/or region

1.9. Data Validation

Four regional data validation meetings were held during data analysis with 96 persons who took part in the Stigma Index study as study participants (with the exception of persons who attended the Southern region meeting). Major findings from the study were presented to elicit discussion from the group about the results in the following areas:

a. Experience of stigma and discrimination
    i. Internalized stigma
    ii. Social exclusion
    iii. Experience of stigma and discrimination by persons living with HIV

b. Access to health services
c. Knowledge of rights, laws and policies
d. Testing and Diagnosis
e. Disclosure and Confidentiality

Group discussions and breakout sessions were conducted that provided more perspective on the findings in each area. It was concluded that the majority of the study findings was supported by experiences of persons living with HIV. In addition, it was acknowledged that the degree of discrimination experienced by respondents depended on the level of disclosure about one's status. It was also acknowledged that especially vulnerable groups, such as MSM and sex workers may have been reluctant to identify themselves in the study for fear of discrimination related to sexual orientation and occupation.

SECTION II: STUDY LIMITATIONS

There were a number of limitations and challenges that that affected the research process and outcomes. Challenges related to the methodology and analyses are described below.

Methodology

1) Key Population Groups:

Although the survey methodology utilized persons living with HIV as interviewers, very few persons from key populations (e.g., MSMs, sex workers, former prisoners, drug users) were identified in the study. Based on the validation meetings, MSM and FSW were reluctant to self-identify in the study although measures were taken to ensure a comfortable, confidential interview environment. However, key populations weren't specifically represented in the interviewer selection process; rather the interviewers were selected based on having a positive HIV status. One key group, MSM, was especially reluctant to identify due to possible negative repercussions related to their sexual orientation.

It was difficult to arrange for discussions with persons living with HIV and disabilities; however, anecdotal evidence suggests that these persons suffer multiple forms of discrimination and feel especially powerless to influence policies and programmes.

The youth population was also reluctant to participate across the regions. Health and Social Workers suggested that this had much to do with the levels of discrimination that young people encounter and/or perceive that they are likely to encounter. Furthermore, younger persons, particularly those who are recently diagnosed, appear to have greater difficulty managing their emotions and are, correspondingly, less amenable to discussing their experiences.

The lack of having a sufficient number of respondents in the key population groups considerably limits our understanding of the level of stigma and discrimination these groups encounter. Based on the study validation sessions that were held, key population groups (MSM, FSW) felt inhibited to disclose their membership in these groups due to stigma. Future stigma studies should include a specific recruitment strategy to engage persons in key population groups (MSM, FSW, youth) and not rely on a general recruitment process. In addition, a separate, focused, study may be required to fully understand the level of stigma and discrimination issues surrounding those who are HIV positive and a member of a key population group.

2) Consistent with the research guidelines, two persons with HIV were hired and trained to enter the data in SPSS. However, the SPSS package proved challenging to

the clerks, and it was determined that it may be useful in the future to hire persons that are more experienced with SPSS data entry regardless of HIV status. An alternative recommendation is to increase the training period for better understanding of SPSS.

3) Although case studies and focus groups were recorded, the subsequent recordings were stolen and no transcript information was available. Quotes included in this version of the report are based on the previous consultants' initial report. Future studies should ensure that qualitative information is transcribed as soon as it is recorded to avoid loss or damage to recordings.

Analysis

1) The quantitative results indicate that, despite monitoring, the interviewers could have improved their probing on certain questions to elicit more and/or consistent responses. For example, there were large numbers of responses to certain questions that were coded as 'not applicable' (e.g., questions related to work, income, education), including in circumstances where further probing may have generated different responses. Therefore, a lengthier and more intensive training period may have improved familiarity with the survey tool and interview techniques.

2) As mentioned previously, very few persons identified being in a key population group (e.g., MSM, prisoner, sex worker, etc.). The number of persons in the key population groups is too low to include in the analysis to make any solid conclusions. Therefore, the analysis has been limited to breakdown by other socio-demographic characteristics. In addition, there were a limited number of persons who classified themselves as transgender (3 persons); the small numbers of respondents within this category makes it difficult to make valid assessments about this group. Transgender respondents were included in selected analysis only.

3) While the survey anticipated 17 persons aged 16-19, only 6 participated in the study. In addition, eighty-three (83) persons living with HIV aged 20-29 participated, as opposed to the 114 anticipated. In depth analysis on age for the younger age groups was therefore limited.

4) The data show a comparatively high proportion of persons living with HIV within the sample living in small towns and villages compared to urban areas. Therefore, care should be taken in the generalization of the results to those residing in large towns/cities.

5) Only three questions were asked related to HIV testing and diagnosis. More insight may have been gained in this area if additional questions were included. For example, questions related to quality of care and treatment received by health care providers, access to drug supplies, and quality of interactions with other clinical staff.

SECTION III: SOCIO-DEMOGRAPHIC CHARACTERISTICS

3.0 Main Characteristics of Interviewed Persons living with HIV and their Households

This section provides the characteristics of the 509 respondents (37.5% males and 62% females) in this study. There were 3 transgender persons (0.6%) in the sample[6].

Age

As shown in Table 5, over a third of the persons living with HIV interviewed were between the ages 30-39, followed by those aged 40-49 (29%), and 50 years and over (19%). Only 9% of study participants were between 25-29 years and 8% were less than 25 years old (Table 5).

Marital status

Close to half of all respondents (46%) reported being single, 28% were married or living with someone and 20% reported being in a relationship but not living together. Only 3% reported being divorced or separated and 2% were widowed (Table 5).

Education

Over 60% of persons living with HIV reported completing secondary school, 26% completed primary school and 12% college/university. Only one percent reported not having any formal education. Male respondents had lower levels of education compared to female respondents, especially in the completion of secondary school (41% vs. 59%) and university (34% vs. 64%). However more females (n=4) than males (n=2) reported not having any formal education.

Level of education differed by location of residence. Persons living in a rural area or small town/village tended to have completed less education than those in large town/cities. Thirty-four percent of residents of a rural town and 28% of those living in a small town / village completed no formal education or just primary education than those living in a large town/city (13%). Furthermore, respondents living in a large town or city were more likely to have completed secondary school (65%) and college/university (22%) than in those living in a rural area or small town/village.

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[6] Due to the insufficient number of transgender persons in the sample, these persons were excluded from some analysis that included sex.

Table 5: Socio-Demographic Characteristics by sex

	Male (N=191) n (%)	*Female (N=315) n (%)*	*Transgender (N=3) n (%)*	*Total (N=509) n (%)*
Age (years)				
16-19	01 (17)	05 (83)	00 (00)	06 (01)
20-24	14 (40)	20 (57)	01 (03)	35 (07)
25-29	11 (23)	37 (77)	00 (00)	48 (09)
30-39	61 (35)	113 (65)	01 (01)	175 (34)
40-49	56 (38)	91 (62)	00 (00)	147 (29)
50+	48 (49)	49 (50)	01 (01)	98 (19)
Total	191 (37.5)	315 (61.9)	03 (0.6)	509 (100)
Marital status				
Married/living with someone	46 (32)	97 (68)	00 (0)	143 (28)
In a relationship, not living together	35 (34)	66 (65)	01 (01)	102 (20)
Single	105 (44)	129 (55)	02 (01)	236 (47)
Divorced/Separated	03 (23)	10 (77)	00 (0)	13 (03)
Widow/widower	00 (0)	10 (100)	00 (0)	10 (02)
Highest level of education				
No formal education	02 (33)	04 (67)	00 (0)	06 (01)
Primary school	54 (41)	78 (59)	01 (0.8)	133 (26)
Secondary school	115 (37)	194 (63)	01 (0.3)	310 (61)
College/University	20 (34)	38 (64)	01 (02)	59 (12)

Household size

Forty-eight percent (48%) of respondents tended to have a household size between one and three persons, followed by a household size of between 4-6 persons (35%). Thirteen percent (13%) of respondents had a family size greater than 7 persons (Table 5).

Household location

Most participants in this study lived in the western region (37%), followed by the southeast (28%), and the northeast (21%). The least number of participants resided in the southern region (14%). Over half of respondents (55%) reported that they resided in a small town or village, followed by a rural area (31%), and a large town (14%). Slightly more female respondents live in the rural area and in a large town/city, whereas more males reported living in a small town/village (Table 5).

Table 6: Proportion of Respondents by region, area of residence and household size by sex

	Male (n=191) n (%)	Female (n=315) n (%)	Transgender (n=3) n (%)	Total (N=509) n (%)
Region				
Southern	33 (46)	38 (53)	01 (01)	72 (14)
Northeast	44 (42)	61 (58)	00 (0)	105 (21)
Western	65 (35)	121 (64)	02 (01)	188 (37)
Southeast	49 (34)	95 (66)	00 (0)	144 (28)
Household Location				
Rural area	51 (33)	103 (66)	01 (01)	155 (31)
Small town/village	114 (41)	165 (59)	01 (01)	280 (56)
Large town/city	24 (35)	44 (64)	01 (01)	69 (14)
Household size				
1-3	103 (42)	139 (57)	02 (01)	244 (48)
4-6	61 (34)	118 (66)	00 (0)	179 (35)
7-9	10 (18)	45 (82)	00 (0)	55 (11)
10-12	03 (33)	05 (56)	01 (11)	09 (02)
13-14	02 (67)	01 (33)	00 (0)	03 (01)

Employment

According to the Labour Market Information System produced by STATIN, the current unemployment rate is 12.65.[7] Over half of all respondents (54%) reported not being employed. Fifteen percent (15%) reported doing casual or part-time work (self-employed), 8.5% were employed part-time as an employee, 8% reported being self-employed, and 2% were students. Only 13% of all respondents reported working full time as an employee.

Employment status did not vary much by location of residence as seen in figure 1. However, more persons residing in a rural area or a small town/village tended to be unemployed or self- employed than those living in a large town or city.

Employment status differed by sex. Overall, more females reported not working (60%) compared to male respondents (47%). In addition, more males reported being employed fulltime compared to females (16% versus 11%) and being self-employed (29% versus 19% respectively) (see figure 2).

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[7] STATIN, Labour Market Information System (LMIS) (www.lmis.gov.jm)

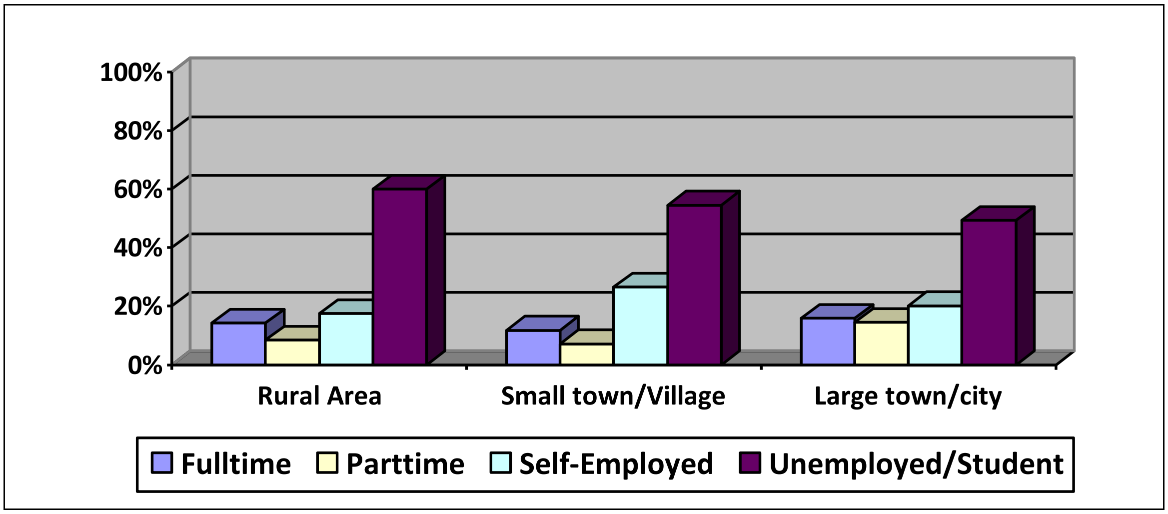

Figure 1: Percentage of Employment by Residential Location (N=503)

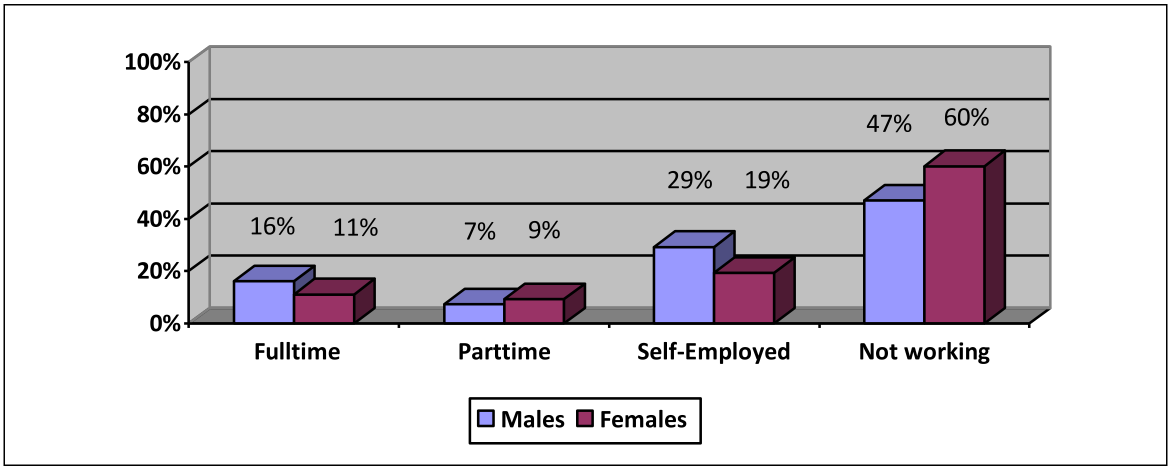

Figure 2: Percentage of Employment by sex (N=505)
Not working=Unemployed or student; sample contained only 8 students (2 males and 6 females)

Income/Food Security

Food security among respondents was a serious issue. In the study, three variables were used to assess income level--income, food security and food availability. Due to the difficulties in the collection of this data, the income and food security variables could not be utilized. Instead, the proxy indicator variable, 'food availability' (In the past 12 months, how often did someone in your household not had enough to eat?) was used in the analysis instead. More than half of all respondents (57%) reported that a member of their household had not had enough to eat in the last 12 months. There was a difference in age and sex in food availability. Respondents over the age of 25 years were more affected than the younger respondents; 47% of males and 63% of females reported that a member of their household did not have enough to eat (Table 6).

Table 7: Food availability by age, sex, and area of residence

	In the last 12 months, has any member of your household not have enough to eat	
	Yes n (%)	No n (%)
Age (years)		
16-19	01 (20)	04 (80)
20-24	16 (47)	18 (53)
25-29	30 (64)	17 (36)
30-39	89 (52)	82 (48)
40-49	90 (63)	53 (37)
50+	55 (57)	41 (43)
Sex		
Male	87 (47)	99 (53)
Female	194 (63)	113 (37)
Transgender	00 (0)	03 (100)
Household Location		
Rural Area	94 (63)	56 (37)
Small town/village	155 (56)	121 (44)
Large town/city	28 (42)	38 (58)

Length of time living with HIV

Less than 10% of respondents reported living with HIV for less than one year, 27% between 1-4 years, 41% between 5 to 9 years, 14% between 10-14 years and 7.5% reported living with HIV for 15 years or more. Only 1% reported not being sure how long they had been infected. The length of time of living with HIV/differed between male and female respondents (see Table 7). Female respondents reported living with HIV for a longer period of time compared to males. Of the three transgender respondents, one respondent reported living with HIV between 1-4 years and two reported being HIV positive between 5-9 years. Length of time living with HIV did not differ between areas of residence (Table 8).

Table 8: Length of time living with HIV by Sex

	Male (n=191) n (%)	**Female (n=315) n (%)**	**Transgender (n=3) n (%)**	**Total (N=509) n (%)**
Length of time living with HIV (yrs)				
0-1	20 (42)	28 (58)	00 (0)	48 (09)
1-4	54 (39)	83 (60)	01 (01)	138 (27)
5-9	72 (35)	132 (64)	02 (01)	206 (41)
10-14	26 (37)	44 (63)	00 (0)	70 (14)
15+	17 (45)	21 (55)	00 (0)	38 (07)
Not sure	02 (33)	04 (67)	00 (0)	06 (01)

Table 9: Distribution of respondents by place of residence and length of time living with HIV

	Length of time with HIV (years) (N=501) n (%)					
	0-1	**1-4**	**5-9**	**10-14**	**15+**	**Not sure**
Rural Area	14 (09)	37 (24)	64 (42)	24 (16)	13(08)	02 (01)
Small town/village	25 (09)	81 (29)	112 (40)	36 (13)	20 (07)	04 (01)
Large town or city	08 (12)	19 (27)	29 (42)	08 (12)	05 (07)	00 (00)
Total	**47 (09)**	**137 (27)**	**205 (41)**	**68 (14)**	**38 (08)**	**06 (01)**

Sexual Activity

Fifty-seven percent (57%) of all respondents reported being sexually active[8], with more male respondents (62%) reporting being active sexually than females (54%). Sexual activity differed by relationship status. More married/cohabitating females (49%) reported being sexually active than their male counterparts (37%). In addition, more single males reported being sexually abstinent (83%) than single females (72%) (see Table 9).

Table 10: Sexually activity by relationship status (N=489)

	Sexually active n (%)		***Sexually Inactive n (%)***		***Total N (%)***
	Males	**Females**	**Males**	**Females**	
Married/Cohabiting	42 (37)	82 (49)	04 (06)	14 (10)	142 (100)
In a relationship but not living together	28 (25)	54 (32)	06 (09)	12 (09)	100 (100)
Single	42 (37)	23 (14)	57 (83)	100 (72)	222 (100)
Divorced/Separated Widowed	01 (0.9)	08 (5.0)	02 (03)	12 (09)	23 (100)
Total	113 (100)	167 (100)	69 (100)	140 (100)	489 (100)

*missing one

Children

Eighty-four percent (84%) of respondents (72% of males and 91% of females) reported having children. Seventeen percent (17%) of all respondents reported having a child in their household living with HIV. Seven percent (7%, n=35) of respondents reported having children in their household whose parents or former guardians have died from AIDS and 3.3% (n=17) reported having youth aged 16-25 years in their household whose parents had died from AIDS.

Of those respondents that reported having a child living with HIV in their household (n=68), the data by region shows that the majority of HIV positive children in this

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[8] The UNAIDS People Living with HIV Stigma Index User Guide, sexually active was defined as follows: "There is not one, all-encompassing definition for the term sexually active. For some people, being sexually active means vaginal or anal sex, for others it means oral sex and for others it might simply mean kissing and touching their partner".

sample resides in the southeast region (21%, n=24), followed by the western region (12%, n=18), northeast (18%, n=16) and southern region (17%, n=10) (See Table 10).

Table 11: Proportion of respondents that have HIV positive children in their household by region

	Region				
	Southern n (%)	Northeast n (%)	Western n (%)	Southeast n (%)	Total N (%)
Have HIV positive children	10 (17)	16 (18)	18 (12)	24 (21)	68 (16)

3.1 Key Populations

The general definition of a key population group was defined by the UNAIDS Stigma Index (see Appendix I). In Jamaica, the key populations are MSM, sex workers, prisoners, IDUs, and the displaced (homeless).

In the survey, respondents were asked if they belonged to or had they in the past, to any specific category of persons (see Appendix II). Eighty-seven percent (87%) of respondents did not identify with any key group. Of those that did identify as a member of a specific population group, 4% were MSM, 2% prisoner, 1% sex worker, 1% gay/lesbian, and 1% displaced person. Four (4) persons reported being in more than one key population category. The breakdown in key populations is shown in figure 4.

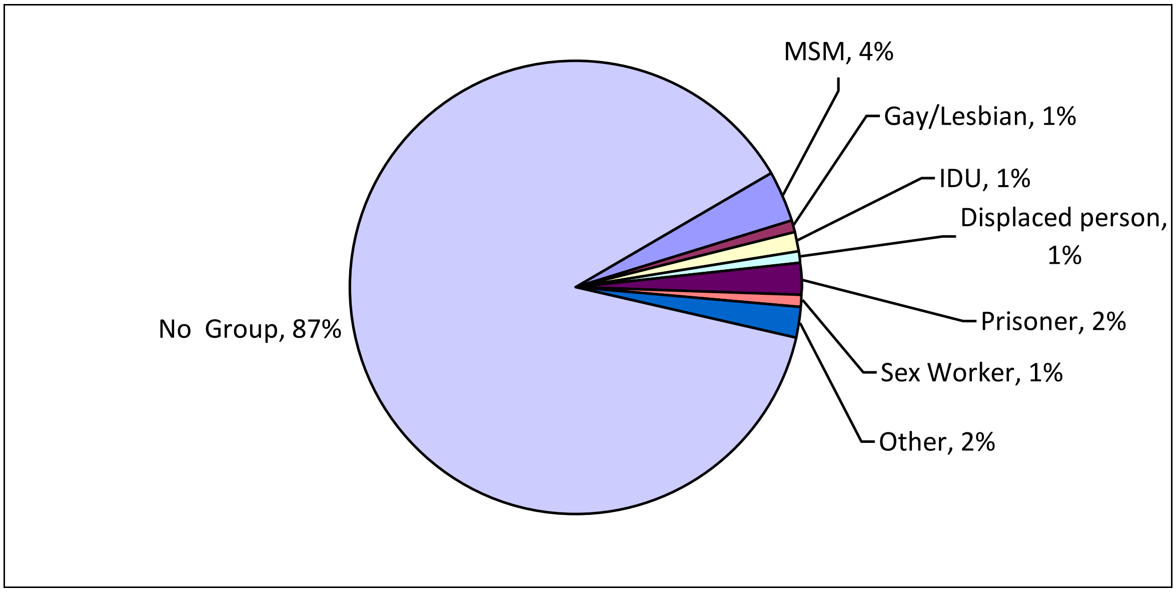

Figure 3: Proportion of respondents that identified themselves as part of a key population group (N=509)

SECTION IV: FEAR AND EXPERIENCE OF STIGMA & DISCRIMINATION

This section describes levels of internal stigma experienced by persons living with HIV, fears of stigma and discrimination based on their status and how fear of discrimination impacts their social and personal lives. This section also provides a description of respondents' actual experience of stigma and discrimination in the communities in which persons reside. Experience of discrimination related to access to work, housing, health and education services are also provided.

4.1 Internalized Stigma

Internal stigma, also referred to as "felt" stigma or "self-stigmatization" is used to describe the way a person living with HIV feels about themselves and specifically if they feel a sense of shame about being HIV-positive[9]. Internal stigma can lead to low self-esteem, a sense of worthlessness and depression[10]. Data suggests that the psychological state of persons living with HIV is characterized by various negative thoughts about their HIV status with experiences of stigma and discrimination in their community. Respondents in this study revealed high levels of internal stigma.

'Blaming oneself' for their HIV status was mentioned by respondents most often (63%), followed by feelings of 'guilt' (53%), and 'shame' (51%) (see figure 4). 'Blaming others' was also reported by 43% of those interviewed. Twenty percent (20%) respondents also reported feeling suicidal.

Levels of internal stigma differed by sex. Male respondents were more likely to 'blame themselves' (68%) than females (59%). In addition, males reported feelings of 'guilt' (53%), and 'shame' (41%). Males also reported having low self-esteem (28%) and 8% of male respondents felt they 'should be punished'. Thirteen percent (13%) of males reported feeling suicidal.

In contrast, 58% of female respondents interviewed reported having feelings of 'shame', 53% felt 'guilty', 14% felt they 'should be punished' and 40% reported having low self-esteem because of their HIV status. Twenty-four percent (24%) of females reported feeling suicidal, almost two times more than male respondents (see figure 4).

Analysis also revealed that these deep feelings of internal stigma exist regardless of age (see Table 11). Half of the persons living with HIV between 16-19 years of age reported having low-esteem, and 67% reported feeling 'ashamed' and 'blamed others' for their HIV status. Respondents in their twenties reported high levels of

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[9] UNAIDS People Living with HIV Stigma Index User Guide, Key Definitions and Concepts
[10] ibid

internal stigma. Those aged 20-29 years reported greater feelings of self-blame and guilt as well as report having low-self-esteem. Thirty five percent (35%) of respondents aged 20-29 years reported feeling suicidal; greater than members of any other age group. Older persons also reported feelings of 'self-blame', 'guilt' and 'shame'. Sixty-six percent (66%) of respondents over the age of fifty blamed themselves and 55% had feelings of 'guilt' (see Table 11).

The length of time living with HIV reduced these negative feelings. Respondents with HIV for 5-9 years reported higher greater feelings of self-blame, 'shame' and 'guilt' than those living with HIV longer (43%, 41% and 43% respectively). Persons living with HIV for 10-14 years had reported blaming themselves less (13%), and had less 'guilt' (14%) and 'shame' (14%) regarding their status. Those that had lived with HIV for 15 or more years also reported less internalized stigma; they reported feeling less self-blame (6%), 'shame' (5%) and 'guilt' (4%) (see Table 11).

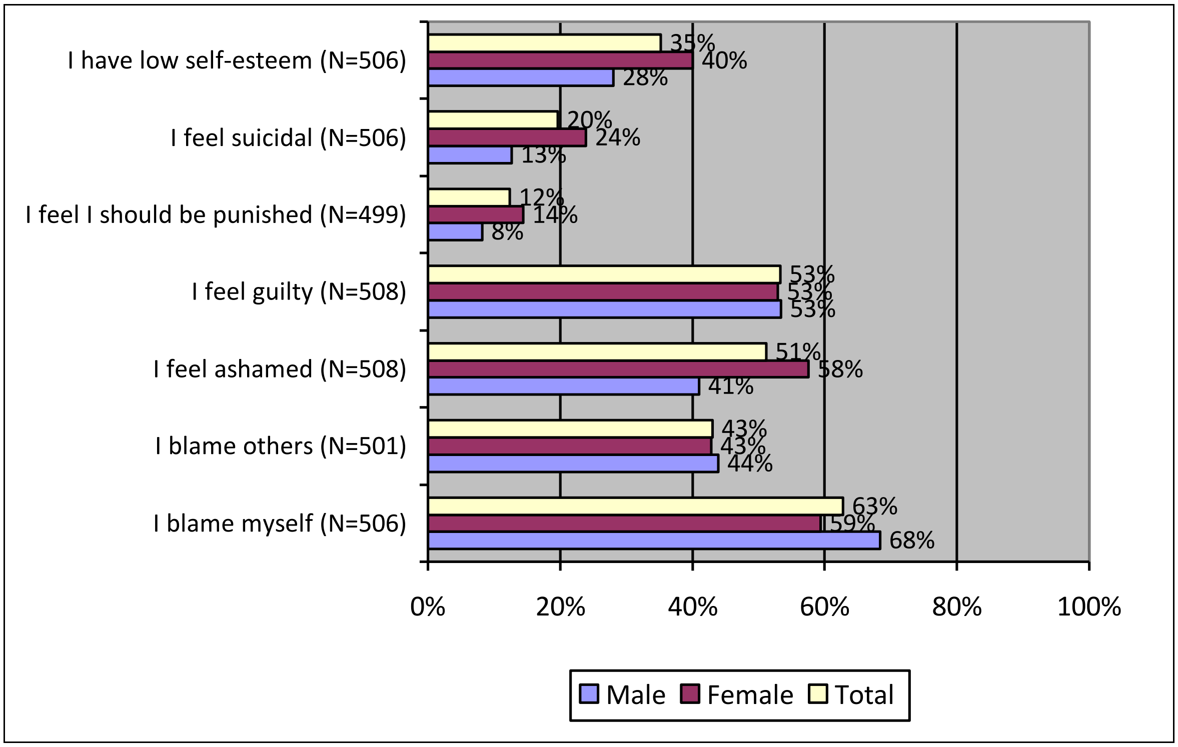

Figure 4: Proportion of respondents that have reported internalized stigma by sex

Table 12: Percentage distribution of internalized stigma by age

	20-29 N=83 (%)	30-39 N=174 (%)	40-49 N=147 (%)	50+ N=98 (%)
I blame myself	67	61	60	66
I blame others	51	36	47	42
I feel ashamed	54	52	51	47
I feel guilty	55	52	53	55
I feel I should be punished	22	10	14	06
I feel suicidal	35	14	20	16
I have low self-esteem	37	29	41	34

*Insufficient numbers of respondents in these groups do not allow for statistically valid conclusions; Categories not mutually exclusive

Social Restrictions

Internal stigma about one's HIV status can result in persons excluding themselves from certain activities. Respondents in this study reported restricting themselves from several activities in the last 12 months because of their HIV status. Twenty-three percent (23%) reported isolating themselves and 23% did not attend a social gathering (see figure 5). Persons also reported avoiding the clinic (10%) or hospital (6%). However, the greatest restrictions persons living with HIV placed on themselves were related to their personal lives. Twenty-six percent (26%) of respondents reported that they decided not to get married, 33% decided not to have sex and 61% decided not to have children because of their HIV status (see figure 5).

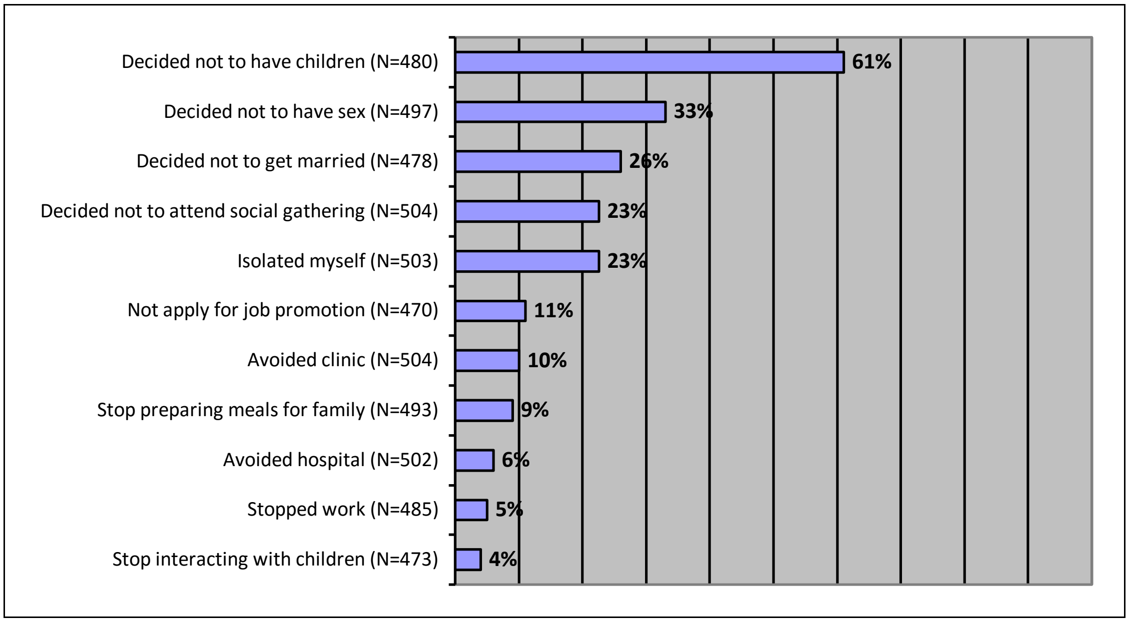

Figure 5: Proportion of activities avoided by PLHIV in the last 12 months because of HIV status

4.2 Experience of Stigma and Discrimination within Communities

Thirty-eight (38%) percent of respondents reported experiencing some form of stigma and discrimination in their community.

Fifteen percent (15%) of those surveyed reported that in the last 12 months someone in their household experienced discrimination as a result of their HIV positive status. Of those that experienced some form of HIV-related stigma or discrimination in the last 12 months, respondents were asked what they thought was the reason or cause of the discrimination. Perception of the reasons for the discrimination varied[11]. Twenty percent (20%) felt that it was because people don't understand how HIV is transmitted and are afraid, 17% felt that people think that having HIV is shameful and that they should not be associated with, 10% thought that people were afraid of being infected, 3% felt that it was because of a person's religious beliefs or moral judgments, 2% felt it was because they looked sick with symptoms associated with HIV, and 1% thought that it was because people disapproved of their lifestyle. Ten percent (10%) reported that they didn't know what the reason was for the discrimination.

Family and Community Discrimination:

One respondent explained that she has been "going through a lot of discrimination". The following has been her experience: *All her utensils at home have been labeled. They have stoned her house in her community. The whole community has told her that she has a life sentence. No one speaks to her; she is left alone. When she walks on the road, people say unkind things. In church, the priest does not allow her to sup from the cup with others -hers is provided separately.*

Psychological Pressure

Twenty-five percent (25%) of all respondents reported being subject to psychological pressure or manipulation like bullying, emotional pressure or verbal abuse. There was no difference in experience in psychological pressure in length of time living with HIV or sex. However there was a slight difference in this experience with age. Those who were under 30 years of age reported more experience with psychological pressure (29%) than those older than 30 years (25%). The majority of respondents (79%) reported never experiencing psychological pressure or manipulation about their HIV status by their spouse or partner.

Sexual Rejection

Seventeen percent (17%) of all respondents reported that they had experienced sexual rejection as a result of their HIV positive status in the last 12 months. More men (22%) than women (15%) reported experiencing sexual rejection, as well as those aged 25-29 years (21%) and those living with HIV for 10-14 years (23%).

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[11] Categories are not mutually exclusive

Gossip, Harassment and Abuse

Persons living with HIV experienced gossip, verbal and physical harassment, and physical assault in the past year. Over half of the respondents reported being gossiped about (54%), 30% reported verbal harassment, 12% physical harassment, and 8% experienced physical assault. Of those that experienced gossip, 70% perceived that the reason was because of their HIV status. Of those that were verbally insulted, harassed and/or threatened, 77% felt it was because of their status. Seventy-one percent (71%) of those that were physically harassed and 61% of those physically assaulted felt that it was because of their HIV status.

Experiences of gossip, harassment and abuse differed however by sex. Female respondents reported experiencing more harassment and abuse than male respondents (see figures 6 and 7). Females experienced slightly more gossip (55%) than males (51%), as well as more verbal insults than males (33% versus 25%). In addition, females reported more physical assault (14%) and physical abuse (9%) than males (10% and 5% respectively).

Persons living with HIV that were physically attacked reported being assaulted by persons outside of the household who was known to them (43%), by their spouse/partner (26%), and 20% were beaten by persons unknown to them.

Experience of Harassment and Abuse: A Tale of Torment

"Getting to know him, he told me that if any woman gave him the virus, he would kill her so I was afraid to tell him. I didn't tell him....He kept threatening and saying he will kill me . He said he will throw me in a pit toilet and no one will know. He monitors where I go. Whenever my friends are having a party, he wants to know where I am. If I am late, he threatens. Because of this, I am afraid to go out. Now that I am out, it is hard for me to go in. You know when you get release, it is hard to go back. He has the virus but I gave him. He curses me all the time that I gave him and he can't do what he wants to. I stay with him because I used to run around a lot and that is how I got HIV. I have to just batter in his hands alone."

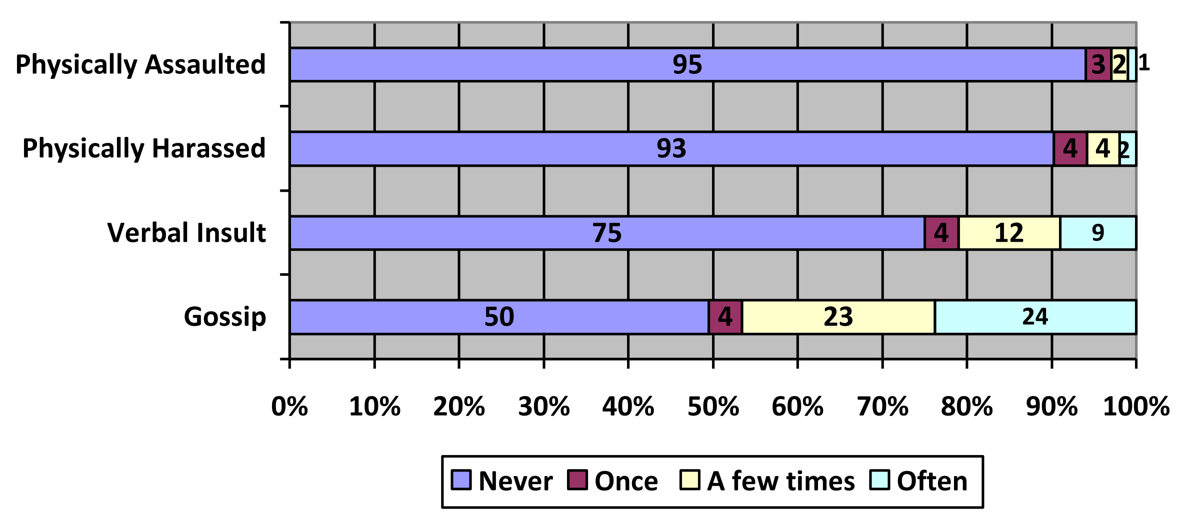

Figure 6: Proportion of types of stigma & discrimination males experienced in the last 12 months, (n=191)

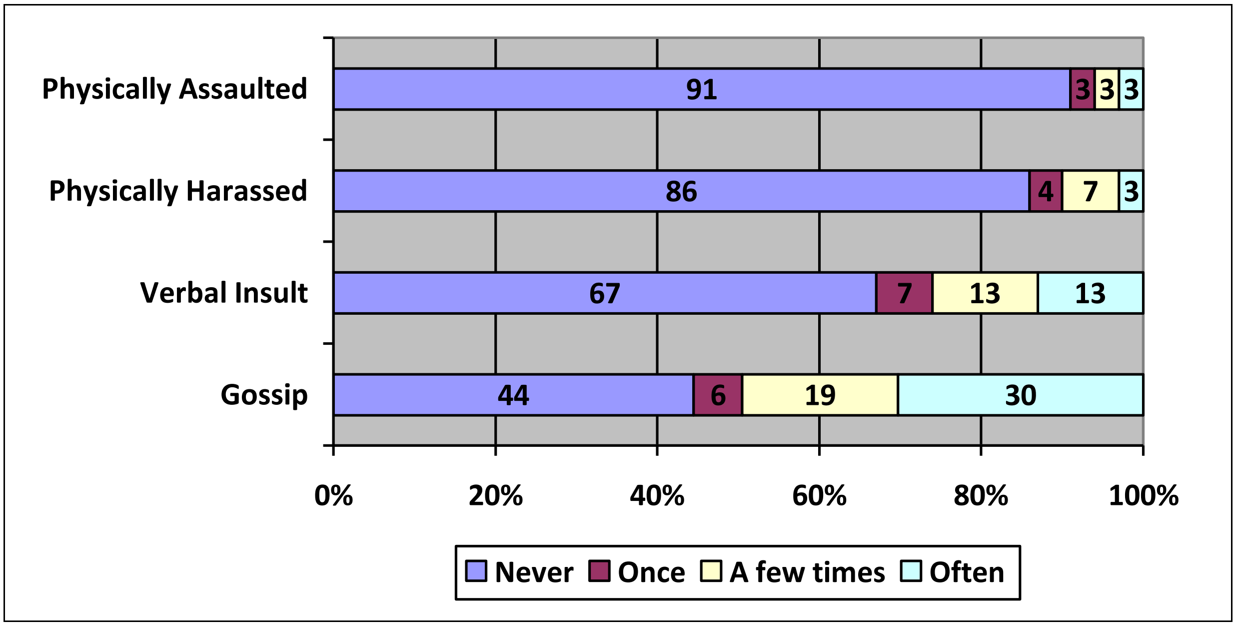

Figure 7: Proportion of types of stigma and discrimination females experienced in the last 12 months, (n=315)

Social Exclusion

Persons living with HIV have been excluded from activities and interactions with family and friends because of their HIV status. Respondents were asked whether or not in the last 12 months if they experienced being excluded from any activities. Thirteen percent (13%) stated that they were left out of social gatherings or activities, 12% were left out of family activities and 7% from religious activities or places of worship. Of those that were left out of social gatherings, 49% felt that it was because of their HIV status. Fifty-one percent (51%) of those left out of religious activities and 57% that were excluded from family activities felt it was because of their status.

Discrimination by other persons living with HIV

Eighty-two percent (82%) of respondents reported never being discriminated against by other people living with HIV. Of those persons who did report being discriminated against by other persons living with HIV, 20.5% reported being discriminated once, 51% reported it being a few times and 28% reported that it happened often. There was a slight difference in the frequency of its occurrence between males and females (see figure 8).

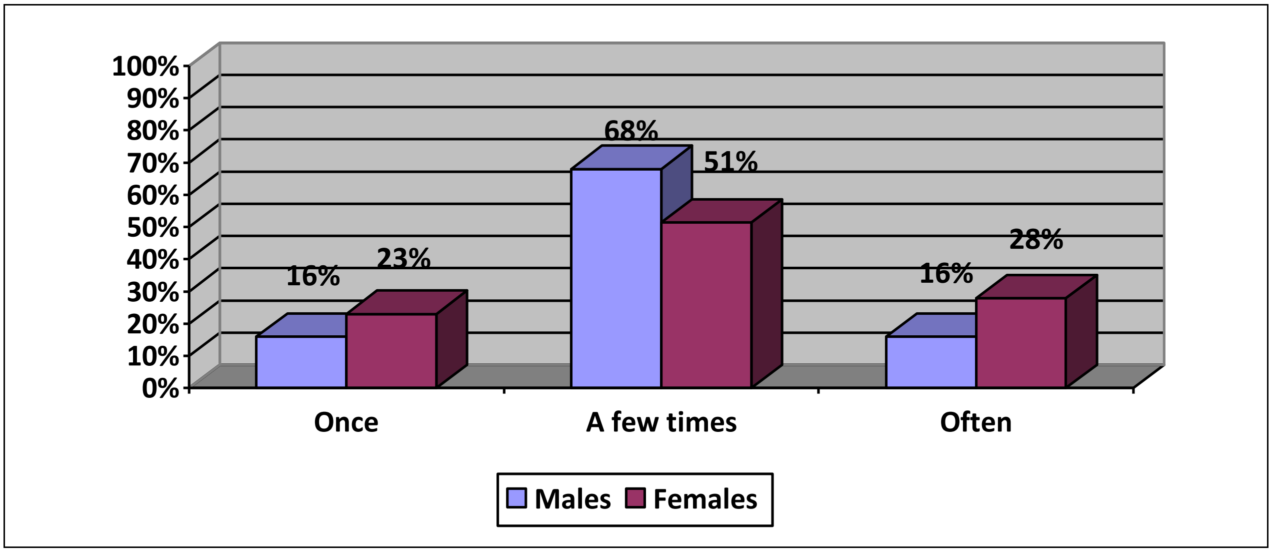

Figure 8: Frequency of Discrimination by PLHIV by sex

Respondents were asked whether they thought discrimination against persons living with HIV has gotten worse over the last five years and whether or not persons were experiencing less discrimination. Fifty-eight percent (58%) of respondents surveyed reported that discrimination did not get worse over the last five years and close to two thirds of respondents felt that persons living with HIV have been experiencing less discrimination.

Persons living with HIV who felt that discrimination has not gotten worse over the last five years tended to be older than 30 years of age (61%), male (65%), and lived in a rural area (67%). This opinion did not differ much by length of time living with HIV. Fifty-eight percent (58%) of those that have had HIV for 4 years or less and 60% of those living with HIV for 5 years or more shared this opinion.

The percentage of respondents that agreed with the statement that persons living with HIV were experiencing less discrimination over the last five years differed slightly by the length time living with HIV. Seventy-six percent (76%) of persons living with HIV for over 15 years had this opinion of experiencing less discrimination versus 67% of those living with HIV for 5-9 years and 64% of those with HIV for 10-14 years. Sixty-one percent (61%) of those living with HIV for 4 years or less had this opinion. In addition, persons 30 years and older (67%), those living all locations (rural small town/village and large town/city), and male respondents (72%) held this belief.

4.3 Fear of Stigma and Discrimination

Fear of Gossip, Harassment and Abuse

In the past 12 months, persons living with HIV reported being fearful of being gossiped about (52%), of verbal insult/harassment (47%), physical harassment (41%) and physical assault (41%) because of their HIV status. As Table 13 shows, these fears differed somewhat by age, sex, household location and length of time living with HIV (see Table 13). Gossip and verbal harassment were feared the most regardless of age, sex, length of time living with HIV, and residential location (see Table 13). Younger persons, especially those less than 25 years of age, were fearful of gossip, verbal and physical harassment and physical assault (see Table 12). Females reported fearing all forms of harassment more than males. Females were most fearful of gossip compared to males (58% versus 42%), physical assault (45% versus 36%) and physical harassment (45% versus 35%). Persons living with HIV residing in rural areas or small towns feared gossip and verbal harassment slightly more than those living in the city. In addition, persons living with HIV living in a large town/city were fearful of physical assault more than their rural area counterparts (46% versus 34% respectively) (see Table 12).

Over 40% of those living with HIV reported fearing gossip regardless of the length of time living with HIV, more than any other form of harassment (see Table 12). Respondents that were recently diagnosed or living with HIV for less than 4 years were more acutely fearful of gossip than others. These fears reduced somewhat the longer the person lived with HIV. Persons living with HIV for 15 or more years were less likely to report fears of verbal or physical harassment, or physical assault.

Table 13: Proportion of respondents that reported fear of gossip, verbal harassment, physical assault/harassment by age, sex, household locations and length of time living with HIV

	In the last 12 months, have you been fearful of any of the following happening to you*? n (%)			
	Gossip	Verbal Harassment	Physical Assault	Physical Harassment
Age (years)				
16-19	04 (67)	03 (50)	03 (50)	03 (50)
20-24	25 (71)	27 (79)	20 (59)	21 (62)
25-29	26 (54)	20 (42)	19 (40)	17 (35)
30-39	87 (51)	79 (47)	69 (41)	71 (42)
40-49	76 (52)	64 (43)	60 (41)	56 (38)
50+	45 (47)	42 (44)	36 (37)	39 (41)
Sex				
Male	80 (42)	82 (43)	68 (36)	67 (35)
Female	182 (58)	151 (49)	138 (45)	140 (45)
Transgender	01 (33)	02 (67)	01 (33)	0 (00)

	In the last 12 months, have you been fearful of any of the following happening to you?* n (%)			
	Gossip	Verbal Harassment	Physical Assault	Physical Harassment
Household Location				
Rural Area	83 (53)	66 (43)	52 (34)	57 (37)
Small town/village	144 (52)	135 (49)	122 (44)	123 (45)
Large town/city	32 (46)	31 (46)	31 (46)	25 (37)
Length of time living with HIV (yrs)				
0-1	27 (57)	20 (43)	19 (40)	20 (43)
1-4	78 (57)	70 (52)	61 (45)	61 (45)
5-9	98 (48)	98 (48)	78 (38)	81 (40)
10-14	38 (54)	32 (46)	33 (47)	29 (41)
15+	16 (43)	09 (24)	10 (27)	10 (27)
Not sure	04 (67)	04 (67)	04 (67)	04 (67)

*Categories were not mutually exclusive

Not only are persons living with HIV fearful of emotional and physical abuse by persons in their community, they also reported being fearful of additional reactions that may follow once community members (including family) were informed of their status.

The forms of discrimination that were most feared by persons living with HIV were neglect (36%) and isolation (21%), followed by house burning (14%) and beatings (7%) (see figure 9). Other forms of discrimination that were feared included their home or workplace being stoned, having their children be discriminated against, or scorn from the community. Sixteen percent (16%) of respondents reported being fearful of all forms of discrimination (neglect, isolation, house burning, beatings).

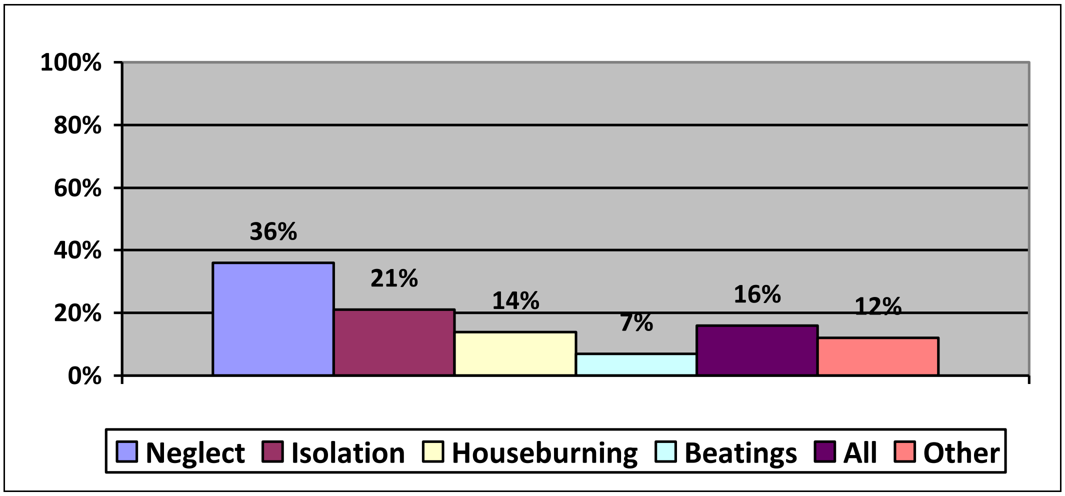

Figure 9: Proportion of types of discrimination PLHIV most fear (N=427)
Categories are not mutually exclusive
Other category includes being stoned, discrimination geared towards family members and scorn.

Fear of Sexual Rejection

Close to half (46%) of all respondents reported being afraid in the past year that someone would not want to be sexually intimate with them because of their HIV positive status. More females (61%) than males (38%) reported having this fear, as well as those aged 30 years and older (64%). Those living with HIV for 4 years or less reported being less fearful of sexual rejection (35%) than those living with HIV for 5 or more years (56%). Respondents living in a rural community (31%) and those living in a small town (60%) reported having this fear more than those living in a large town/city (9%).

Perception of Worst Forms of Discrimination

Eighty six percent (86%) of respondents reported that there are some groups of persons living with HIV that experience more severe forms of discrimination than others. More than half of the respondents (56%) felt that gays, lesbians, bi-sexuals were most likely to experience the worst forms of discrimination, followed by those who have signs or symptoms of illness such as rashes or sores on their skin (14%), sex workers (8%), those that disclose their status (7%) and the poor (6%) (see figure 10).

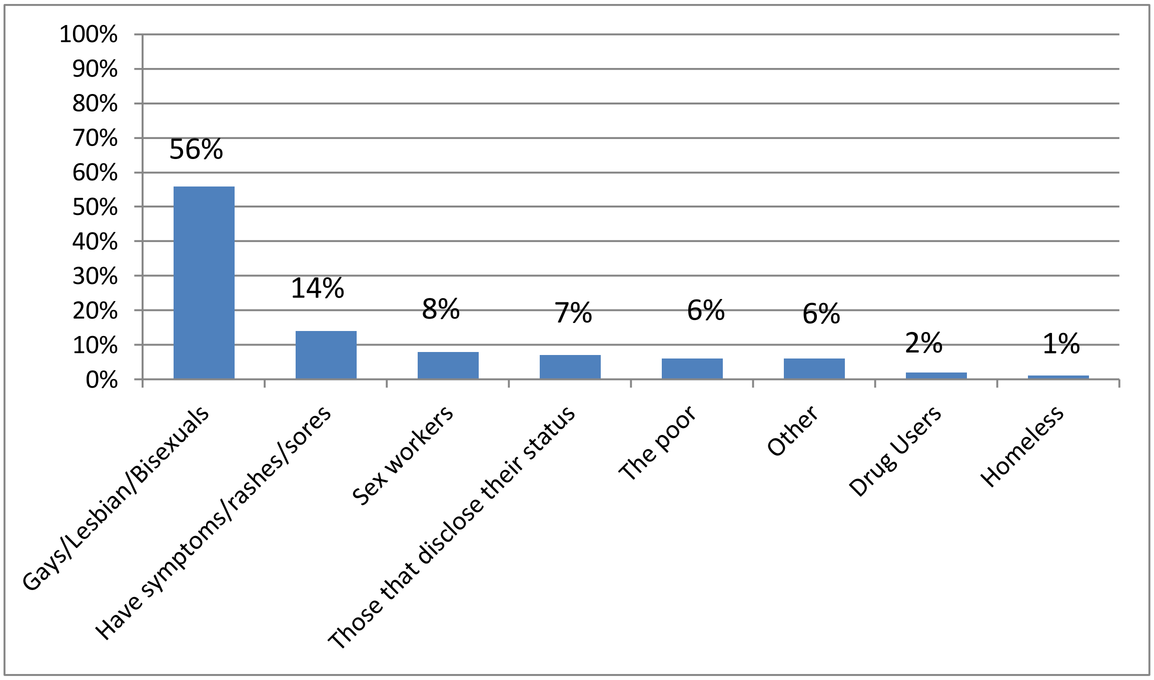

Figure 10: Perception of types of groups of PLHIV that experience worse forms of discrimination

Categories are not mutually exclusive

4.4 Access to work, housing, health and education services

In general, denial of access to housing, health and education services were infrequently reported.

Housing

In the last 12 months, 13% of respondents had been forced to change their place of residence or had been unable to rent accommodation. Of those that had been forced to move (n=64), 66% or 42 persons reported that it happened once, 14% had it happen a few times and 20% reported that it happened often. Sixty-seven percent (67%) felt that it was because of their HIV status. Female respondents and those living in a small town were more likely to have this experience.

Work

There was a high percentage of missing values (=>25%) with variables related to losing a job, refusal of employment and refusal of job promotion[12]. These variables therefore were not analysed.

Educational services

Only 1% (or 4 persons) reported that they had ever been dismissed, suspended or prevented from attending an educational institution because of their HIV status.
Due to the few number of persons who reported discrimination while attending an educational institution, no additional analysis was conducted with this variable.

Of those respondents that had children, 1% (n=5) reported that their child had ever been dismissed, suspended or prevented from attending an educational institution because of their (the respondents) HIV status. Three percent or 12 respondents were not sure whether their children had experienced this form of discrimination.

Access to health services

Three percent of study respondents (n=15) reported that in the last 12 months they had been denied access to health services because of their HIV status. Persons that reported being denied access to health services were over 30 years of age, living in a rural area or small town, and had been living with HIV for 15 years or more (see Table 13).

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[12] Job loss= "In the last 12 months, have you lost a job or another source of income?"
Refusal of employment or work opportunity="In the last 12 months have you been refused or a work opportunity because of your HIV status"
Refusal of promotion= "In the last 12 months, has your job description or the nature of your work changed or have you been refused promotion, as a result of your HIV status?

Table 14: Proportion of respondents that have been denied health services by age, sex, location, and length of time living with HIV

	***In the last 12 months, have you been denied health services, including dental care, because of HIV* status?** n (%)	
	Never	One or more times
Age (years) (N=500)		
16-19	05 (100)	0 (00)
20-24	32 (97)	01 (03)
25-29	48 (100)	0 (00)
30-39	160 (97)	05 (03)
40-49	138 (97)	05 (03)
50+	89 (96)	04 (04)
Sex (N=500)		
Male	176 (96)	07 (04)
Female	293 (97)	08 (03)
Transgender	03 (100)	0 (00)
Household Location (N=495)		
Rural Area	145 (97)	05 (03)
Small town/village	260(97)	09 (03)
Large town/city	63 (98)	01 (02)
Length of time living with HIV (yrs)(N=497)		
0-1	44 (100)	0 (00)
1-4	124 (97)	04 (03)
5-9	198 (98)	04 (02)
10-14	65 (95)	03 (05)
15+	33 (92)	03 (08)
Not sure	05 (83)	01 (17)

Four percent (4%, n=23) of persons living with HIV reported being denied family planning services. Of those that had been denied family planning services, 52% (n=12) were living in a rural area, and 35% (n=8) were in a small town. Females (87%, n=20) were more likely to have been denied family planning services than males. Persons were also more likely to be between the ages 30- 49 years (74%, n=17) and living with HIV between 1-4 years (48%, n=11) and 5-9 years (26%, n=6).

Four percent (4%, n=21) of persons living with HIV were also denied sexual and reproductive health services because of their status, and it occurred most frequently in a rural area (43%, n=9) or small town (48%, n=10). Females were more likely to have been denied sexual and reproductive health services (71%, n=15), those who were between age 30-39 (71%, n=15), and those living with HIV between 5-9 years (48%, n=10).

Regarding reproductive options, only 44% (n=181) of respondents reported ever receiving reproductive counseling (29% of male and 71% of female respondents) after being diagnosed (Table 14). Females between the age of 30-39 years, residing in a small town/village and living with HIV for 5-9 years were more likely to have received reproductive counseling.

Table 15: Proportion of respondents that ever received reproductive counseling by age, sex, location and length of time living with HIV

	Ever received reproductive counseling? n (%)	
	No (n=234)	Yes n=(181)
Age (years)		
16-19	02 (01)	01 (01)
20-24	17 (07)	11 (06)
25-29	21 (09)	20 (11)
30-39	72 (31)	87 (47)
40-49	75 (32)	49 (27)
50+	48 (20)	16 (09)
Sex		
Male	92 (39)	53 (29)
Female	143 (61)	130 (71)
Transgender	0 (00)	01 (01)
Household Location		
Rural Area	67 (29)	63 (35)
Small town/village	136 (58)	96 (53)
Large town/city	31 (13)	22 (12)
Length of time living with HIV (yrs)		
0-1	24 (10)	14 (08)
1-4	64 (27)	49 (27)
5-9	100 (43)	72 (39)
10-14	23 (10)	34 (18)
15+	18 (08)	14 (08)
Not sure	03 (01)	01 (01)

Twenty-eight percent (28%) of persons living with HIV were advised by a health care professional not to have children (22% of males and 78% of females). Furthermore, 10% of all respondents (7% male and 93% female respondents, (n=40)) reported that they were coerced into being sterilized. The relationship status of the respondents did not make a difference in coercion rates. Persons who lived in a rural area (37.5%) or a small town/village (55%) were more likely than those living in a large town/city (7.5%) to be coerced into sterilization.

In the last 12 months, seven females reported that they were forced by a health care professional to terminate their pregnancy. Five terminations (71%) were forced in the western region, one respectively in each of the southern and southeast regions.

SECTION V: EFFECTING CHANGE: COMBATING STIGMA AND DISCRIMINATION

5.0 Knowledge of Rights, Laws and Policies

Declaration of Commitment

Study respondents were asked about their knowledge of rights, laws and policies that protect the rights of persons living with HIV. Forty-one percent (41%, n=209) reported that they had heard of the Declaration of Commitment on HIV/AIDS and 38% reported that they discussed the content of the Declaration. Respondents that were familiar with the Declaration were female (65%) and 85% were older than 30 years of age. There was a difference in knowing about the Declaration of Commitment on HIV/AIDS and length of time living with HIV. Persons who have lived with HIV between 1-4 years (25%), and 5-9 years (42%) were more likely to know about the Declaration, followed by those living with HIV between 10-14 years (16%). The least likely were those living with HIV for less than a year and those living with HIV 15 years or more (9%). Persons residing in the southeast (32%) and western regions (31%) had knowledge of the Declaration compared to persons living in the northeast and southern regions (20% and 18% respectively).

National HIV Policy

Forty-nine percent (49%, n=250) of respondents reported that they knew of the National HIV Policy which protects the rights of persons living with HIV. Females (65%), those older than 30 years of age (84%) and persons living with HIV between 5-9 years (45%) and 1-4 years (26%) were more likely to know about the national policy (see Table 16). Persons living with HIV for one year or less (5%) were the least likely with that knowledge. Respondents living in the western (34%) and southeast (33%) regions were more familiar of the National HIV policy than those residing in the northeast (18%) and southern (16%) regions (see Table 15).

Abuse of Rights

Eleven percent (11%) of respondents (or 54 persons) reported that in the last 12 months their rights as a person living with HIV were abused, with 14 persons (or 26%) trying to get legal redress for their abuse. The types of human rights abuse experienced by persons living with HIV because of their HIV status varied. Being forced to submit to medical or health procedures was the most reported form of discrimination, followed by being denied health or life insurance (see Table 16).

Table 16: Proportion of respondents that report knowledge of National HIV Policy by age, sex, household location, length of time living with HIV

	Have you heard of the National HIV Policy which protects the rights of people living with HIV in this country? n (%)
	(N=250)
Age (years)	
16-19	02 (01)
20-24	16 (06)
25-29	22 (09)
30-39	100 (40)
40-49	65 (26)
50+	45 (18)
Sex	
Male	87 (35)
Female	163 (65)
Transgender	0 (00)
Household Location	
Rural Area	78 (31)
Small town/village	136 (55)
Large town/city	35 (14)
Length of time living with HIV (yrs)	
0-4	78 (31)
5-9	112 (45)
10+	60 (24)
Not sure	0 (00)
Region Respondent Resides	
Southern	37 (18)
Northeast	42 (20)
Western	64 (31)
Southeast	66 (32)

Table 17: Proportion of respondents that experienced specific forms of discrimination because of HIV Status

Type of Discrimination (N=509)	*n (%)*
Denied access to an educational facility	03 (0.6)
Forced to submit medical/ health procedure	17 (3.3)
Denied Health or Life Insurance	08 (1.6)
Arrested or Charged	03 (0.6)
Had to disclose status to enter another country	05 (1.0)
Had to disclose status for residence in another country	02 (0.4)
Detained, quarantined, isolated or segregated	05 (1.0)

Only 9% (n=48) of respondents reported being involved in any efforts to develop legislation, policies or guidelines related to HIV. Persons that have been involved in these efforts tended to be female, had completed secondary school, live in a small town/village and have been living with HIV between 5-9 years.

This may be due to 46% of persons living with HIV feeling that they did not have the power to influence decisions in any area (see Table 17). The areas persons felt they could influence were: legal/rights affecting persons living with HIV (31%), followed by local projects intended to benefit the HIV community (21%) and national programs or projects (18%).

Table 18: Areas of influence reported by respondents

Feel that PLHIV can influence decisions in the following areas (N=509)	*n (%)*
Legal/rights affecting PLHIVs	146 (31)
Local projects intended to benefit PLHIVs	102 (21)
National programmes/projects intended to benefit PLHIVs	84 (18)
Local government policies affecting PLHIVs	64 (13)
National government policies affecting PLHIVs	50 (10)
International agreements/ treaties	42 (08)
Cannot influence decisions in any area	232 (46)

Categories are not mutually exclusive

5.1 Confronting Discrimination

In the last 12 months, 24% of respondents reported that they had confronted, challenged or educated someone who was stigmatizing or discriminating against them. Persons more likely to confront discrimination were female (70%), between the 30-49 years (66%), and living in a small town (46%) (see Table 18).

Table 19: Characteristics of PLHIV more likely to confront discrimination

	In the last 12 months, have you confronted, challenged or educated someone who was stigmatizing and/or discriminating against you? (N=122)
	n (%)
Age (years)	
16-19	02 (02)
20-24	10 (08)
25-29	16 (13)
30-39	51 (42)
40-49	29 (24)
50+	14 (11)
Sex	
Male	36 (29)
Female	85 (70)
Transgender	01 (01)
Household Location*	
Rural Area	39 (32)
Small town/village	56 (46)
Large town/city	26 (22)
Length of time living with HIV (yrs)	
0-4	32 (26)
5-9	55 (45)
10+	35 (29)
Not sure	0 (00)

*missing 1

5.2 HIV Support Organizations

Sixty-two percent (62%) of respondents reported supporting other persons living with HIV in the last 12 months. The types of support offered to persons living with HIV were predominately emotional support (81%), physical support (like providing food or money), doing an errand (46%), followed by providing referrals to other services (17%).

Forty percent (40%) of persons living with HIV reported that they knew of groups or organizations that would help if they experienced stigma or discrimination. Knowledge of these organizations varied by age and sex. Older females were more likely to have knowledge of these groups/organizations. In addition, knowledge of these organizations varied by length of time living with HIV. Persons living with HIV between 5-9 years were more likely to be knowledgeable of organizations or groups that they can go to for help if they experienced stigma and discrimination (47%), followed by those living with HIV 10 or more years (27%) than those persons had been diagnosed for 4 years or less (25%).

The most recognized type of organization to help with stigma and discrimination issues were an HIV support group (84%), followed by a national NGO (e.g., Red Cross) (27%), a network of persons living with HIV (20%) and the National AIDS Council (19%) (see Table 19). Twelve percent (12%) of respondents (or 23 persons) reported knowing of other organizations, the majority of which were identified as a health centre/clinic or persons associated with a health centre (e.g., social worker, nurse).

Table 20: Proportion of respondents that have knowledge of types of organizations/support groups that can help with Stigma /Discrimination

Type of Organization* **(N=193)**	***n (%)***
PLHIV support group	162 (84)
National non-governmental organization	53 (27)
Network of people living with HIV	38 (20)
National AIDS Council	37 (19)
UN Organization	29 (15)
Local (community based) NGO	19 (10)
Faith Based Organization	19 (10)
A legal practice	05 (<1)
Human rights organization	25 (13)
International non-governmental organization	10 (05)

*Categories are not mutually exclusive

Even though most respondents were knowledgeable about support organizations for persons living with HIV, only 37% reported being a current member of an HIV support group or network. Members of support organizations were more likely to be female, live a small town/village in the southeast region, were over 30 years old and have been living with HIV between 5-9 years (see Table 20).

Table 21: Characteristics of Support Group Members by age, sex, location and length of time living with HIV and region

	Support Group Members n (%)
	(N=185)
Age (years)	
16-19	01 (20)
20-24	11(32)
25-29	14 (29)
30-39	74 (43)
40-49	57 (39)
50+	28 (29)
Sex	
Male	67 (36)
Female	118 (64)
Transgender	0 (00)
Household Location*	
Rural Area	56 (30)
Small town/village	90 (49)
Large town/city	38 (21)
Length of time living with HIV (yrs)	
0-4	44 (24)
5-9	88 (49)
10+	32 (17)
Not sure	0 (00)
Region Respondent lives	
Southern	34 (18)
Northeast	32 (17)
Western	40 (22)
Southeastern	79 (43)

5.3 Recommendations for HIV Support Organizations

Respondents were almost evenly split on what the most important activity an HIV support organization should be doing to address stigma and discrimination: advocating for the rights for all persons living with HIV (25%), educating persons living with HIV about living with HIV (including treatment literacy) (24.5%), raising awareness and knowledge of the public about AIDS (24%), and providing support to persons living with HIV by providing emotional, physical and referral support (20%). However, only 4% of respondents felt that advocating for the rights and/or support to particularly marginalized groups (e.g., MSM, injecting drug users, sex workers) was the most important activity for HIV support groups/organizations (see figure 11).

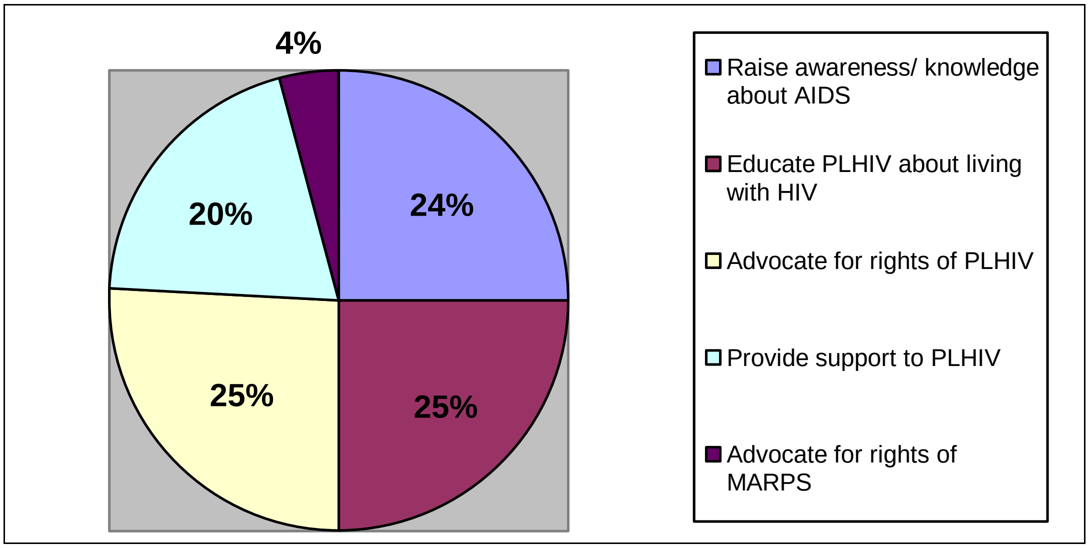

Figure 11: Recommendations for HIV support organizations for programming related to stigma and discrimination (N=488)

Recommendations for support organizations varied by certain socio-demographic characteristics. Persons living with HIV for four years or less felt that support organizations should assist persons living with HIV about living with HIV, including treatment literacy. This is a significant finding that has policy implications for service delivery related to treatment, care and support.

Persons living with HIV for 5-9 years were more likely to report that raising awareness and knowledge of the public about AIDS was the most important thing that organizations should be doing to address stigma and discrimination. Those living with HIV for 10 years or more were almost evenly split in their feeling what support organizations should be doing to address stigma and discrimination. This group reported that organizations should advocate for rights and/or support marginalized groups (26%) as well as advocate for the rights of all persons living with HIV (25%) (Table 21).

Suggestions for what organizations should do to address stigma and discrimination also varied by sex (see Table 21). Twenty-six percent (26%) of male respondents felt that the most important thing organizations should be doing is advocating for the rights of all persons living with HIV, as well as providing physical and emotional support (23%), raising awareness and knowledge of the public about AIDS (23%). Twenty-seven percent (27%) of female respondents reported that educating people living with HIV about living with HIV was the most important thing an organization should do followed by raising the awareness and knowledge of the public about AIDS (25%).

Table 22: Recommendations for what organizations should be doing to address stigma and discrimination by age, sex, household location, and length of time living with HIV

	What would you recommend as the most important thing that we should be doing as an organization to address stigma and discrimination? n (%) (N=489)					
	Advocate for rights of all PLHIV	Provide support to PHIV	Advocating for the rights/ support of MARPs	Educating PLHIV about living with HIV	Raising awareness/ knowledge about AIDS	All
Age (yrs)						
16-19	0 (00)	01 (17)	0 (00)	04 (67)	01 (17)	0 (00)
20-24	08 (24)	08 (24)	01 (03)	03 (09)	13 (39)	0 (00)
25-29	11 (24)	08 (18)	0 (00)	11(24)	14 (31)	0 (02)
30-39	39 (23)	39 (23)	02 (01)	41 (24)	42 (25)	07 (04)
40-49	33 (23)	28 (19)	12 (08)	38 (26)	30 (21)	02 (01)
50+	31 (34)	12 (13)	05 (05)	23 (25)	19 (21)	01 (01)
Sex						
Male	48 (26)	42 (23)	10 (05)	39 (21)	43 (23)	03 (02)
Female	73 (24)	53 (18)	10 (03)	81 (27)	75 (25)	08 (03)
Transgender	01 (33)	01 (33)	0 (00)	0 (00)	01 (33)	--
Household Location*						
Rural Area	38 (25)	27 (18)	06 (04)	43 (28)	35 (23)	03 (02)
Small town/village	69 (26)	52 (20)	12 (04)	62 (23)	65 (24)	05 (02)
Large town/city	15 (22)	16 (23)	02 (03)	15 (22)	17 (25)	02 (03)
Length of time with HIV (yrs)						
0-1	07 (16)	14 (32)	04 (09)	10 (23)	08 (18)	01 (02)
1-4	34 (26)	23 (17)	03 (02)	39 (29)	30 (23)	03 (02)
5-9	49 (24)	40 (20)	06 (03)	44 (22)	57 (28)	04 (36)
10-14	16 (24)	14 (21)	03 (04)	18 (27)	14 (21)	02 (03)
15+	14 (37)	05 (13)	02 (05)	06 (16)	10 (26)	01 (03)
Not sure	01 (25)	0 (00)	01 (25)	02 (50)	--	--

Missing 4

SECTION VI: Disclosure and Confidentiality

Eighty-eight percent (88%) of respondents reported never feeling pressured to disclose their status from persons living with HIV or from other individuals (e.g., family, friends) not living with HIV. An analysis was conducted to examine disclosure of HIV status.

Persons living with HIV consider it prudent not to disclose their status in order to safeguard themselves from discrimination as well as to maintain important relationships.

"Some information is our death sentence".

"My family is loving and cohesive. We have a loving relationship, but they don't know about the HIV part".

"If my family knows about this [HIV positive status], I wouldn't have anyone. No one would bury me".

6.0 Pressure to Disclose to Persons Living with HIV

There was no difference between male and female respondents in pressure to disclose to other persons living with HIV (11% and 12% respectively) (see Table 23). Persons residing in a small town or village (16%) were more likely to feel pressure to disclose their status than those living in rural areas (6%) or a large town or city (7%). Sixteen percent (16%) of persons aged 20-24 years reported feeling pressure from other persons living with HIV or from groups/networks of people living with HIV to disclose their HIV status. Nineteen percent (19%) of respondents living with HIV between 10-14 years reported feeling the most pressured to disclose their status from other persons living with HIV, followed by those living with HIV for 5-9 years (13%) and those living with HIV for 15 or more years (13%) (see Table 23). Those living with HIV for less than a year reported feeling the least pressured. This may be indicative of the lack of disclosure overall by newly diagnosed persons.

6.1 Pressure to Disclosure to Others

Pressure to disclose to other persons, specifically those not living with HIV, was explored. There was no difference in male (14%) and female (13%) respondents in reporting feeling of pressure to disclose (see Table 23). However, there were slight differences in pressure experienced by respondents from others not living with HIV by age and household location. Persons 25-29 years old (24%) reported feeling more pressure to disclose their HIV status than other respondents (see Table 23). Slightly more pressure was felt by persons living with HIV in a rural area (16%) than in a small town/village (12%) or a large town/city (12%) to disclose their status. Persons living with HIV for longer periods reported feeling more pressure than others. Those living with HIV for 10 years or more felt the most pressured to disclose their status (23%) (see Table 22).

Table 23: Proportion of respondents that felt pressure to disclose their HIV status from persons living with HIV or Others by age and, sex, household location and length of time living with HIV (N=502)

	Felt pressure from PLHIV to disclose status N (%)		***Felt pressure from Others to disclose status*** N (%)	
	Never	One or more times*	Never	One or more times*
Age (years)				
16-19	06 (100)	--	06 (100)	--
20-24	26 (84)	05 (16)	27 (84)	05 (16)
25-29	42 (88)	06 (12)	35 (76)	11 (24)
30-39	155 (89)	19 (11)	147 (86)	24 (14)
40-49	128 (88)	16 (12)	128 (91)	13 (09)
50+	87 (89)	09 (11)	84 (88)	11 (12)
Sex				
Male	167 (89)	21 (11)	157 (86)	25 (14)
Female	275 (88)	36 (12)	265 (87)	39 (13)
Transgender	02 (67)	01 (33)	03 (100)	--
Household Location†				
Rural Area	145 (94)	10 (06)	118 (84)	23 (16)
Small town/village	233 (84)	43 (16)	242 (88)	33 (12)
Large town/city	62 (93)	05 (07)	80 (88)	08 (12)
Length of time living with HIV (yrs)				
0-1	45 (96)	02 (04)	41 (93)	03 (07)
1-4	124 (92)	11 (08)	118 (89)	15 (11)
5-9	176 (87)	27 (13)	174 (88)	23 (12)
10-14	57 (81)	13 (19)	53 (77)	16 (23)
15+	33 (87)	05 (13)	32 (86)	05 (14)
Not sure	06 (100)	--	06 (100)	--

*Due to insufficient numbers in the individual categories (once, a few times, often and unsure), responses were grouped into one category ('one or more times')

6.2 Disclosure

When respondents decided to reveal their status, it was predominately to those they may have felt needed to know. Persons living with HIV disclosed their status to health care providers (61%), social workers (59%) their partners (58%) and other adult family members (57%). However, respondents were less likely to disclose their status to someone they were dating, children in their family or friends/neighbors (see Table 23).

Disclosure by others without the respondent's consent was most common among friends and neighbors (26%), community leaders (15%) and other persons living with HIV (15%). Respondents also reported that health providers and social workers were also told about their without their consent (26% respectively). Persons least likely to know of the respondents' HIV status were community leaders (79%), employers (62%) and children in the family (47%).

Table 24: Proportion of respondents that have disclosed their status to others †

	I told them	Someone else told them with my consent	Someone else told them without my consent	They don't know my status
Husband/wife/partner	58	03	13	26
Someone you are dating	46	02	11	40
Adult family member	57	03	13	27
Children in your family	43	02	08	47
Your friends/neighbors	29	<01	26	45
Other PLHIV	55	01	15	28
Co-workers*	22	--	14	63
Employers	23	01	14	62
Clients *	30	--	07	63
Injecting drug partner*	06	--	11	83
Religious leaders	29	01	11	59
Community leaders	04	02	15	79
Health care workers	61	10	26	03
Social workers	59	11	26	03
Teachers*	12	--	05	83
Government officials*	13	--	07	80
Media*	07	--	07	86

* The insufficient number of respondents in these groups does not allow for valid conclusions.

6.3 Reaction to Disclosure

Reaction to disclosure of HIV status varied (see Table 24). Respondents reported that health care workers and social workers were more supportive (83% and 91% respectively) than discriminatory (4% and 1% respectively) towards persons living with HIV. Spouses/partners and other adult family members that knew of the respondents' HIV status were supportive but may also show signs of discrimination. Seventeen percent (17%)of respondents reported that their spouses/partners were discriminatory towards them. Children of the respondents were also reported to be very supportive (57%). Religious leaders were more likely to be supportive and tolerant with 9% reporting a level of discrimination. Friends and neighbors tended to be discriminatory towards persons living with HIV (30%) followed by co-workers (22%).

Table 25: Reaction to respondent's HIV status

	Very discriminatory	Discriminatory	No different	Support-ive	Very Supportive
Husband/wife/partner	13	04	14	22	47
Someone you are dating	06	03	16	36	39
Adult family member	10	06	13	25	46
Children in your family	04	03	09	27	57
Your friends/neighbors	20	10	16	31	23
Other PLHIV	03	03	18	51	25
Co-workers	10	12	16	40	21
Employers	09	11	15	30	34
Clients*	--	07	29	43	21
Injecting drug partner*	25	--	25	37	12
Religious leaders	07	02	24	31	37
Community Leaders*	10	--	20	50	20
Health care workers	02	02	14	55	28
Social workers	--	01	09	51	40
Teachers*	10	10	02	50	10
Government officials*	--	--	50	17	33
Media*	--	25	--	75	--

* The insufficient number of respondents in this group does not allow for valid conclusions.

6.4 Disclosure and Empowerment

Sixty-five percent (65%) of those that disclosed felt that telling persons about their HIV status was empowering. Slightly more males than females felt empowered by disclosing their status (56% versus 53%). Fifty-nine percent (59%) of those aged 30-39 years and 55% of those 40-49 years felt the most empowered by their disclosure. Younger persons felt the least empowered from the disclosure of their status (<1%). This is probably because this age group was the least likely to disclose their status. Persons living in rural areas (59%) and large town/cities (58%) were feeling slightly more empowered with their disclosure compared to those living in a small town or village (52%).

6.5 Confidentiality and Health Services

Half of all respondents felt that a health care professional never told other people about their HIV status without their consent. However, 39% weren't sure if the health care worker told someone or not. Respondents were less sure about the confidentiality of their medical records. Over half (52%) of the respondents felt that they weren't sure if their medical record was kept completely confidential and 16% felt that it was clear to them that their medical records were not being kept confidential at all. This is a concern for the health system if patients perceive that there is a general lack of confidentiality surrounding the privacy of their status and their medical records.

Characteristics of persons living with HIV that were confident that their medical record is kept confidential were persons that were over 50 years of age, male, living in the southern region and have been living with HIV for a year or less (see Table 26). Those that were unsure of the privacy of their medical record were between the ages of 30-39 years (63%), female (55%), had been living with HIV for between 1-4 years (57%) and resided in the western or southern region (56% respectively).

Persons that didn't trust that their health centre was keeping their health information relating to their HIV status private were more likely to be younger, female, and living in the southern region (see Table 25).

Table 26: Proportion of respondents that report level of confidentiality with medical record by age, sex, length of time living with HIV and region

	How confidential do you think the medical records relating to your HIV are? (N=475) n (%)		
	I am sure that my MR will be kept confidential	I don't know if my MR will be kept confidential	It is clear to me that my MR are not being kept confidential
Age (years)			
16-19	02 (40)	02 (40)	01 (20)
20-24	10 (29)	17 (50)	07 (21)
25-29	14 (30)	25 (53)	08 (17)
30-39	34 (21)	101 (63)	26 (16)
40-49	53 (38)	63 (45)	23 (16)
50+	36 (40)	40 (45)	13 (15)
Sex			
Male	63 (35)	88 (49)	29 (16)
Female	84 (29)	160 (55)	49 (17)
Transgender	02 (100)	--	--
Length of time living with HIV (yrs)			
0-1	18 (42)	23 (53)	02 (05)
1-4	25 (31)	46 (57)	09 (11)
5-9	62 (32)	98 (51)	31 (16)
10-14	09 (27)	15 (45)	09 (27)
15+	14 (39)	16 (44)	06 (17)
Not sure	01 (17)	03 (50)	02 (33)
Region Respondent Resides			
Southern	29 (43)	23 (34)	16 (23)
Northeast	29 (29)	53 (53)	17 (17)
Western	45 (27)	93 (56)	29 (17)
Southeast	46 (33)	79 (56)	16 (11)

MR=medical record

SECTION VII: HIV TESTING, DIAGNOSIS, AND TREATMENT

7.0 HIV Testing

Over 74% of respondents reported that they made the decision themselves to get tested for HIV. However 11% reported getting tested without their knowledge, 9% reported being forced to get the test, and 4% reported that they took the decision to get tested but was under pressure to do so. The decision to get tested themselves varied slightly between male (78%) and female respondents (74%); however female respondents also reported that they were made to take an HIV test (11%) slightly more than males (7%) (See Table 26).

The decision to get tested for HIV also varied by age and area of residence (see Table 27). Eleven percent (11%) of persons living in a small/town village reported that they were forced to take an HIV test, and 14% were tested without their knowledge compared to those living in a large town/city or rural area (9% and 7% respectively).

Table 27: Decision to get tested by sex, age, and location

	Decision to get tested (N=502) n (%)			
	Took decision myself to get tested (voluntary)	Took the decision to get tested but under pressure from others	I was made to take an HIV test (coercion)	I was tested without my knowledge and only found out after test done
Sex				
Male	147 (78)	08 (04)	14 (07)	20 (11)
Female	229 (74)	13 (04)	34 (11)	34 (11)
Age (years)				
16-19	03 (60)	00 (00)	01 (20)	01 (20)
20-24	27 (79)	01 (03)	05 (15)	01 (03)
25-29	35 (76)	01 (02)	05 (11)	05 (11)
30-39	136 (79)	07 (04)	12 (07)	17 (10)
40-49	107 (73)	06 (04)	17 (12)	17 (12)
50+	70 (71)	06 (06)	08 (08)	14 (14)
Location*				
Rural area	127 (82)	05 (03)	11 (07)	11 (07)
Small town/village	195 (71)	12 (04)	29 (11)	38 (14)
Large town/city	53 (75)	04 (06)	06 (09)	06 (09)

*missing 5

Study respondents reported a variety of reasons for getting tested for HIV without consent. The most common reasons for being tested included referral due to suspected HIV symptoms (22%), pregnancy (17%), just wanted to know (16%) and illness or death of a spouse or family member (15%) (see Table 27).

Table 28: Reason Tested for HIV

*Reason tested for HIV** (N=502)	*n (%)*
Referred due to suspected HIV related symptoms	111 (22)
Pregnancy	87 (17)
I just wanted to know	80 (16)
Illness or the death of husband/wife/partner/family member	79 (15)
Husband/wife/partner/family member tested positive	40 (08)
Became ill	32 (07)
Referred by a clinic /STI	24 (05)
Employment	14 (03)
Prepare for marriage/sexual relationship	05 (01)
Weight loss/rash	05 (01)
Donated blood	05 (01)
Travel/migration	04 (<1)
Rape	03 (<1)
Other	36 (08)

*Categories are not mutually exclusive
Other reasons included: test taken in prison, gossip, had pap smear, had surgery

7.1 HIV Pre-Post Test Counseling

Forty-three percent (43%) of respondents revealed that they did not receive any counseling when they got tested and 23% reported that they only received post-test counseling only. Only 30% reported that they received both pre-and post-test counseling (see Table 28).

In addition, 44% of those aged 30-39 years reported that they didn't receive any HIV counseling and close to half of those aged 50 and over did not receive any counseling when they were tested for HIV (Table 290). Persons living in rural areas were also less likely to receive HIV counseling (Table 29). These findings show that more work needs to be done in training health care providers in following HIV testing protocols, especially with younger persons.

Table 29: Type of HIV Counseling Received

HIV Counseling (n=499)	n (%)
Did not receive any counseling	213 (43)
Received both pre and post-test counseling	148 (30)
Received post-test counseling only	116 (23)
Received pretest counseling only	16 (03)
Don't remember	06 (01)

Table 30: Type of HIV Counseling received by age, sex, and location

	Did you receive counseling when you were tested for HIV (N=499) n (%)				
	Received both pre/post HIV test counseling	Received pre-test counseling only	Received post-test counseling only	Did not receive any counseling	Don't remember
Sex					
Male	58 (31)	06 (03)	41 (22)	82 (44)	00 (00)
Female	90 (29)	10 (03)	74 (24)	130 (42)	05 (02)
Age (years)					
16-19	01 (20)	00(00)	00 (00)	04 (80)	00 (00)
20-24	11 (33)	02 (06)	07 (21)	13 (39)	00 (00)
25-29	14 (29)	03 (06)	13 (27)	17 (35)	01 (02)
30-39	52 (30)	05 (03)	38 (22)	75 (44)	02 (01)
40-49	49 (34)	03 (02)	33 (23)	58 (40)	01 (01)
50+	21 (22)	03 (03)	25 (26)	46 (47)	02 (02)
Location*					
Rural area	40 (26)	01 (01)	41 (27)	69 (45)	03 (02)
Small town/village	88 (32)	08 (03)	59 (22)	113 (42)	03 (01)
Large town/city	20 (29)	07 (10)	15 (22)	27 (39)	00 (00)

*missing 5

7.2 Health status

Overall, most respondents reported that they were in excellent/very good health; 61% of females and 56% of males reported being in excellent health. Over two-thirds of persons residing in rural areas and those living in large towns also reported being in excellent health. Persons who were more likely to report being in fair or poor health were aged 40-49 years (21%), male (19%), residing in a small town / village (19%) and had been living with HIV for a year or less (23%) (see Table 30).

Table 31: Health status of respondents by age, sex, household location and length of time living with HIV

	Health status (N=506) n (%)		
	Excellent/ v. good	Good	Fair/Poor
Age (years)			
16-19	04 (67)	01 (17)	01 (17)
20-24	17 (50)	11 (32)	06 (18)
25-29	29 (60)	10 (21)	09 (19)
30-39	114 (65)	36 (21)	24 (14)
40-49	85 (58)	30 (20)	31 (21)
50+	51 (53)	29 (30)	17 (17)
Sex			
Male	108 (56)	47 (25)	36 (19)
Female	189 (61)	70 (22)	52 (17)
Transgender	03 (100)	--	--
Household Location*			
Rural Area	102 (66)	32 (21)	21 (13)
Small town/village	152 (55)	70 (25)	54 (19)
Large town/city	44 (64)	14 (20)	11 (16)
Length of time living with HIV (yrs)*			
0-1	22 (47)	14 (30)	11 (23)
1-4	81 (62)	37 (27)	18 (13)
5-9	127 (60)	42 (20)	36 (18)
10-14	42 (60)	14 (20)	14 (20)
15+	25 (66)	08 (21)	05 (13)
Not sure	02 (33)	01 (33)	03 (50)

7.3 Anti-retroviral Treatment

Use and Access of ART

Eighty five percent (85%) of all respondents reported currently taking anti-retroviral treatment (88% males and 83% females) (see Table 31). There wasn't any difference in the proportion of those on anti-retroviral treatment by location of household (rural area (86%), small town/village (85%) or large town/city (83%); however there was a difference in age and among those who had been living with HIV longer. The age groups least likely to report taking ART are those 16-19 years (33%) and 20-24 years (62%). The majority of persons living with HIV over the age of 30 were taking ART in this sample.

Overall, 89% of respondents reported access to ART even if they weren't currently taking it. The high proportion of persons reporting access to and taking anti-retroviral treatment can be partially attributed to the recruitment of participants from HIV treatment sites.

There was no difference between males and females in access to ART (Table 33). Persons living with HIV less than 25 years of age however were less likely to report having access to ART than their older counterparts (77% on ART less than 25 years; 92% of those aged 25-39 years; 88% of those aged 40+ years). Those living with HIV for four years or less were also less likely to report being in antiretroviral treatment. There was no difference in access to ART based on location (rural area (89%), small town/village (89%) or large town/city (87%). Over 15% of respondents reported that their ability to obtain antiretroviral treatment was conditional on the use of certain forms of contraception.

Table 32: Proportion of respondents that reported currently taking ART by age, sex, household location and length of time living with HIV

	Are you currently taking anti-retroviral treatment (N=427)
	n (%)
Age (years)	
16-19	02 (33)
20-24	21 (62)
25-29	31 (66)
30-39	154 (89)
40-49	129 (88)
50+	90 (93)
Sex	
Male	167 (88)
Female	257 (83)
Transgender	03 (100)
Household Location*	
Rural Area	134 (86)
Small town/village	233 (85)
Large town/city	57 (83)
Length of time living with HIV (yrs)*	
0-1	32 (70)
1-4	109 (80)
5-9	182 (89)
10-14	65 (93)
15+	31 (82)
Not sure	05 (83)

*missing 3

7.4 Treatment of Opportunistic Infections

Nineteen percent (19%) reported they are taking medication to prevent or treat opportunistic infections (OI) (see Table 33). There was only a slight difference in proportion of males (18%) and females (20%) on OI medication. There was a difference however in the residential location of persons living with HIV taking medication to prevent or treat opportunistic infections. Persons living in a rural area or a small town/village were more likely to be taking OI medication (21% and 20% respectively) than those living in a large town/city (12%). However those living in a small town/village reported not being unsure of where to access OI medication (24%) than those residing in a large town/city (22%) or in a rural area (18%).

Table 33: Access to and use of antiretroviral treatment by sex

	Sex		*Total*
Currently taking ART	**Male (n=189) (%)**	**Female (n=311) (%)**	**(N=500) (%)**
Yes	88	83	85
Access to antiretroviral treatment, even if currently not taking it	**Male (n=188) (%)**	**Female (n=304) (%)**	**(N=492) (%)**
Yes	89	89	89
No/ Don't know	11	11	11

Table 34: Access to and current treatment for opportunistic infections by sex

	Sex		*Total*
Access to treatment for opportunistic infections, even if currently not taking	**Male (n=176) (%)**	**Female (n=287) (%)**	**(N=463) (%)**
Yes	**78**	**79**	**78**
No/ Don't know	**22**	**21**	**22**
Treating opportunistic infections	**Male (n=188) (%)**	**Female (n=312) (%)**	**(N=500) (%)**
Yes	18	20	19

Stopping ART Treatment

Of those reporting currently taking on ARTs, 44% revealed that they had ever stopped or had a strong desire to stop taking their medication. Reasons for stopping/ or wanting to stop taking their medication varied. The most common reason for wanting to stop their treatment included not liking the medication (22%), not having the required food to eat while on ART (22%), having to hide their medication from person in their households (9%) and the side effects (8%) (see Table 33). Females (47%) reported being more likely to stop the use/have the desire to stop taking anti-retrovirals than males (40%). Persons living in a small town/village (46%) were also more likely to report having ever stopped/ had a strong desire to stop taking ART than those living in a rural area or a large town/city (42% respectively).

Table 35: Proportion of respondents that reported stopping or having the desire to stop treatment

*Reason for stopping medication** (N=189)	*n (%)*
Don't like them	42 (22)
Don't have the required food to eat while on anti-retrovirals	42 (22)
Have to be hiding them from people in my household	17 (09)
Side effects/makes me sick	15 (08)
Too many pills/ pills too big	14 (07)
Feel tired of living sometimes	13 (07)
Experiences at the treatment site clinic	10 (05)
Tired of taking them	10 (05)
Don't remember to take them	09 (05)
Feel like they are not working	07 (04)
Don't know	10 (05)
Other**	20 (10)

*Categories are not mutually exclusive

**Other category includes depression, alternative medication, inadequate counseling

Discussion about treatment options

In the last 12 months, 57% of persons living with HIV reported that they have had a constructive discussion with a health care professional related to their HIV treatment options. Males were more likely than females to have this type of discussion (59% vs. 55%) and those living in a rural area (65%) were more likely to have this discussion than those living in a small town/village (52%) or a large town/city (56%).

In the last 12 months, 40% of respondents reported having had a constructive discussion with a health care professional on a subject related to sexual and reproductive health, sexual relationships, emotional well-being, drug use or something else. There was no difference in males or females in having discussions of this nature (39% respectively). Persons living in a rural area were more likely to have this type of discussion (45%) than those residing in a small town/village (37%) or a large town/city (40%).

SECTION VIII: CONCLUSION

Stigma and discrimination have been recognized as the main factors that need to be confronted to implement an effective, sustained response in HIV prevention, care and treatment (USAID, 2006). This research study provides insight into the level of stigma and discrimination experienced by persons living with HIV in Jamaica. The findings from this study demonstrate that fear of and experience with stigma, discrimination and the violation of human rights, are widespread. Hence, this report serves as a baseline for government and civil society organizations to not only improve the quality of HIV service delivery, but as evidence for anti-stigma and discrimination legislation.

This study was conducted in August and September 2010 with a sample of 509 persons living HIV in the four health regions across Jamaica. The study participants were predominately single (47%), unemployed (54%), females (62%) residing in small towns (56%) or rural communities (31%). The respondents were mostly between 30-49 years of age (63%) and have been living with HIV between 5-9 years (41%). Even though the study attempted to include persons from key vulnerable populations (e.g., MSM, sex workers), few persons identified as a member of these groups thereby limiting our knowledge of their experience with stigma and discrimination. The study however does provide an understanding of the perceptions and experiences of stigma and discrimination in their communities, levels of internalized stigma, awareness of the rights, laws, and policies affecting persons living with HIV, levels of and reaction to disclosure of their status, and recommendations on how to implement changes to enable persons living with HIV to live long, healthy, and fulfilled lives.

Findings from this assessment of stigma and discrimination among people living with HIV reinforce the literature that speaks to the vulnerability of persons living with HIV towards depression and anxiety (Collins, 2006; Katon, 1992, Myer, 2008). The data from this study show that persons living with HIV are suffering from depression, regardless of location of residence, age, sex, and length of time of living with HIV. On the whole, males are more likely to blame themselves and have feelings of guilt because of their HIV status. Females are more likely to report having feelings of shame, guilt and have low self-esteem. These feelings of shame, guilt and self-blame were common regardless of age. Persons in their early twenties were more likely to feel that they should be punished and felt suicidal than those in other age groups.

Perceptions and experiences of people living with HIV were stigma and discrimination in small towns and rural communities are exacerbated by social exclusion by family and friends. In addition, persons living with HIV restrict themselves from social activities because of fear of gossip, harassment and abuse. The forms of discrimination that were most feared by more than half of persons living with HIV in this study were neglect and isolation.

Disclosing one's HIV status is an important step in managing a chronic illness. Respondents expressed some pressure to disclose their status by persons living with HIV and others. Persons living with HIV in this study were more likely to disclose their status to their partners, adult family members, a health care worker or social worker. Persons were least likely to disclose their HIV status to friends, neighbours or community leaders. In the social environment, reaction to disclosure was overall positive, if they were the person to disclose or consent to the disclosure. However respondents encountered stigmatizing attitudes among neighbours and friends, especially when their status was shared without their consent.

Very few respondents reported being denied access to health facilities; however persons living with HIV encounter discriminatory practices in health care settings, where there are limited discussions about treatment options, sexual and reproductive health, sexual relationships and emotional well-being. Study participants also reported having noticed a general lack of confidentiality surrounding the privacy of their status and their medical records. In addition, respondents reported inconsistent HIV testing and counseling procedures by health care providers; almost half of all persons tested reported not receiving either pre or post-test HIV counseling.

Respondent's knowledge of rights, laws and policies that protect and support persons living with HIV were low. The majority of persons were not aware of the Declaration of Commitment on HIV/AIDS and the National HIV Policy. In addition, very few persons were familiar with the National HIV Related Discrimination Reporting and Redress System. This lack of knowledge makes it difficult for those seeking a legal remedy for abuse of their rights.

Persons living with HIV in this study had different opinions on how support organizations should be addressing stigma and discrimination. These recommendations varied in length of time of living with HIV. Newly diagnosed persons felt that organizations should be supporting persons living with HIV with information on treatment literacy and educating about living with HIV, while persons living with HIV for a longer period of time were more likely to report that raising awareness and knowledge of the public about AIDS was the most important thing that organizations should be doing to address stigma and discrimination. Very few persons reported for the need to advocate for the rights of key population groups. HIV support organizations need to use these findings to develop more specific outreach programmes.

In conclusion, these study findings point to the need for persons living with HIV to receive psychosocial support, regardless of age, sex and length of time living with HIV. To ignore the prevalence of anxiety and depression could result in unnecessary negative outcomes such as diminished quality of life and poor clinical outcomes. In addition, the National HIV Programme must address issues in service delivery to improve the quality of care of persons living with HIV. Ignoring these issues would not only result in decreased health seeking behavior, but would be seen as a tacit acceptance of the discrimination in health services to the HIV community. Finally, the research findings support the need for anti-stigma and discrimination legislation which would not only support and strengthen HIV programming efforts, but also inform the development and implementation of national policies that protect the rights of people living with HIV.

SECTION IX: POLICY and PROGRAMME RECOMMENDATIONS

The Policy and Programme recommendations presented in this section are based on the findings and gaps identified from the People Living with HIV Stigma Index study.

Findings	Issues	Policy & Programme Recommendations
Experience of Stigma and Discrimination		
• **Thirty-eight percent of PLHIV reported experiencing some form of S&D because of their HIV status.** • **The most common forms of discrimination experienced were gossip and verbal abuse** • **Discrimination amongst persons living with HIV differs slightly between males females. Females reported being gossiped about and being more physically harmed than men** • **The fear of S&D doesn't change over time; persons living with HIV for 10 years or more continue to live in fear** • **The greatest fear for PLHIV were being neglected and isolated** • **Discrimination was reportedly committed by other PLHIV** • **PLHIV perceive that gays, lesbians and bisexuals were more likely to experience worst forms of discrimination**	Lack of anti-discrimination and related legislation to protect those at risk of S&D because of HIV status Anti-stigma and discrimination campaigns in rural areas and small towns are insufficient Myths and misperceptions surrounding HIV and AIDS continue	*Programme:* • Strengthen coalition with governmental, non-governmental and faith based organizations to support anti-discrimination legislation • Develop anti-stigma and discrimination campaigns as part of HIV programming for rural areas and small towns • Continue to engage persons living with HIV in the design, planning and advocacy process to ensure that their concerns are adequately represented *Policy:* • Advocate for the development of an anti-discrimination legislation that included PLHIV and vulnerable populations including MSM, sex workers, youth, the mentally disabled, the physically challenged and others • Support the amendment or repeal of laws which discriminate on particular grounds or against specific groups of people

Findings	Gaps	Policy & Programme Recommendations
Access to health services		
• **40% of persons tested for HIV did not receive any pre or post-test counseling** • **Over 50% of study respondents were not sure if their medical records were kept confidential** • **Less than half of the respondents ever received reproductive health counseling** • **Female respondents reported being advised not to have children, being coerced in getting tubal ligations, and being forced to end their pregnancies.** • **PLHIV living in rural areas and small towns are more likely to be denied family planning and sexual and reproductive health services** • **Over 15% of respondents reported that their ability to obtain ART was conditional on the use of contraception** • **89% of study participants reported currently taking anti-retroviral medication;**	A comprehensive case management framework is needed to facilitate appropriate care and treatment Lack of psychosocial support providers to provide counseling to PLHIV HIV testing and counseling procedures are not implemented as mandated No policy guidelines on sexual and reproductive health for PLHIV The quality of health care service delivery for PLHIV living in rural areas and small towns needs to be monitored Lack of sanctions and/or enforcement of codes of conduct for health care works that violate patient rights Insufficient dissemination of	• Develop and implement a comprehensive case management framework for the care, treatment and support of persons living with HIV to remove ambiguity around patient management (including breaches of confidentiality) • Educate persons living with HIV to the case management framework to sensitize them as to how they will be supported by health facility staff • Increase psychosocial support for persons living with HIV to provide coping strategies as part of overall care and support regardless of length of time living with HIV • Review service delivery in rural areas and small towns to ensure that equitable services are being offered • Develop patient literacy strategy and tools • Review and improve HIV testing and counseling procedures • Develop a module for health care providers related to sexual and reproductive counseling • Train health care professionals on sexual diversity and its

19% reported currently treating an opportunistic infection	information related to appropriate clinic services	implications for care and treatment • Conduct sessions with health care workers on improving communication and listening skills *Policy* • Develop a comprehensive Sexual and Reproductive Health policy that includes HIV. • Enforce existing codes of conduct with health care providers that violate the rights of the patient • Review and improve sanctions for health care providers that display inappropriate professional behavior • Develop a patient rights document that identifies the rights and responsibilities of patients • Review HIV policies as it relates to confidentiality

Findings	**Gaps**	**Policy & Programme Recommendations**
Knowledge of Rights, Laws and Policies		
○ **Less than half of study respondents were aware of the Declaration of Commitment on HIV/AIDS or the National HIV Policy** • **11% reported their rights as a person living with HIV were abused** • **9% of respondents**	Lack of awareness by PLHIV of the rights, laws and policies that have been developed to protect the rights of PLHIV PLHIV have a lack of knowledge of the mechanisms to report and address stigma and discrimination	*Programme* • Develop and implement an anti-stigma and discrimination communication strategy • Improve a visibility campaign of the National HIV Related Discrimination Reporting and Redress System • Generate a listing of legal aid providers that support individuals

reported being involved in any efforts to develop HIV legislation, policies or guidelines; less than 50% felt that they can affect any decision related to legal rights or policies • **Most respondents surveyed knew of a support group for PLHIV** • **Only 40% of persons knew of a group that can help PLHIV with stigma and discrimination**	Lack of anti-discrimination and related legislation to protect those at risk of S&D because of HIV status	interested in legal recourse for discriminatory cases for HIV support organizations • Develop a guide for persons living with HIV on what constitutes a violation of human rights *Policy* • Advocate for the development of an anti-discrimination legislation that includes / addresses vulnerable populations including MSM, sex workers, youth, the mentally disabled, the physically challenged and others

Findings	**Gaps**	**Policy & Programme Recommendations**
Disclosure and Confidentiality		
• **Most persons living with HIV are reluctant to disclose their status for fear of discrimination** • **Twelve percent of respondents felt pressure to disclose to other persons living with HIV or others** • **Persons disclose their HIV status most often to a spouse or partner, an adult family member, someone they are dating or other persons living with HIV. Reactions from these persons tended to be supportive.** • **Persons living with**	Insufficient dissemination of information related to appropriate clinic services Lack of funds to maintain HIV support organizations Insufficient number of HIV support organizations in rural areas and small towns Lack of understanding of how to support PLHIV	*Programme* • Develop and implement support group sessions on appropriate care and treatment services • Improve referral systems at treatment sites for enrollment in HIV support organizations • Offer and publicize services of HIV support organizations • Engage and encourage persons living with HIV to join HIV support organizations • Support community education interventions that focus on misperceptions surrounding HIV and AIDS • Increase psychosocial support for persons living with HIV to provide coping strategies as part of overall care and support

HIV were least likely to disclose to friends, neighbors whose reactions tended to be discriminatory • **Sixty-five percent of those that disclosed felt it was an empowering experience**	Lack of anti-discrimination and related legislation to protect those at risk of S&D because of HIV status	regardless of length of time living with HIV *Policy* • Advocate for the development of an anti-discrimination legislation for vulnerable populations including MSM, sex workers, youth, the mentally disabled, the physically challenged and others

Findings	Gaps	Policy & Programme Recommendations
Additional studies		
Few persons from key population groups (MSM, sex workers, prisoners, etc.) identified themselves in the study	Lack of studies of studies on the experience of stigma and discrimination among vulnerable populations Lack of information on quality of life of persons living with HIV	*Programme* • Future People Living with HIV Stigma Index studies should recruit and interview key population groups using a separate private and confidential approach and conducted in a different environment/location from other PLHIV interviews. Investigate issues related to: • Experience of stigma and discrimination among HIV positive MSM, persons with disabilities, and sex workers • Quality of life of children living with HIV • Sexuality and sexual decision making among key populations • Childbearing choices and practices among persons living with HIV • Factors that impact Relationship Choices/ Decision making processes (e.g., marriage) • Migration patterns among persons living with HIV post diagnosis. • Evaluate anti-stigma campaigns to determine its impact on stigmatizing behavior.

Future Stigma Index Studies

In addition to the programme and policy recommendations above, specific recommendations for the methodology and analysis for future People Living with HIV Stigma Index studies are provided below:

Methodology:

1. *Training*

- A literacy assessment should be conducted with interviewers to evaluate literacy levels. The assessment scores should be included in the interviewer selection criteria.
- Increase the number of training days on the survey so that interviewers have an in-depth understanding and comprehension of the instrument. In addition, training topics should include basic customer service and communication skills.
- Increase the number of training days for persons responsible for data entry for thorough comprehension of SPSS data entry
- Survey supervisors/team leaders should be trained on how to review surveys in the field to capture interviewer errors

2. *Survey Instrument*

- The Jamaica specific survey questions should be reviewed to ensure that questions are clear, that appropriate survey responses are included, and a place to record or capture the information is provided

3. *Recruitment*

- The study should recruit key populations in a more deliberate manner. Organizations that work with and support key population groups should be asked to invite and recruit potential participants into the study. Interviews with key populations should take place at locations that are safe and private, and not in the same location as other PLHIV interviews.
- Youth populations should also be recruited using a special approach to ensure their participation in the study

Analysis:

1. *Data analysis*

- The steering committee should review the data prior to the report being written to determine what variables would be preferred for inclusion.
- A corresponding data manual should be developed and part of the Terms of Reference for the consultancy. The data manual should include labels of newly constructed variables as well as a description of why and how these variables were created
- Funds for the transcription of qualitative data should be provided as part of the consultancy

Other:

- Funds should be provided as part of the study for the development of a Communication and Dissemination plan that details how the findings from the study should be shared with stakeholders.

SECTION X: OUTLINE FOR DISSEMINATION STRATEGY

The goal of the dissemination of the People Living with HIV Stigma Index report is to inform multiple stakeholders on the level of stigma and discrimination experienced by persons living with HIV in Jamaica. The objective of the dissemination strategy is to inform stigma and discrimination reduction programming in the national response to HIV.

The dissemination strategy should be supported by the development of a formal Communication plan that would detail the components of the approach. Findings from the People Living with HIV Stigma Index report should be used in conjunction with similar studies recently conducted in Jamaica.

The key findings from this study should be disseminated on the community-based, national and international levels. Factors to consider in developing a Communication plan for this study should include the: overall dissemination goal; audience; medium for dissemination; responsible organisations and the format for dissemination. Below is a suggested approach for each level of dissemination, with proposed examples for executing the dissemination.

Community-Level

1. Audience: HIV support organizations, NGOs, FBOs
2. Medium: Research summary, articles, report, power point presentation
3. Suggested Responsible Organization: Jamaica Network of Seropositives
4. Execution examples:
    - Disseminate findings in the form of a summary document to HIV support organizations (i.e., Jamaica Network of Seropositives, Red Cross, Eve for Life, Greater Involvement of Person living with HIV/AIDS (GIPA)) in a form that HIV support organizations can provide to its members
    - HIV support organizations host community forums to discuss general issues around HIV (i.e., transmission) and the study findings to the wider public
    - HIV support organizations conduct discussion sessions with persons living with HIV for policy recommendations related to HIV care, treatment and support

National

1. Audience: National stakeholders within the public and private sector. These include Health Policy Project, Ministry of Health, Ministry of Labour and Social Security, UWI HARP, CHART, Ministry of Justice
2. Medium: Research summary, Report, Policy Brief, power point presentation, press release, stakeholders meeting
3. Suggested Responsible Organization: Ministry of Health, National HIV Programme
4. Execution examples:
    - Disseminate report as a policy brief that articulate key findings to national stakeholders that work in the field of HIV policy and programming
    - Conduct a research summary presentation to national level stakeholders
    - Develop a press release for dissemination for local media (television, newspaper, radio)
    - Disseminate to health professional societies (nursing, medical and social work)
    - Encourage training organizations to integrate information from findings into the infectious disease curriculum
    - Encourage HIV Care and Treatment organizations to place the report on their websites

International (Regional/Extra-Regional)

1. Audience: International stakeholders
2. Medium: Research summary, articles, report
3. Suggested Responsible Organization: UNAIDS
4. Execution examples:
    - Survey findings should be disseminated at international research conferences, such as the International AIDS Society (IAS)
    - Research articles should be submitted to research journals such as The West Indian Medical Journal, AIDS and Behavior, AIDS Care: Psychological Socio-Medical Aspects of HIV/AIDS, AIDS Prevention and Mental Health
    - Provide the Stigma Index report to regional organizations such as Caribbean HIV AIDS Alliance (CHAA), Caribbean Public Health Agency (CARPHA), University of the West Indies and encourage them to place report or a summary on their websites
    - Include findings as evidence in reports to international donors (USAID/Pepfar, Global Fund, etc.)

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Appendix I: People Living with HIV Stigma Index Key Definitions and Concepts

APPENDIX 1 KEY DEFINITIONS AND CONCEPTS

Blame	To blame someone is to suggest that they are responsible for something wrong; to find fault with them; to accuse them.
Coercion	The application of force to restrain or prevent someone from doing something, or to force or intimidate them to do something.
Confidential	To keep information private or secret. Ensuring confidentiality implies making sure that information is kept private or secret and is not shared or made known to others. Confidentiality is often associated with a feeling of trust, or the belief that if you tell someone something private or secret he/she will not share this information with others without your permission.
Consent	Voluntary agreement or permission. Written consent means giving permission in writing and oral consent means giving spoken permission.
Constructive discussion	A discussion which is helpful and productive, in contrast with one which has the effect of destroying or undermining a person.
Discrimination	Discrimination involves treating someone in a different and 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." For example, HIV-related discrimination occurs when someone is treated differently (and to their disadvantage) because they are known to be living with HIV, suspected of being HIV-positive, or closely associated with people living with HIV (such as their partner or a member of their household). Discrimination occurs at many different levels. It can occur within a family or community setting. For example, when people: • avoid people living with HIV or do not allow them to use the same eating utensils as other members of the household; or • reject people living with HIV by not allowing them entry or membership into a group, or by not being willing to be associated with them. It can also occur within an institutional setting, for example, when: • people living with HIV are segregated from other patients in a health facility or denied access to health care services or medical insurance because they are HIV-positive; • when a supervisor does not uphold the rights of a positive person and discloses their HIV-positive status without their consent to work colleagues; or • HIV-affected children are denied entry into school. Discrimination can also occur at a national level, when it is sanctioned or legitimized through laws and policies. Such examples include: • refusing a person living with HIV entry into a country because of their HIV positive status; • prohibiting people living with HIV from certain occupations and types of employment; or • the compulsory screening and testing of individuals or groups for HIV. Discrimination against people living with HIV, or those thought to be infected, is a violation of their human rights and is something that the legal system in a country can address.

Empowering	Something is empowering when it helps a person have greater control over their own life. It is often associated with increased confidence and a sense of strength. A person who is empowered feels they have the power to meet their own needs and can put their skills and energy to use in their community and act on the issues they feel are important.
Exclude	To leave out or keep out; to not include.
Family planning	The conscious effort of couples or individuals to plan for and attain their desired number of children and to regulate the spacing and timing of their births. Family planning is achieved through contraception and through the treatment of involuntary infertility.
Guilt	When a person feels bad about having done something they believe they should not have done (or experiences similar feelings when thinking about something they have not done but believe they should have done).
Household	A group of people who live in the same place (a house or other dwelling place), sharing space and resources; they are often – but not necessarily – members of the same family.
Index	In this context, index refers to a collection of information (data) organized in a way which allows us to reach overall conclusions about particular issues and to measure differences between the situation in different places and/or how a situation has changed over time. The People Living with HIV Stigma Index, for example, will give a measure of how much HIV-related stigma and discrimination there is at a certain point in time, in a certain community. Once we have this point of reference, we believe it will be possible to survey people from the same community in the future and get a sense of whether HIV-related stigma and discrimination is increasing or decreasing in the community.
Indicator	A measure that tells us the presence or absence of something. An indicator can help us determine, for example, whether or not a project has achieved its purpose over time.
Indigenous group	A group of people who have a longstanding historical association with a particular region or part of a region – in many cases, before the region was colonized by others. Often the group has maintained customs or traditions over many generations and see themselves as part of a distinct community with special bonds of kinship, language and culture. Examples of indigenous peoples are the San of the Kalahari desert in Southern Africa, the indigenous peoples of the Americas (often referred to as Native Americans or First Peoples), the Ngunnawal and Eora peoples in Australia and the Maori in New Zealand.
Informed consent	Voluntary agreement or permission that is given with full knowledge of what is involved (e.g. risks and benefits). For example, if someone decides that they want to take an HIV test and they receive comprehensive and understandable information about the test from a counsellor, following which they consent to take an HIV test, this would be called giving informed consent. Similarly, if you are an interviewer administering this questionnaire and you provide a potential interviewee with a comprehensive account of what it will involve to respond to the questionnaire, following which the potential interviewee then says they would like to participate in the survey, the interviewee is then indicating that they are informed and that their participation in the survey is voluntary.

Injecting drug user (IDU)	There are several ways of using drugs, and one way is through injecting. In HIV work, the term "injecting drug use" describes the behaviour of someone who injects drugs. Injecting drug users face the same sex-related risks of HIV as other people, and those who share contaminated drug injecting equipment (such as a needle or a syringe) are at an additional risk of acquiring HIV through the use of contaminated drug equipment.
Internal stigma	Internal stigma, also referred to as "felt" stigma or "self-stigmatization", is used to describe the way a person living with HIV feels about themselves and specifically if they feel a sense of shame about being HIV-positive. Internal stigma can lead to low self-esteem, a sense of worthlessness and depression. Internal stigma can also result in a person living with HIV withdrawing from social and intimate contact, or excluding themselves from accessing services and opportunities out of a fear of having their status revealed or being discriminated against because of their HIV-positive status. See page 47 for a definition of "stigma".
Internally displaced person	A person who is forced to move from their home (for example, because of a conflict situation, a natural disaster or because they and their family or community is being discriminated against or threatened) and settle in another area. Like refugees, they are forced to flee from their original home but in this case they stay within the borders of their country of origin.
Law/legislation	A set of rules or norms of conduct which define how people must behave. Law is normally administered through a system of courts, in which lawyers argue cases before judges.
Legal redress	"Setting right" a wrong done to someone and possibly compensating them for the loss resulting from this wrong. Legal redress implies doing this through the courts, a human rights commission or similar forum. It may involve having a lawyer or advocate represent the person who was wronged and using the law to argue that the wrong be addressed in some way.
Men who have sex with men (MSM)	This is a term that refers to the behaviour of men who have sex with other men. It is a term that recognizes that some men who have sex with men also have sex with female partners and that men who have sex with other men may not necessarily identify as "gay", "homosexual" or "bisexual" – all of which are examples of categories of sexual orientation and identity. Men who have sex with men often face a double stigma because they are marginalized for their sexual behaviour and seen as part of a group that is associated with being at particular risk for HIV infection.
Network of people living with HIV	A network of people living with HIV is a group, association or an affiliation of HIV-positive individuals who unite together for a common purpose.
Orphan	A child, under 18 years of age, who has lost both parents through death. While not all children become orphaned as a result of their parents dying of AIDS, in many communities where the prevalence of HIV is high, it is likely that many of the orphans have lost one or both of their parents to AIDS.
People living with HIV support group	A people living with HIV support group is a group of HIV-positive people who meet to give each other support, given that they share a common experience – that of living

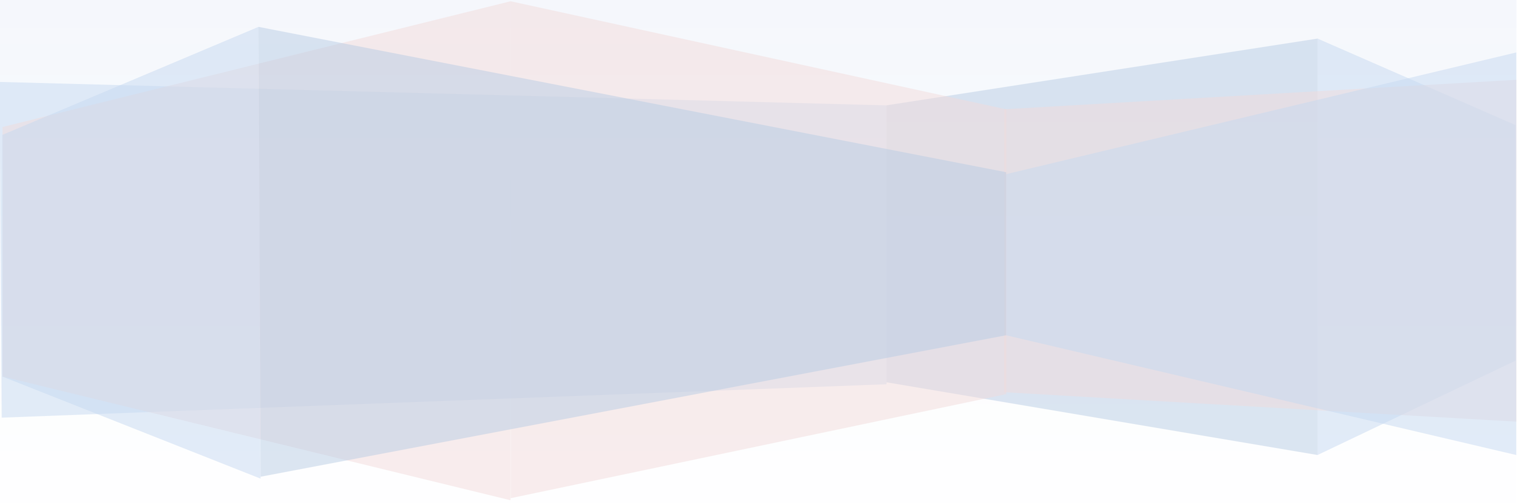
	with HIV. A people living with HIV support group may also be involved in HIV-related advocacy work.
Physical disability	A partial or total loss of a bodily function or part of a body. It includes sensory impairments such as being deaf, hearing impaired, or visually impaired.
Policy/policies	A plan or course of action adopted and pursued by government or, by extension, an official in a decision-making position.
Programme	A collection of projects working towards a common and broader goal.
Project	A series of activities with a common objective, usually small in size and engaging in a unique activity with clear start and end points. Often the smallest operational unit of a programme.
Quarantine	Keeping people in isolation from the rest of the community on the basis that they have a contagious disease.
Refugee/asylum seeker	Those who are forced to cross international borders because of conflict or political instability that causes them to fear being persecuted because of their race, religion, nationality, membership in a particular social group or their political opinion.
Rights	A right is something to which one has a just claim or entitlement. Rights exist at local, national and international levels. Human rights are those rights that one has because one is a human being. These include the rights to life, privacy, freedom of expression, freedom of association, an adequate standard of living, education and health. Human rights are founded on the dignity and worth of each person. People are entitled to enjoy their rights regardless of their race, colour, sex, language, religion, political or other opinion, national or social origin, or other status. (Many governments have defined "other status" to also include HIV status.) Human rights are legally guaranteed by human rights law, which exists to protect individuals and groups from actions that interfere with their freedom and dignity, and promote access to the things that help people realize their rights. Human rights law exists at the international level (e.g. treaties and covenants) and at the national level (e.g. constitution, bill of rights, domestic laws).
Self-esteem	How you value or respect yourself. For example, when we refer to someone as having low self-esteem it means that that person does not value themselves or have confidence in their ability or the contribution they can make generally.
Sex worker	The term sex worker is used to describe either a man or a woman who engages in sexual activity for payment.
Sexual and reproductive health services	Sexual and reproductive health services are health care and counselling services that contribute to sexual and reproductive health and well-being, through preventing and solving sexual and reproductive health problems. Sexual and reproductive health services include information about sexual and reproductive issues; access to safe, effective, affordable and acceptable methods of family planning; care for pregnancy and childbirth; care and counselling related to sexually transmitted infections, including HIV; and services to prevent and solve sexual and reproductive health problems.

Sexual rejection	A negative response; the refusal by a sexual partner to engage in any form of sexual activity.
Sexuality	The expression of sexual sensation and related intimacy between human beings, as well as the expression of identity through sex.
Sexually active	There is not one, all-encompassing definition for the term sexually active. For some people, being sexually active means vaginal or anal sex, for others it means oral sex and for others it might simply mean kissing and touching their partner.
Shame	A feeling of dishonour, disgrace or condemnation. To be ashamed of oneself refers to one having this feeling of shame.
Stigma	A sign of disgrace or shame. It originates from the ancient practice of branding or marking someone who was thought to be "morally flawed" or to have behaved badly and therefore ought to be avoided by other members of society. 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 or worth in the eyes of others. 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. 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. See also "internal stigma", described on page 45.
Traditional or complementary medicine	Medical skills and practices traditionally used within societies, which were developed to maintain health and treat illness before the era of modern (or what is often termed "western") medicine. Traditional medicine is seen as providing an alternative or complementary set of health care practices that are not always found in the main health care system.
Transgender	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.
Treatment literacy	Treatment literacy is knowledge about treatment and how it works. When people have this knowledge, they can make informed choices about their own treatment options: whether to begin taking treatment, when to begin treatment, what treatment options are available to them, side effects of treatment, strategies to stay on treatment (adherence) and what to do when staying on treatment becomes difficult. Treatment literacy is also important for people providing care to people living with HIV – it enables them to support others on treatment. Information resources, support groups and training programmes are all ways of promoting treatment literacy.

Appendix II: The People Living with HIV Stigma Index Survey

The People Living with HIV Stigma Index

An index to measure the stigma and discrimination experienced by people living with HIV



IC:_ _ _ _ _ _ _ _ _ _ _ _ _ _ _

QUESTIONNAIRE

Before starting the interview, you must:
1. Give the interviewee the information sheet and allow him /her to read through it. If he/she is unable to read, you must read it out to him/her.
2. Read the informed consent form to the interviewee. If he/she agrees to participate in the study, complete two copies of the form. After both forms have been signed, give one to the interviewee for him/her to keep and you keep the other one.

On finishing the interview, please complete the following:

REFERRALS AND FOLLOW UP

1. Did the interviewee need a referral (recommendation for supporting services)?

Yes	[ ] 1
No	[ ] 2

2. If yes, what kind of referral(s)?

Legal	[ ] 1
Counselling	[ ] 2
Support Group	[ ] 3
Other	[ ] 4

If **Other**, where did you refer them to? ____________________________________

3. What steps have you taken to help the interviewee with the above referral (s)?
(Tick more than one box if appropriate)

I have given sufficient information on the referral (s) already	[ ] 1
I will send the required information to the interviewee	[ ] 2
Further follow up is needed	[ ] 3

Please give details of what you promised to do about referral(s) after the interview, if anything:
____
____
____

4. Is this interviewee a potential candidate for case study?

Yes	**[ ] 1**
No	**[ ] 2**

If yes, record a time and date for a case study meeting:
Time: ____
Date: ____

IC:_ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _

QUALITY CONTROL PROCEDURES

	Name	Signature	Date
Interviewer			
Team Leader			
Data Entry 1			
Data Entry 2			

*Tasks:

***The interviewer must ensure that all sections of the questionnaire are completed properly and in full, unless the interviewee does not wish to complete them – in which case this must be noted alongside the relevant question (s).**

***The team leader must check the questionnaire carefully and query any apparent discrepancies with the interviewer. The quality checks section at the end of this questionnaire will help the interviewer and team leader with these tasks.**

***Data entry people 1 and 2 must enter all data from the questionnaire correctly. They must enter the data from every questionnaire independently, following the procedures outlined the user guide.**

IC:_ _ _ _ _ _ _ _ _ _ _ _ _ _ _

PEOPLE LIVING WITH HIV STIGMA INDEX: QUESTIONNAIRE
CONFIDENTIAL AND ANONYMOUS

SECTION 1. INFORMATION ABOUT YOU

1. Sex

Male [ ] 1
Female [ ] 2
Transgender [ ] 3

2. How old are you?

Youth aged 16-19 years [ ] 1
Adult aged 20-24 [ ] 2
Adult aged 25-29 [ ] 3
Adult aged 30-39 [ ] 4
Adult aged 40-49 [ ] 5
Adult aged 50+ [ ] 6

3. For how long have you been living with HIV? (Tick one box only)

0-1 year [ ] 1
1-4 years [ ] 2
5-9 years [ ] 3
10-14 years [ ] 4
15+ years [ ] 5

4. Current relationship status (Tick one box only)
Are you married or cohabiting (living with someone) and is your husband/wife/partner currently living in the household? [ ]1

Are you married or cohabiting (living with someone) and is your husband/wife/partner temporarily living/working away from the household
[ ]2

Are you in a relationship but not living together [ ] 3

Are you single [ ] 4

Are you divorced/separated [ ] 5

Are you a widow/widower [ ] 6

5. If you are in a relationship now, how long have you been involved with your husband/wife/partner?

0-1 year [ ] 1
1-4 years [ ] 2
5-9 years [ ] 3

10-14 years [ ] 4
15+ years [ ] 5

6. Are you sexually active at the moment?
Yes [ ]1
No [ ]2

IC:_ _ _ _ _ _ _ _ _ _ _ _ _ _ _

7. Do you belong to, or have you in the past belonged to, any of the following categories? (Tick at least one box. You can tick more than one if appropriate)

Men who have sex with men [ ]1
Gay or lesbian [ ]2
Transgender [ ]3
Sex worker [ ]4
Injecting Drug User [ ]5
Refugee or Asylum Seeker [ ]6
Internally Displaced Person [ ]7
Member of an indigenous group [ ]8
Migrant worker [ ]9
Prisoner [ ]10
I don't belong to, and have not in the past belonged to, any of these categories [ ]11

JM*Are there categories not listed to which you now belong or belonged to in the past? ?**
Please state ____

8. Do you have a physical disability of any kind (not including general ill health related to HIV)?
Yes [ ]1
No [ ]2
If yes, please describe this physical disability

9. What is the highest level of formal education you have completed? (Tick one box only)

No formal education [ ]1
Primary School [ ]2
Secondary School [ ]3
JM* **Circle the relevant one: Technical College/University [ ]4**

10. Which one of these statements best describes your current employment status? (Tick at least one box. You can tick more than one if appropriate)

In full time employment (as an employee) [ ]1
In part time employment (as an employee) [ ]2
Working full-time but as an employee (self-employed) [ ]3
Doing casual or part-time work (self-employed) [ ]4
Unemployed/not working at all [ ]5
JM*Student [ ]

11. How many people currently live in your household in each of these categories? (*Ensure that you insert the numbers of persons.* *The respondent is a member of the household***)**

Number of people
Children aged 0-14 [ ] 1
Youth aged 15-19 years [ ] 2
Adults aged 20-24 [ ] 3
Adults aged 25-29 [ ] 4
Adults aged 30-39 [ ] 5
Adults aged 40-49 [ ] 6
Adults aged 50+ [ ] 7

Are there any children in your household whose parents/former guardians have died from AIDS?

Yes [ ]1
No [ ]2

JM* **Are there any youth (16-25) in your household whose parents/former guardians have died from AIDS?**

Yes [ ]1
No [ ]2

12. **If yes, how many children and youth have parents who died from AIDS?**

____

13. Is your household in (Tick one box only. ***Please see categorization attached*****)**

A rural area [ ]1
A small town or village [ ]2
A large town or city [ ]3

JM* **Which parish do you live in? _________________________**

14. Approximately how much income has your household made per month over the last year ____
JM*(Include money from relatives overseas)

For data capturers:

Annual income in local currency:

Current exchange from local currency to US dollars

Annual income in US dollars

15. In the last 12 months, has any member of your household NOT **had enough to eat?**
Yes [ ]1

No [ ]2

If yes, *for how many days* has any household member not had enough food______________________

IC:_ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _

SECTION 2A
YOUR EXPERIENCE OF STIGMA AND DISCRIMINATION FROM OTHER PEOPLE

1a. In the last 12 months, how often have you been left out of social gatherings or activities (weddings, funerals, parties, clubs, dances)? Tick one box only.

Never [ ]1
Once [ ]2
A few times [ ]3
Often [ ]4

If the answer is NEVER, please go to question 2A.

1b. If so, do you think this was … (Tick one box only)

Because of your HIV status? [ ]1
For (an)other reason (s)? [ ]2
Both because of your HIV status and (an) other reason (s)? [ ]3
Not sure why [ ]4

2a. In the last 12 months, how often have you been left out of religious activities or places of worship (churches)?

Never [ ]1
Once [ ]2
A few times [ ]3
Often [ ]4

If the answer is NEVER, please go to question 3A.

2b. If so, do you think this was … (Tick one box only)

Because of your HIV status? [ ]1
For (an)other reason (s)? [ ]2
Both because of your HIV status and other reason (s)? [ ]3
Not sure why [ ]4

3a. In the last 12 months, how often have you been left out of family activities (e.g. cooking, eating together, sleeping in the same room)? (Tick one box only)

Never [ ]1
Once [ ]2
A few times [ ]3
Often [ ]4

If the answer is NEVER, please go to question 3c.

IC:_ _ _ _ _ _ _ _ _ _ _ _ _ _ _

3b. If so, do you think this was … (Tick one box only)

Because of your HIV status? [ ]1
For (an)other reason (s)? [ ]2
Both because of your HIV status and other reason (s)? [ ]3
Not sure why [ ]4

***JM**3c. In the last 12 months, how often have you been left out of school activities or other educational facilities (Tick one box only.** This question is only applicable to persons who indicated that they are students**.)**

Never [ ]1
Once [ ]2
A few times [ ]3
Often [ ]4

If the answer is NEVER, please go to question 4A.

If so, do you think this was … (Tick one box only)

Because of your HIV status? [ ]1
For (an)other reason (s)? [ ]2
Both because of your HIV status and other reason (s)? [ ]3
Not sure why [ ]4

4a. In the last 12 months, how often have you been aware of being gossiped (people talking about you) about? (Tick one box only)

Never [ ]1
Once [ ]2
A few times [ ]3
Often [ ]4

4b. If so, do you think this was … (Tick one box only)

Because of your HIV status? [ ]1
For (an)other reason (s)? [ ]2
Both because of your HIV status and other reason (s)? [ ]3
Not sure why]4

5a. In the last 12 months, how often have you been verbally insulted, harassed (intimated, tormented) and/or threatened? (Tick one box only)

Never [ ]1
Once [ ]2
A few times [ ]3
Often [ ]4

5b. If so, do you think this was … (Tick one box only)

Because of your HIV status? [ ]1
For (an)other reason (s)? [ ]2
Both because of your HIV status and other reason (s)? [ ]3
Not sure why [ ]4

IC:_ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _

6a. In the last 12 months, how often have you been physically harassed (intimated) and/or threatened? (Tick one box only)

Never [ ]1
Once [ ]2
A few times [ ]3
Often [ ]4

6b. If so, do you think this was … (Tick one box only)

Because of your HIV status? [ ]1
For (an)other reason (s)? [ ]2
Both because of your HIV status and other reason (s)? [ ]3
Not sure why [ ]4

7a. In the last 12 months, how often have you been physically assaulted? (Tick one box only)

Never [ ]1
Once [ ]2
A few times [ ]3
Often [ ]4

7b. If so, do you think this was … (Tick one box only)

Because of your HIV status? [ ]1
For (an)other reason (s)? [ ]2
Both because of your HIV status and other reason (s)? [ ]3
Not sure why [ ]4

7c. If so, who physically assaulted you? (Tick one box only)

My husband/wife/partner [ ]1
Another member of the household [ ]2
Person(s) outside of the household who is/are known to me [ ]3
Unknown persons [ ]4

JM* CASE STUDY QUESTIONS 7d-7i

***JM** Do you experience stigma and discrimination in your community (from community members)?**

YES [ ]
NO [ ]

***JM** What forms of discrimination are you most fearful of?**

Isolation [ ]1
Beatings [ ]2
House-burning [ ]3
Neglect [ ]4
Other [ ]5

If OTHER, please identify ____________________

IC:_ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _

***JM** Do you think there are some groups of PLHIVs that experience more severe forms of discrimination than others?**

YES [ ]
NO [ ]

***JM** If yes, which group of PLHIVs do you think experience the worst forms of discrimination?**

____

***JM** Do you think that discrimination against PLHIVs has got worse over the last 5 years?**

YES [ ]
NO [ ]

***JM** Do you think that PLHIVs have been experiencing less discrimination over the last 5 years?**

YES [ ]
NO [ ]

8. In questions 1-7, if you experienced stigma and/or discrimination for reasons other than your HIV status, please choose one category that best explains why you felt you were stigmatized and/or discriminated against. (Tick one box only)

Sexual orientation (men who have sex with men, including bi-sexual men, gay or lesbian, transgender)

MSM[ ]1

Sex worker [ ]2

Injecting drug user [ ]3
Refugee or asylum seeker [ ]4
Internally displaced person [ ]5
Member of an indigenous group [ ]6
Migrant worker [ ]7
Prisoner [ ]8
None of the above – it was because of an(other) reason(s) [ ]9

If you chose none of the above, please explain why you think you were stigmatized or discriminated against.

Have you ever been subject to psychological pressure (bullying, emotional pressure, verbal abuse) or manipulation?
YES [ ] 1
NO [ ] 2

IC:_ _ _ _ _ _ _ _ _ _ _ _ _ _

9. In the last 12 months, have you been subjected to psychological pressure or manipulation by your husband/wife or partner in which your HIV-positive was used against you?
Never [ ]1
Once [ ]2
A few times [ ]3
Often [ ]4

***JM**Above you noted that you are/ you are not sexually active?**
Circle the correct response.

10. In the last 12 months, how often have you experienced sexual rejection as a result of your HIV-positive status?
Never [ ]1
Once [ ]2
A few times [ ]3
Often [ ]4

CASE STUDY QUESTION
11. In the last 12 months, have you been discriminated against by other people living with HIV? If no, tick 'never'; if yes, state how often (Tick one box only)
Never [ ]1
Once [ ]2
A few times [ ]3

Often [ ]4

CASE STUDY QUESTIONS

12. In the last 12 months, has your wife/husband or partner, or any members of your household experienced discrimination as a result of your HIV-positive status. If no, tick 'never'; if yes, state how often (Tick one box only)

Never [ ]1
Once [ ]2
A few times [ ]3
Often [ ]4

13. If you have experienced some form of HIV-related stigma or discrimination in the last 12 months, why do you think this is? (Tick more than one box if appropriate)

People are afraid of getting infected with HIV from me	**[ ]1**
People don't understand how HIV is transmitted and are afraid I will infect them with HIV through casual contact	**[ ]2**
People think that having HIV is shameful and they should not be associated with me	**[ ]3**
Religious beliefs or 'moral' judgments	**[ ]4**
People disapprove of my lifestyle or behaviour	**[ ]5**
I look sick with symptoms associated with HIV	**[ ]6**
I don't know/I am not sure of the reason (s)	**[ ]7**

(Please state any other consideration, not listed above) ______________________________

IC:_ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _

SECTION 2B YOUR ACCESS TO WORK AND HEALTH AND EDUCATION

1a. In the last 12 months, have you been forced to change your place of residence or been unable to rent accommodation? If no, tick 'never'; if yes, state how often (Tick one box only)

Never [ ]1
Once [ ]2
A few times [ ]3
Often [ ]4

1b. If so, do you think this was … (Tick one box only)

Because of your HIV status? [ ]1
For (an)other reason (s)? [ ]2
Both because of your HIV status and other reason (s)? [ ]3
Not sure why [ ]4

If interviewee has not been earning an income (either through some form of formal employment or on a casual or part-time basis) or has not been self-employed during the last 12 months, go to question 5.

2a. In the last 12 months, have you lost a job (if employed) or another source of income (if self-employed or an informal casual worker)? If no, tick 'never'; if yes, state how often (Tick one box only)

Never [ ]1
Once [ ]2
A few times [ ]3
Often [ ]4

2b. If so, do you think this was … (Tick one box only)

Because of your HIV status [ ]1
For (an)other reason (s)? [ ]2
Both because of your HIV status and other reason (s)? [ ]3
Not sure why [ ]4

2c. If because of HIV status (wholly or partly), did you lose your work/income? (Tick one box only)

Because of discrimination by your employer or co-workers [ ]1
Because you felt obliged to stop working due to poor health [ ]2
Because of a combination of discrimination and poor health [ ]3
Because of another reason [ ]4
If so, what was the other reason ___________________________

3. In the last 12 months, have you been refused employment or a work opportunity because of your HIV status?

YES [ ]1
NO [ ]2

IC:_ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _

4a. In the last 12 months, has your job description or the nature of your work changed, or have you been refused promotion, as a result of your HIV status? If no, tick ‘never’; if yes, state how often (Tick one box only)

Never [ ]1
Once [ ]2
A few times [ ]3
Often [ ]4

4b. If so, did this happen? (Tick one box only)

Because of discrimination by your employer or co-workers [ ]1
Because poor health prevented you from doing certain things [ ]2
Because of a combination of discrimination and poor health [ ]3
Because of another reason [ ]4
If so, what was the other reason ___________________________

5. In the last 12 months, have you been dismissed, suspended or prevented from attending an educational institution because of your HIV status. If no, tick ‘never’; if yes, state how often (Tick one box only)

Never [ ]1
Once [ ]2
A few times [ ]3
Often [ ]4
Not Applicable [ ]5

6. In the last 12 months, have your children been dismissed, suspended or prevented from attending an educational institution because of your HIV status. If no, tick ‘never’; if yes, state how often (Tick one box only)

Never [ ]1
Once [ ]2
A few times [ ]3
Often [ ]4
Not Applicable [ ]5

7. In the last 12 months, have you been denied health services, including dental care, because of your HIV status? If no, tick ‘never’; if yes, state how often (Tick one box only).

Never [ ]1
Once [ ]2
A few times [ ]3
Often [ ]4
Not Applicable [ ]5

8. In the last 12 months, have you been denied family planning services because of your HIV status? If no, tick ‘never’; if yes, state how often (Tick one box only)

Yes [ ]1
No [ ]2
Not Applicable [ ]3

9. In the last 12 months, have you been denied sexual and reproductive health services because of your HIV status. If no, tick ‘never’; if yes, state how often (Tick one box only)

Yes [ ]1
No [ ]2

IC:_ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _

SECTION 2C INTERNAL STIGMA (THE WAY YOU FEEL ABOUT YOURSELF) AND YOUR FEARS

1.In the last 12 months, have you experienced any of the following feelings because of your HIV status (Tick one box for each category)

I feel ashamed	**YES [ ]1**	**NO [ ]2**
I feel guilty	**YES [ ]1**	**NO [ ]2**
I blame myself	**YES [ ]1**	**NO [ ]2**
I blame others	**YES [ ]1**	**NO [ ]2**
I have low self-esteem	**YES [ ]1**	**NO [ ]2**
I feel I should be punished	**YES [ ]1**	**NO [ ]2**
I feel suicidal	**YES [ ]1**	**NO [ ]2**

2.In the last 12 months, have done any of the following because of your HIV status (Tick one box for each category)

I have chosen not to attend social gatherings	**YES [ ]1**	**NO [ ]2**
I have isolated myself from my family and/or friends	**YES [ ]1**	**NO [ ]2**
I took the decision to stop working	**YES [ ]1**	**NO [ ]2**
I decided not to apply for a job/work or for a promotion	**YES [ ]1**	**NO [ ]2**
***I chose not to attend school**	**YES [ ]1**	**NO [ ]2**
I withdrew from education/training or did not take up an opportunity for education/training	**YES [ ]1**	**NO [ ]2**
I decided not to get married	**YES [ ]1**	**NO [ ]2**
I decided not to have sex	**YES [ ]1**	**NO [ ]2**
I decided not to have (more) children	**YES [ ]1**	**NO [ ]2**

I avoided going to a local clinic when I needed to	**YES [ ]1**	**NO [ ]2**
I avoided going to a hospital when I needed to	**YES [ ]1**	**NO [ ]2**
JM***I stopped preparing meals for my family**	**Yes [ ]1**	**No [ ]2**
JM*I stopped interacting with children	**Yes [ ]1**	**No [ ]2**

3. In the last 12 months, have you been fearful of any following things happening to you – whether or not they actually have happened to you?

Being gossiped about	**YES [ ]1**	**NO [ ]2**
Being verbally insulted, harassed and/or threatened	**YES [ ]1**	**NO [ ]2**
Being physically harassed and/or threatened	**YES [ ]1**	**NO [ ]2**
Being physically assaulted	**YES[ ]1**	**NO [ ]2**

IC:_ _ _ _ _ _ _ _ _ _ _ _ _ _ _

4. In the last 12 months, have you been afraid that someone would not want to be sexually intimate with you because of your HIV-positive status?

Yes [ ]1
No [ ]2

SECTION 2D RIGHTS, LAWS AND POLICIES

1a. Have you heard of the Declaration of Commitment on HIV/AIDS, which protects the rights of people living with HIV?

Yes [ ]1
No [ ]2

1b. If yes, have you ever read or discussed the content of this Declaration?

Yes [ ]1
No [ ]2

2a. Have you heard of the National HIV Policy, which protects the rights of people living with HIV in this country?

Yes [ ]1
No [ ]2

2b. If yes, have you ever read or discussed the content of this policy?

Yes [ ]1
No [ ]2

3. In the last 12 months, have any of the following things happened to you because of your HIV status? (Tick more than one box if appropriate)

JM***I was denied access to the school of my school/educational facility of my choice**
[ ]

I was forced to submit to a medical or health procedure (including HIV testing)
[ ] 1

I was denied health insurance or life insurance because of my HIV status?
[ ]2

I was arrested or taken to court on a charge related to my HIV status
[ ]3

I had to disclose my HIV status in order to enter another country
[ ]4

IC:_ _ _ _ _ _ _ _ _ _ _ _ _ _

I had to disclose my HIV status to apply for residence or nationality
[ ]5

I was detained, quarantined, isolated or segregated
[ ]6

None of these things happened to me
[ ]7

4a. In the last 12 months, have any of your rights as a person living with HIV been abused?

YES [ ]1
NO [ ]2
Not sure [ ]3

If no, please go to the next section (Section 2E: Effecting Change)

4b. If yes, have you tried to get legal redress for any abuse of your rights as a person living with HIV?

YES[ ]1
NO [ ]2
Not sure [ ]3

If the answer is No or Not SURE, please go to question 4e.

*JM**Did you report the abuse
YES[ ]1
NO [ ]2

*JM**If so, where?

4c. Has this process begun in the last 12 months?
YES[ ]1

NO [ ]2

4d. What was the result?

The matter has been dealt with [ ]1
The matter is still in the process of being dealt with [ ]2
Nothing happened/the matter was not dealt with [ ]3

4e. If the response to question 4b was No or Not Sure, what was the reason for trying to legal redress?

Insufficient financial resources to take action [ ]1
Process of addressing the problem appeared too bureaucratic [ ]2
Felt intimated or scared to take action [ ]3
Advised against taking action by someone else [ ]4
No/little confidence that the outcome would be successful [ ]5
None of the above [ ]6

IC:_ _ _ _ _ _ _ _ _ _ _ _ _ _

5a. Have you tried to get a government agency (for example, Ministry of Health, Ministry of Justice, Ministry of Labour) to take action against an abuse of your rights as a person living with HIV?

YES [ ]1
NO [ ]2

5b. Did this happen in the last 12 months?

YES [ ]1
NO [ ]2

5c. What was the result?

The matter has been dealt with [ ]1
The matter is still in the process of being dealt with [ ]2
Nothing happened/the matter was not dealt with [ ]3

6a. Have you tried to get a local or national politician to take action against an abuse of your rights as a person living with HIV?

YES [ ]1
NO [ ]2

6b. Did this happen in the last 12 months?

YES [ ]1
NO [ ]2

6c.What was the result?

The matter has been dealt with [ ]1
The matter is still in the process of being dealt with [ ]2
Nothing happened/the matter was not dealt with [ ]3

JM* **Have you heard about the National HIV Related Discrimination Reporting & Redress System?**

YES	**[**	**]1**
NO	**[**	**]2**

JM* Have you used this system?

YES	**[**	**]1**
NO	**[**	**]2**

IC:_ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _

SECTION 2E EFFECTING CHANGE

1. In the last 12 months, have you confronted, challenged or educated someone who was stigmatizing and/or discriminating against you?

YES	[ ]1
NO	[ ]2

2a. Do you know of any organizations or groups that you can go to for help if you experience stigma or discrimination?

YES	[ ]1
NO	[ ]2

2b. If yes, which kinds of organizations or groups do you know about?
(Tick more than one box if appropriate)

People living with HIV support group (e.g. JN Plus)	[ ]1
Network of people living with HIV	[ ]2
Local (community-based) non governmental organization	[ ]3
Faith-based organization (churches)	[ ]4
A legal practice	[ ]5
A human rights organization (e.g. Jamaicans for Justice)	[ ]6
National non governmental organization (e.g. Red Cross)	[ ]7
National AIDS council or committee	[ ]8
International non governmental organization	[ ]9
UN organization (e.g. (UNAIDS)	[ ]10
Other	[ ]11

2c. If you ticked **OTHER**, please describe the kind of organization or group you are referring to:

____

3. Have you sought help from any of the above organizations or groups to resolve an issue of stigma or discrimination?

YES	[ ]1
NO	[ ]2

4. If you have tried to resolve an issue of stigma and discrimination either on your own or with the assistance of others, briefly 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?

____

____

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

____

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

IC:_ _ _ _ _ _ _ _ _ _ _ _ _ _

*Have you experienced discrimination at any other organization that is responsible for defending the rights of PLHIVs?

YES [ ]1
NO [ ]2

*If yes, how were you discriminated against?

*Why do you feel you were discriminated against?

5a. In the last 12 months, have you supported other people living with HIV?

YES [ ]1
NO [ ]2

5b. If yes, what types of support did you provide (Tick more than one box if appropriate)
Emotional support (i.e. counseling, sharing personal stories and experiences) [ ]1
Physical support (i.e. providing money or food, doing an errand for them) [ ]2
Referral to other services [ ]3

6. Are you currently a member of a people living with HIV support group and/or network?
YES [ ]1
NO [ ]2

7. In the last 12 months, have you been involved, either as a volunteer or as employee, in any programme or project (either government or non-governmental) that provides assistance to people living with HIV?
YES [ ]1
NO [ ]2

8. In the last 12 months, have you been involved in any efforts to develop legislation, policies or guidelines related to HIV?
YES [ ]1
NO [ ]2

9. Do you feel that you have the power to influence decisions in any of the following aspects? (Tick at least one box. You can tick more if appropriate)

Legal/rights matters affecting PLHIVs [ ]1
Local government policies affecting PLHIVs [ ]2
Local projects intended to benefit PLHIVs [ ]3
National government policies affecting PLHIVs [ ]4
National programmes/projects intended to benefit PLHIVs [ ]5
International agreements/treaties [ ]6
None of these things [ ]7

IC:_ _ _ _ _ _ _ _ _ _ _ _ _ _ _

10. There are a number of organizations of people living with HIV working against stigma and discrimination. If one of them asked you, " What is the most important thing that we should be doing as an organization to address stigma and discrimination?" what would you recommend (Tick one box only)

Advocating for the rights of all PLHIVs [ ]1
Providing support to PLHIV by providing emotional, physical and referral support [ ]2
Advocating for the rights and/or providing support to particularly marginalized groups (men who have sex with men, injecting drug users, sex workers) [ ]3

Educating people living with HIV about living with HIV (including treatment literacy) [ ]4

Raising the awareness and knowledge of the public about AIDS [ ]5

IC:_ _ _ _ _ _ _ _ _ _ _ _ _ _ _

SECTION 3A TESTING/DIAGNOSIS

1. Why were you tested for HIV (Tick one or more boxes as appropriate)

Employment [ ]1
Pregnancy [ ]2
To prepare for a marriage/sexual relationship [ ]3
Referred by a clinic or sexually transmitted infections [ ]4
Referred due to suspected HIV-related symptoms (eg. tuberculosis) [ ]5
Husband/wife//partner/family member tested positive [ ]6
Illness or the death of husband/wife//partner/family member [ ]7
I just wanted to know [ ]8
Other [ ]9

If you ticked other, please describe the reason:

2. Was the decision to be tested for HIV up to you? (Tick one box only)

Yes, I took the decision myself to be tested (that is, was it voluntary) [ ]1
I took the decision to be tested but it was under pressure from others [ ]2
I was made to take an HIV test (coercion) [ ]3
I was tested without my knowledge – I only found out
after the test had been done [ ]4

3. Did you receive counseling when you were tested for HIV? (Tick one box only)

I received both pre and post HIV test counseling [ ]1
I only received pre-test HIV counseling [ ]2
I only received post-test HIV counseling [ ]3
I did not receive any counseling when I had an HIV test [ ]4

IC:_ _ _ _ _ _ _ _ _ _ _ _ _ _

SECTION 3B DISCLOSURE AND CONFIDENTIALITY

1. For each of the following people or groups of people, please describe how they were first told about your HIV status, if they have been told.

(Please tick your answers. Only tick more than one box in each line if the answer is different for different individuals)

	I told them	Someone else told them, **WITH** my consent	Someone else told them, **WITHOUT** my consent	They don't know my status	Not applicable
Your husband/wife/partner					
*JM**Someone you are dating					
Other adult family member					
Children in your family					
Your friends/neighbors					
Other people living with HIV					
People who you work with					
Your employers/boss					
Your clients					
Injecting drug partners					
Religious leaders (Lay leaders or clergy)					
Community leaders					
Health care workers					
Social workers/counselors					
Teachers					
Government officials					
The media					

2. (a) Have you felt pressure from other individuals living with HIV or from groups/networks of people living with HIV to disclose your HIV status? If no, tick never, If yes, tick how often. (Tick one box only)

Often [ ]1
A few times [ ]2
Once [ ]3
Never [ ]4

2. (b) Have you felt pressure from other individuals not living with HIV (eg family members, social workers, non governmental organization employees) to disclose your HIV status? If no, tick never, If yes, tick how often. (Tick one box only)

Often [ ]1
A few times [ ]2

Once [ ]3
Never [ ]4

3. Has a health care professional (for example, a doctor, nurse, counselor, laboratory technician) ever told other people about your HIV status without your consent?

Yes [ ]1
No [ ]2
Not sure [ ]3

IC:_ _ _ _ _ _ _ _ _ _ _ _ _ _

4. How confidential do you think the medical records relating to your HIV status are? (Tick one box only)

I am sure that my medical records will be kept completely confidential [ ]1
I don’t know if my medical records will be kept completely confidential [ ]2
It is clear to me that my medical records are not being kept completely confidential [ ]3

5. How would you describe the reactions of these people (in general) when they first knew about your HIV status? (Tick one box only for each category of people)

(Tick not applicable if these people do not know your HIV status or don’t know what there reaction was)

	Very discriminatory	Discrimi-natory	No different	Supportive	Very supportive	Not applicable
Your husband/wife/partner						
Someone you are dating						
Other adult family member						
Children in your family						
Your friends/neighbors						
Other people living with HIV						
People who you work with						
Your employers/boss						
Your clients						
Injecting drug partners						
Religious leaders						
Community leaders						
Health care workers						
Social workers/counselors						
Teachers						

Government officials						
The media						

6. Did you find the disclosure of your HIV status an empowering experience? (Tick Not applicable if you have not disclosed your HIV status)

Yes [ ]1
No [ ]2
Not applicable [ ]3

IC:_ _ _ _ _ _ _ _ _ _ _ _ _ _

SECTION 3C TREATMENT

1. In general, how would you describe your health at the moment? (Tick one box only)

Excellent [ ]1
Very good [ ]2
Good [ ]3
Fair [ ]4
Poor [ ]5

2. (a) Are you currently taking antiretroviral treatment? (Tick one box only)

Yes [ ]1
No [ ]2

JM* If yes (above), have you ever stopped or had a strong desire to stopped taking your antiretrovirals?

Yes [ ]1
No [ ]2

JM*Do you think it is because you: Feel they are not working [ ]1
Don’t like them [ ]2
Have to be hiding them from people in my household [ ]3
Found a better alternative that replaces your antiretrovirals [ ]4
The counseling is not adequate [ ]5
Feel just tired of living sometimes [ ]6
Feel just feel tired of living all the time [ ]7
Experiences at the treatment site/clinic [ ]8
Don’t have the required food to eat while you are on the antiretrovirals [ ]9
Don’t know [ ]10

2(b) Do you have access to anti retroviral treatment, even if you are not currently taking it? (Tick one box only)

Yes [ ]1

No [ ]2
Don’t know [ ]3

3(a) Are you currently taking any medication to prevent or to treat opportunistic infections? (Tick one box only)

Yes [ ]1
No [ ]2

3(b) Do you have access to medication for opportunistic infections, even if you are not currently taking it? (Tick one box only)

Yes [ ]1
No [ ]2
Don’t know [ ]3

IC:_ _ _ _ _ _ _ _ _ _ _ _ _ _

4.In the last 12 months, have you had a constructive (helpful) discussion with a health care professional (s) on the subjects of your HIV-related treatment options.

Yes [ ]1
No [ ]2

5.In the last 12 months, have you had a constructive (helpful) discussion with a health care professional(s) on other subjects such as your sexual and reproductive health, sexual relationship(s), emotional well-being, drug use, etc?

Yes [ ]1
No [ ]2

IC:_ _ _ _ _ _ _ _ _ _ _ _ _ _ _

SECTION 3D HAVING CHILDREN

Questions 1-5 can be completed by both male and female interviewees

1. (a) Do you have a child/children?

Yes [ ]1
No [ ]2

1. (b) If yes, are any of these children known to be HIV positive?

Yes [ ]1
No [ ]2
Not sure ____

2. Since being diagnosed HIV positive, have you ever received counselling about your reproductive options?

Yes [ ]1
No [ ]2
No applicable [ ]3

3. Has a health care professional ever advised you not to have a child since you were diagnosed as HIV positive?

Yes [ ]1
No [ ]2
Not applicable [ ]3

4. Has a health care professional ever coerced (forced) you into being sterilized (vasectomy, tubal ligation) since you were diagnosed HIV positive?

Yes [ ]1
No [ ]2
Not applicable [ ]3

5. Is your ability to obtain antiretroviral treatment conditional on the use of certain forms of contraception?

Yes [ ]1
No [ ]2
Not applicable [ ]3
Don’t know [ ]4

IC:_ _ _ _ _ _ _ _ _ _ _ _ _ _ _

Questions 6 and 7 should be completed by female interviewees only

6. In the last 12 months, have you been coerced (forced) by a health care professional in relation to any of the following because of your HIV status?

	Yes	No	Not applicable
Termination of pregnancy			
Method of giving birth			
Infant feeding practices			

7. (a) Have you ever been given antiretroviral treatment to prevent mother-to-child transmission of HIV during pregnancy? (Tick one box only)

Yes – I have received such treatment [ ]1
No – I did not know that such treatment existed [ ]2
No – I was refused such treatment [ ]3
No – I did not have access to such treatment [ ]4
No – I was not HIV-positive when pregnant [ ]5

7 (b) If yes, were you also given information about healthy pregnancy and motherhood as part of the programme to prevent mother-to child transmission of HIV?

Yes [ ]1
No [ ]2

IC:_ _ _ _ _ _ _ _ _ _ _ _ _ _ _

SECTION 2E PROBLEMS AND CHALLENGES

What do you see as the MAIN PROBLEMS and CHALLENGES in relation to:

1.Testing and Diagnosis

____
____
____
____

2.Disclosure and Confidentiality about being HIV positive

____
____
____
____

3.Antiretroviral Treatment

____
____
____
____

4.Having children when you are HIV-positive

____
____
____
____

*JM**5.Support - Long term post diagnosis counseling and accompaniment

____
____
____
____

*JM**6. Living with HIV while being employed

____
____
____
____

This is the end of the interview. Before completing the quality check section with the interviewee, thank the interviewee for their time. Once you have completed the quality check, complete the referral and follow-up section at the beginning of the questionnaire and confirm any follow-up arrangements. Provide the interviewee with the honorarium and thank them again for their time.

After the interview, take some time alone reflecting on the interview that you have just conducted: review the notes that you took during the interview, make sure that you recorded all the details that you wanted to and add your notes if necessary. Write down anything that you feel you need to discuss or need advice about from your team leader.

IC:_ _ _ _ _ _ _ _ _ _ _ _ _ _

QUALITY CHECKS

This section is designed to help the interviewer and team leader to check the questionnaire to make sure that it has been properly and fully completed. However you also need to use your own judgment to make sure that a good job has been done. The team leader will check the interviewer's responses on his/her return to base. The interviewer should respond to the following points before the closure of the interview so that the interviewee is able to assist you to complete the responses to these questions.

1. Has the interviewee answered every question in Sections 1-3 of the questionnaire? YES ______ NO_________

If NO, please specify which questions have not been answered and give reason why:
____
____
____

2. Do the answers to question 7 in Section 1 and question 8 in Section 2A (groups the interviewee has belonged to or does belong to) appear consistent?

YES ______ NO_________

If NO, please specify which questions have not been answered and give reason why:
____
____
____

3. Does the information given in Section 1 (questions 14 and 15) seem credible (believable)? (that is, is the poverty level of the household roughly consistent with their experience of having insufficient money to buy food for the household---taking into account that some low-income households may grow their own food?)

YES ______ NO_________

If there are differences, have you checked the reasons with the interviewee and recorded why there are these differences below? YES ______________

____
____
____

4. Has the front page of the questionnaire been completed? YES _______

The last quality check can be completed by the interviewer after the interviewee has left but before the interviewer leaves the place of the interview:

5. Has the interview code been written in the top-right hand corner of every page? YES ____

Appendix III: The PLHIV Stigma Index, 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: __________________________
Contact details [INSERT the name of the team leader plus appropriate contact details such as their Telephone number(s), email address and their physical address.]: ____

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, I will now sign this form to confirm that your consent has been obtained.

Signature/initials of interviewer: ___________________________

Date of interview: ________________________

Your verbal consent is all that is needed to go ahead with the interview. If you feel comfortable enough doing so, however, you can also sign your name or initials below to indicate that you have consented in writing to participating in this interview. However, please remember that verbal consent is all that is needed. You do not have to provide us with written consent, but you can if you would like to.

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/initials of interviewee:__________________________

Date of interview: ____________________