

THE PEOPLE LIVING WITH HIV STIGMA INDEX

Sierra Leone

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Acronyms

AHF	AIDS Healthcare Foundation
AIDS	Acquired Immune Deficiency Syndrome
ANC	Anti Natal Care
ART	Anti-Retroviral Therapy
ARV	Anti-Retroviral
CSO	Civil Society Organizations
CWI	Concern Women Initiative
DHS	Demographic Health Survey
FDID	Foundation for Democratic Initiative and Development
FGD	Focused Group Discussion
FSW	Female Sex Workers
GNP+	Global Network of People living with HIV
НСТ	HIV Counselling and Testing
HIV	Human Immuno-deficiency Virus
HRC-SL	Human Right Commission – Sierra Leone
ICW	International Community of Women living with AIDS
IPPF	International Planned Parenthood Federation
КАР	Knowledge Attitude and Practice
MoHS	Ministry of Health and Sanitation
MSM	Men who have Sex with Men
NAC	National AIDS Commission
NACP	National AIDS Control Program
NAS	National AIDS Secretariat
NETHIPS	Network of HIV Positives in Sierra Leone
NGO	Non-Governmental Organization
NSP	National Strategic Plan
Ols	Opportunistic Infections
OVC	Orphans and Vulnerable Children
PLHIV	People Living with HIV
PMTCT	Prevention of Mother to Child Transmission
PWID	People Who Inject Drugs
SLANGO	Sierra Leone Association of Non-Governmental Associations
SLDHS	Sierra Leone Demographic and Health Survey
SOLTHIS	Therapeutic Solidarity and Initiatives against HIV/AIDS
SPSS	Statistical Package for Social Science
SRH	Sexual and Reproductive Health
SSL	Statistics Sierra Leone
STI	Sexually Transmitted Infections
ТВ	Tuberculosis
UNAIDS	United Nations Joint Programme on AIDS
UNICEF	United Nations Children's Fund
VOW	Voice of Women



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Contents

ACRONYMS	3
ACKNOWLEDGEMENTS	4
CONTENTS	5
LIST OF TABLES	7
LIST OF FIGURES	8
EXECUTIVE SUMMARY	9
INTRODUCTION	9
METHODOLOGY	9
FINDINGS	9
Analysis	10
RECOMMENDATIONS	11
INTRODUCTION	
Background	13
NATIONAL HIV EPIDEMIC	
NATIONAL HIV RESPONSE	14
STIGMA AND DISCRIMINATION RELATED TO HIV AND AIDS IN SIERRA LEONE	15
Study Rationale	15
METHODOLOGY	17
Background	
OBJECTIVES OF THE STIGMA INDEX	
Oversight	
SAMPLING	
Survey Methodology	20
DATA PROCESSING AND ANALYSIS	21
ETHICAL CONSIDERATIONS	22
LIMITATIONS	22
FINDINGS	23
DEMOGRAPHICS OF RESPONDENTS	23
HOUSEHOLD CHARACTERISTICS OF RESPONDENTS	27
Understanding of Stigma and Discrimination	
Experience with Stigma and Discrimination from other people	
Access to work, health and education services	
Internalised Stigma and Fears	
RIGHTS, LAWS AND POLICIES	
EFFECTING CHANGE	
TESTING AND DIAGNOSIS	
DISCLOSURE AND CONFIDENTIALITY	
HAVING CHILDREN	
ANALYSIS	
RECOMMENDATIONS	78
ANNEX	80

LIST OF STEERING COMMITTEE MEMBERS	80
FOCUS GROUP DISCUSSION GUIDELINES	81
RECOMMENDED ACTIVITIES AND STAKEHOLDERS	84



List of Tables

Table 1: Sampling distribution for Stigma Index Survey based on equal proportions of	
females Table 2: Personal demographics of respondents	
Table 3: Key and vulnerable population respondents	
Table 4: Personal characteristics and background of respondents	
Table 5: Household characteristics of respondents	
Table 6: Exclusion from gatherings	
Table 7: Experience of gossip, insults, harassment and threats	
Table 8: Experience of physical harassment, assaults and threats	
Table 9: Reasons for stigma and discrimination apart from HIV status	
Table 10: Psychological pressure, sexual rejection and discrimination against household	
Table 11: Reasons for HIV related stigma and discrimination	
Table 12: Experience and perceived reasons for loss of accommodation	
Table 13: Stigma and discrimination related to the workplace	
Table 14: Stigma and Discrimination related to educational services	
Table 15: Stigma and Discrimination related to health services	
Table 16: Internalised sigma: respondent feelings due to HIV status	
Table 17: Internalised sigma: respondent behaviour due to HIV status	
Table 18: Internalised stigma: respondent fears	
Table 19: Respondent awareness of global and national legal frameworks	
Table 20: Rights violations against respondents	
Table 21: Abuse of PLHIV rights and legal redress	
Table 22: Involvement of authorities in rights abuse issue	54
Table 23: Confronting stigma and discrimination	
Table 24: Support mediums for stigma and discrimination	
Table 25: HIV testing among respondents	60
Table 26: Respondent disclosure of HIV status to family / community members	62
Table 27: Means of respondent HIV status disclosure to family and community groups	63
Table 28: Pressure of disclosure	
Table 29: Confidentiality in health care setting	65
Table 30: Reactions to disclosure	66
Table 31: Disclosure as an empowering experience	68
Table 32: Health and treatment experience of respondents	69
Table 33: HIV and family planning options	
Table 34: Health and pregnancy	73

List of Figures

Figure 1: Sierra Leone map of regions and districts	13
Figure 2: Years survey respondents have known about HIV status	23
Figure 3: Highest level of education attained by respondents	26
Figure 4: Average monthly income by sex	28
Figure 5: Respondent experience with at least one incident of exclusion	31
Figure 6: Persons who physically assaulted the respondent	
Figure 7: Reasons for stigma and discrimination apart from HIV	35
Figure 8: Reasons experiencing HIV related stigma and discrimination	38
Figure 9: Respondent reported feelings due to being HIV positive	44
Figure 10: Reported respondent behaviour changes due to knowledge of HIV status	46
Figure 11: Internalised Stigma - Respondent fears due to HIV status	48
Figure 12: Awareness of respondents to International and National HIV legal frameworks	49
Figure 13: Respondents with rights violated due to HIV status	52
Figure 14: Percentage of respondents to report abuse of PLHIV rights	53
Figure 15: Support groups known by respondents to help during experiences of sti	igma and
discrimination	56
Figure 16: Percentage of respondents currently belonging in HIV support groups	57
Figure 17: Respondent reasons for getting an HIV test	59
Figure 18: Percentage of respondents that disclosed their HIV status to someone	62
Figure 19: Percentage of respondents receiving pressure about disclosing HIV status	64
Figure 20: Percentage of respondents that believe health care professionals disclosed their I	HIV status
without consent	65
Figure 21: Reaction to disclosure of HIV status, all respondents	67
Figure 22: Percentage of respondents that found disclosure to be an empowering experience	e68
Figure 23: Respondents' health at the moment of the survey	69
Figure 24: Percentage of respondents with children who are HIV positive	70

Executive Summary

Introduction

Stigma with its resulting discrimination is considered to be a strong factor in the spread of the HIV epidemic; however, there is a dearth of information on the predictors, magnitude and effects of stigma. Worldwide, the effects of stigma have been reported at different levels including individual, family, community and country level. Despite the low HIV prevalence in Sierra Leone, people living with HIV (PLHIV) face stigma and discrimination.

Due to the limited information available regarding HIV-related Stigma and discrimination in Sierra Leone, it is imperative that evidence be collected and shared with PLHIV, their networks and the organizations that support them in order to garner further support for their work and build the capacity of PLHIV on their rights. For this reason, Sierra Leone has conducted its first People Living with HIV (PLHIV) Stigma Index Study.

The PLHIV Stigma Index is a project that has been developed and implemented by and for people with HIV, and aims to collect information about the experiences of people living with HIV related to stigma, discrimination and their rights. The information that is gathered from people living with HIV in the stigma index study will enable researchers to better understand and quantify experiences of PL HIV within Sierra Leone regarding HIV-related stigma and discrimination in order to inform the development and implementation of national policies that protect the rights of PLHIV.

Methodology

This stigma index was a mixed methods study. The methodology included a quantitative component based on the globally approved questionnaire and a qualitative method which involved focus group discussions. Having mixed methods provided an opportunity to quantify the level of stigma and discrimination in the environment while the qualitative part explored the experiences, stories and opinions of the study participants in their own words. Respondents were sampled from the general population as well as from key vulnerable populations including female sex workers (FSWs) and men who have sex with men (MSM). A total number of 577 PLHIV were interviewed, 70 percent of whom were females and 30 percent of whom were males. Members of key populations were also sampled. There was a low level of formal education among the respondents; more than 70 percent of respondents received either no formal education or only primary school education.

Findings

This study provides evidence of the existence of stigma and discrimination in different forms and at varying degrees in the Sierra Leonean context including but not limited to loss of income, exclusion from social, religious and family gatherings as well as through threats and harassments.



The study draws attention to the fact that internalised stigma with its consequences including personal insecurities and inferiorities is rife and a major factor in the lives of many a PLHIV. This finding was supported from both the quantitative as well as qualitative components. Internalised stigma is further manifested in the fear of consequences rather than just consequences itself. This heightened stress and paranoia is not conducive for a healthy lifestyle neither does it support positive health seeking behavior.

This study concurs and affirms the widely held belief that key populations, especially those with HIV within the populations of FSW, MSM, and PWID, are hidden and are particularly vulnerable. Reports of rights abuse, inability to access care and experiences of stigma and discrimination were more frequently reported by MSM and FSW respondents than the general PLHIV group. This report provides evidence that they require specific interventions that will target their unique situations in addition to reducing the harm and risk that they encounter through the daily challenges they face.

The economic empowerment of PLHIV to favourably and fairly compete in a stigmatising community is of utmost importance. Close to 40 percent of respondents reported making an average monthly income of less than 199,999 Leones (44.44 USD) which translates to less than USD 2 per day. This suggests that PLHIV and their families live in considerable poverty. The lack of economic and social resources may act as barriers for PLHIV who need to access basic services.

Participants from the focus group discussions frequently brought up concerns regarding access to treatment and discrimination from health workers. This raises concerns regarding the quality of treatment that PLHIV receive in the facilities and their general confidence in the health system regarding confidentiality and sensitization to stigma and discrimination. Health facilities and workers are the first and recurring line of contact for PLHIV, therefore this connection must be strengthened for quality patient care and support.

The Stigma Index also clearly points to a lack of understanding of HIV Acts and legislature promulgated to promote and protect the rights of PLHIV. While knowledge of the existence of these legislatures was high, the understanding of the content as well as its implementation in protecting the rights of PLHIV from abuse and discrimination is low.

The symbiotic relationship between the health facility and the populations is critical to the success or otherwise of HIV programs. This report highlighted a perceived stigma and lack of confidentiality by PLHIV of their HIV status especially from members of key populations. The unauthorized disclosure of health records is a huge gap that needs to be redressed if confidence in health institutions is to be reinforced.

Analysis

As the first comprehensive assessment of HIV related stigma and discrimination in Sierra Leone, several lessons were found from the study. These include:

- PLHIV stigma and discrimination exists
- Self-stigma is very high among PLHIV

- Fears of stigma and community reaction to HIV status is high
- Supportive environment is not enough to encourage disclosure of HIV status
- Key populations are hidden and silent even among PLHIV network and support groups
- Key populations are especially vulnerable due to specific stigma and discrimination related to their practices
- Health service access and quality needs improvement and consistency in delivery
- Patient confidentiality is not respected and upheld
- Abuse of rights by authority figures pose security and health risk for PLHIV
- Presence of HIV Acts and PLHIV supportive policies is not enough
- PLHIV support groups and NETHIPS must be further capitalized as an entry point and communication and conduit
- Stronger messaging regarding HIV and pregnancies and children are needed
- Discordant couples are at high risk of HIV transmission
- Needs of male sex workers have to be considered
- The role of the media in the HIV response needs to be emphasized
- HIV related stigma in the workplace is prevalent
- PLHIV support groups could be an entry point for targeted PLHIV interventions

Recommendations

This report recognizes the role of stigma and discrimination as a cross cutting issue that needs to be addressed, therefore specific recommendations are made to address stigma and discrimination as well as mitigate its effects on people living with HIV in Sierra Leone.

- Strengthen psychological and social support to PLHIV from HIV facilities
- Provide informational sessions to PLHIV regarding stigma and discrimination
- Stigma and discrimination sensitization sessions for health workers and authority figures
- Stronger counseling needed for disclosure and discordant couples
- Regular HIV radio program to be broadcasted
- Strengthen family planning sessions provided to HIV support groups
- Mainstream stigma and discrimination
- Further integrate and utilize PLHIV networks and support groups in interventions
- Provide training and sensitization sessions regarding legal rights of PLHIV and key populations
- Local evidence base needs to be strengthened through iterative research
- Strengthen the functional capacities of PLHIV networks and support groups

Finally, this PLHIV Stigma Index project is a process that has been implemented by and for people living with HIV. The network of HIV positives in Sierra Leone as well as PLHIV support groups have taken leadership, ownership and responsibility for the planning, coordination and implementation of the stigma index process with the active support of its partners. A key finding of this study is that PLHIV networks are the main support pillars for PLHIV when they



experience situations of stigma and discrimination. It is clear that PLHIV networks and their affiliate support groups are necessary and should be strengthened functionally, structurally, organisationally and operationally in order to be able to respond adequately to the responsibilities that come with dealing with the myriad of issues that stigma and discrimination conveys. The capacities of PLHIV networks and support groups need to be developed to ensure a sustainable response and to fulfil their natural roles as change agents and gate keepers.

Introduction

Background

Sierra Leone is located on the west coast of Africa and covers an area of about 72,000 square kilometres. It is bordered by the Republic of Guinea in the north and north-east, by the Republic of Liberia on the east and southeast, and by the Atlantic Ocean in the west and southwest. The population of Sierra Leone increased from 2.2 million in 1963 to 4.9 million in 2004. The population was estimated at 6 million people in Slightly more than one-third of the 2014. population (37 percent) lives in the urban settings. The female population accounts for 52% of the total population with an average total fertility rate of 5.1 children per woman. The country is recovering from a traumatic history of civil conflict that spanned a period of ten years.



Figure 1: Sierra Leone map of regions and districts

Administratively, Sierra Leone is divided into four provinces, namely the Western Area, Northern, Eastern and Southern. The Provinces are further sub-divided into districts, and then into chiefdoms. Overall, there are fourteen (14) districts and 149 chiefdoms in the country.

As illustrated in Figure 1, the Northern Province comprises of the five districts of Kambia, Bombali, Koinadugu, Port Loko and Tonkolili; Southern Province is sub-divided into four districts of Moyamba, Bo, Bonthe and Pujehun; while the Eastern Province comprises of the three districts of Kono, Kenema and Kailahun. The Western Area is host to Freetown, the capital city and is sub-divided into two districts: Western Area Urban and Western Area Rural. The 14 Districts were constituted into 19 Local councils following the enactment of the Decentralization Act. The 19 Councils comprise of 6 City Councils, including Freetown the capital and 13 district councils.

National HIV Epidemic

The HIV epidemic in Sierra Leone has been considered as mixed, generalized and heterogeneous. HIV affects different population sub-groups and all sectors of the population through multiple and diverse transmission dynamics. The HIV prevalence in Sierra Leone increased from 0.9% in 2002 to 1.5% in 2005 and has remained at the same level since 2008 (SLDHS 2008). This stabilization means the country is rated as one of the least affected compared to others in the sub-region and globally. Prevalence was 2.7% in urban areas compared to 1.2% in rural areas.



Women are disproportionately infected by the epidemic. An estimated 60,000 Sierra Leoneans are living with HIV out of which 34,000 are women and 5,000 are children. According to the SLDHS report 2008, prevalence rate for men was 1.2% while that for women was 1.7%. In 2014, it was estimated that 22,438 adults (15+) were in need of antiretroviral therapy (ART), however only 8,680 were receiving it; that is a coverage rate of 39% among adults. According to the Survival Study conducted in 2011, 70% of PLHIV who should remain on treatment remain under treatment 12 months after initiation, and the survival rate of those under treatment is 92%.

HIV prevalence among pregnant women attending antenatal clinics (ANC) also declined progressively from 4.4% in 2007 to 3.5% in 2008 to 3.2% in 2010 respectively but 3.2% is still twice higher than the national prevalence of 1.5%. There was a three-fold increase in syphilis prevalence among pregnant women from 0.4% in 2006 to 1.4% in 2010; concerns being that STIs are co-factors known to increase the risk of becoming infected with HIV. Syphilis prevalence is higher amongst rural pregnant women (1.8%) compared to their urban counterparts (1.3%).

Key populations contribute significantly to the dynamics of the epidemic in Sierra Leone. The 2010 HIV modes of transmission study revealed that commercial sex workers, their clients and partners of clients contribute 39.7% of the new infections. People in discordant monogamous relationships contribute 15.6% of new infections of which clients of sex workers account the most (25.6%); sex workers contribute to 13.7% of new infections, and partners of newly infected account the remaining of 0.37%. Fisher folks contribute 10.8%, traders 7.6%, transporters 3.5% and mine workers 3.2%. MSM and People Who Inject Drugs (PWID) have also been identified to be at higher risk of HIV infection; 2.4% and 1.4% of the new infections respectively.

National HIV Response

The National AIDS Commission (NAC) and the National HIV/AIDS Secretariat (NAS) have been established in the Office of the President with the responsibility of providing leadership in coordinating, monitoring and mobilising resources for the national response. With the support of the key stakeholders, NAS is providing strategic direction for the national multi-sectoral and decentralized response in the programmatic areas of HIV prevention, treatment of HIV and other related conditions, care and support, policy and advocacy. The National AIDS Control Programme (NACP), which is placed within the Ministry of Health and Sanitation, is focused on providing support to the health programming and service provision of the national response.

The national response is guided by the National Strategic Plan of 2011-2015 which charts the roadmap for Sierra Leone to achieve the Millennium Development Goal to have halted and begun to reverse the spread of the HIV/AIDs by 2015. It is multi-sectoral with the overall vision towards zero New Infection, Zero Discrimination and zero Aids related deaths. The thematic areas of the NSP are (i) Coordination, institutional arrangements, resource mobilisation and management; (ii) Policy, advocacy, human rights and legal environment; (iii) Prevention of new infections (iv) Treatment of HIV and other related conditions (v) Care and support for infected and affected by HIV and AIDS and (vi) Research, monitoring and evaluation. The Mid-Term Review of the NSP was conducted in December 2013 and the country is about to prepare an



Operational Plan for 2014-2015. Treatment, care and support services have gradually been scaled up across the country since the inception of multi-sectoral response. Key population groups including FSW, MSM, PWID were identified as priority populations, alongside the fisher folks; transporters; uniformed service personnel; prisoners; miners; cross-border and informal traders; women, girls and children; youths and general population. Over the years, guidelines have been developed and reviewed for effective service delivery. These guidelines include HCT guidelines, ART guidelines, OVC guidelines, Nutritional guidelines, Home-based Care guidelines and workplace policy.

The National HIV and AIDS Commission Act 2011 was enacted to establish the National HIV and AIDS Commission to be responsible for making policies for all HIV and AIDS related services in the country. The Act makes provision for the monitoring of the HIV Prevalence and contains penalties for discriminatory acts against those infected and affected by HIV and AIDS.

Stigma and Discrimination related to HIV and AIDS in Sierra Leone

Stigma with its resulting discrimination is considered to be a strong factor in the spread of the HIV epidemic; however, there is a dearth of information on the predictors, magnitude and effects of stigma. Worldwide, the effects of stigma have been reported at different levels including individual, family, community and country level. Despite the low HIV prevalence in Sierra Leone, people living with HIV (PLHIV) face stigma and discrimination.

Over the years, the National AIDS Secretariat (NAS) in conjunction with various stakeholders such as the Ministry of Health and Sanitation (MOHS), UNAIDS, Statistics Sierra Leone (SSL) have embarked on many studies to investigate the level of awareness of HIV and AIDS, the HIV prevalence and behaviours of the population in matters related to HIV so as to provide the national health system with reliable estimates of the national epidemic and response. However, information regarding stigma and discrimination related to HIV and AIDS is not well studied or documented in Sierra Leone.

People living with HIV often face stigma and discrimination and are unaware of their rights and how to uphold them. There are a various organisations within Sierra Leone involved with advocacy against HIV-related stigma and discrimination. These organizations are actively involved in fighting for improved rights for people living with HIV; however, with limited evidence of HIV-related stigma and discrimination, it is difficult to appropriately program interventions or provide support to the PLHIV networks.

Study Rationale

Due to the limited information available regarding HIV-related Stigma and discrimination in Sierra Leone, it is imperative that evidence be collected and shared with PLHIV, their networks and the organizations that support them in order to garner further support for their work and build the capacity of PLHIV on their rights. For this reason, Sierra Leone has conducted its first People Living with HIV (PLHIV) Stigma Index Study.



The PLHIV Stigma Index is a project that has been developed and implemented by and for people with HIV, and aims to collect information about the experiences of people living with HIV related to stigma, discrimination and their rights. The information that is gathered from people living with HIV in the stigma index study will enable researchers to:

- Record the diverse experiences of PL HIV within Sierra Leone regarding HIV-related stigma and discrimination;
- Inform the development and implementation of national policies that protect the rights of PLHIV;
- Shape the design of programmatic interventions so that they consider the issue of HIV-related stigma and discrimination within their content;
- Measure changes over a period of time with regard to stigma, discrimination and the rights of PLHIV in Sierra Leone;
- Provide an evidence base for policy change and programmatic interventions.

The primary aim of collecting the information and presenting it in the form of an index is to widen the understanding of the extent and forms of stigma and discrimination faced by people living with HIV. The information from Sierra Leone's Stigma Index can then be compared on a global level with other countries who have conducted the same study, thus making this information available to be used as a local, national and global advocacy tool to fight for improved rights for people living with HIV.

Methodology

Background

This Stigma Index Study follows the protocol and design stipulated within the Stigma Index User Guide¹. The PLHIV Stigma Index used the globally approved questionnaire and protocol provided in the Stigma Index User Guide. This questionnaire formed the core of the study for the purpose of international comparability.

The study is driven and led by the Network of People Living with HIV in Sierra Leone, NETHIPS, with support from its technical partners; these organizations composed the Stigma Index Steering Committee in order to coordinate the overall process of the study. The Program Coordinator was selected from NETHIPS and was supported by a Program Assistant; NETHIPS selected an advisor from UNAIDS in order to ensure technical expertise and compliance to the study. A complete list of Steering Committee members is found in the Annex.

The Stigma Index study includes quantitative and qualitative research in which PLHIV participated actively in all stages of the study, including adaptation of the questionnaire to Sierra Leone's context, creation of a focus group discussion tool, interviewer recruitment and training, data collection, and report writing. A research partner was selected in order to lead the technical aspects of conducting the study; Statistics Sierra Leone was chosen due to their survey expertise and mandate to support national studies.

Objectives of the stigma Index

The primary objective of the stigma index¹ is to collect information and present it in the form of an index to broaden understanding of the extent and forms of stigma and discrimination faced by people living with HIV in Sierra Leone. The intention of the participating organizations is to make the index widely available so that it can be used as a local, national and global advocacy tool to fight for improved rights for people living with HIV. The specific objectives of the stigma index include:

- To document the various experiences of people living with HIV in Sierra Leone regarding HIV-related stigma and discrimination
- To inform the development and implementation of national policies that protect the rights of people living with HIV;
- To shape the design of programmatic interventions so that they consider the issue of HIV-related stigma and discrimination within their content.
- To measure changes over a period of time and explore the perceived trends of the level and depth of HIV and AIDS related stigma
- To provide an evidence base for policy change and programmatic interventions.

 $^{^{1}}$ The people living with HIV Stigma Index. Available at www.stigmaindex.org



Oversight

A proper governance structures was necessary to provide overall guidance to the process of the Stigma Index Study. The steering committee was created with the primary objective of coordinating, planning and implementing the PLHIV Stigma Index. The steering committee comprised of senior technical members from multi-sectoral partners. A complete list of the Steering Committee members is found in the Annex.

The Steering Committee was comprised of local and international organisations and included representatives from government, multilateral agencies, non-governmental organisations as well as networks of PLHIV and key population groups. The network of HIV positives in Sierra Leone led the steering committee in order to establish national and PLHIV ownership of the survey; this was crucial to implementation, capacity building and utilization of survey results. The steering committee also functioned as a peer-review mechanism throughout the study, thus providing a medium to discuss methodology and implementation methods. The Steering Committee was chaired by the Program Coordinator for the Stigma Index, NETHIPS.

The objectives and tasks of the steering committee included the following:

- To ensure transparent decision-making
- To identify a collaborative approach to fund-raising
- To promote understanding for and utilization of survey results
- To oversee smooth implementation

The complete Terms of Reference for the Steering Committee can be found in the Stigma Index Guidelines.

Sampling

The Sierra Leone Stigma Index targeted a district level implementation (third level of aggregation after the national and regional levels). This was done in order for various local councils to be able to access and utilise the results of the PLHIV Stigma Index study at the district level to inform policy towards reducing stigma, discrimination and the rights of people living with HIV within their districts. Furthermore, having access to results at the district level will greatly aid national partners in their advocacy efforts. District disaggregated data will not be presented in this report but will be made available to local councils and district health management teams to inform and guide their activities especially as they relate to HIV treatment, care and support.

The sample size required to have a representative estimate at the district level has been determined to be at least 560 respondents. NETHIPS has a register of approximately 8,000 people living with HIV (PLHIV), and 560 people represent approximately 7% of this population. The sampling methodology that has been utilised is a *Probability-based sampling of a defined population*.

The 8,000 registered people on the NETHIPS register served as the population of interest and thus the sampling frame. The register was then divided into male and female categories and the male to female ratio was used to determine the proportion of males and females to



interview from the 560 respondents. Once the male and female registers were generated, the selection of males and females from their respective registers followed a systematic random sampling procedure. The selection had the same proportion of males and females as the NETHIPS register, and the sample size was 560 people.

Region	District	Males	Females	Total
Eastern	Kailahun	20	20	40
	Kenema	20	20	40
	Kono	20	20	40
Southern	Во	20	20	40
	Bonthe	20	20	40
	Moyamba	20	20	40
	Pujehun	20	20	40
Northern	Bombali	20	20	40
	Kambia	20	20	40
	Koinadugu	20	20	40
	Port Loko	20	20	40
	Tonkolili	20	20	40
Western Area	Western Rural	20	20	40
	Western Urban	20	20	40
Sierra Leone		280	280	560

Table 1: Sampling distribution for Stigma Index Survey based on equal proportions of males and females

It must be noted that while 560 was the targeted number of respondents, in the end, a total of 577 people were interviewed. This increase in the total numbers was foreseen and data collectors were prepared with additional questionnaires and tools for this eventuality. Table 1 shows the sample frame based on an equal number of males and females in the parent population. Additionally, although an even distribution between female and male respondents was planned, the consenting interviewers resulted in a shift of ratio of respondents (as evident in findings shown below).

In addition to the 560 respondents necessary for satisfying sampling conditions above, certain key populations are also of interest to the study; in this case, they are female sex workers (FSW), men who have sex with men (MSM), and people who inject drugs (PWID). Due to the sensitive networks and undisclosed nature of the members of key populations who are also HIV positive, members of the MSM population were also individually interviewed for the questionnaire at the time of focus group discussion as they did not want to be identified within group settings as being HIV positive. Due to the small numbers of known PWID in Sierra Leone and the lack of information regarding their HIV status, it was not possible to gather a group for PWID. Additionally, interviewees were offered the option of not responding to a question if they were not comfortable; this non-response option resulted in the number of respondents varying from question to question.



Random sampling was used for the focus group discussions. The general PLHIV group was compiled by taking the complete list of PLHIV within the Freetown Urban area and selecting 20 randomly from the list (every 5th name in the membership list). The FSW group was planned to undergo the same selection process, however due to unavailability of the individuals selected, the study continued with known FSW PLHIV from one specific support group. The MSM group was comprised of individual PLHIV known to the NGO involved with MSM.

Survey Methodology

The survey methodology used both quantitative and qualitative methods. For the quantitative survey, the globally approved questionnaire was used. To gather a more in-depth understanding of PLHIV sentiments regarding stigma and discrimination, three focus group discussions (FGD) were organised; one for general PLHIV, one for members of MSM population who were HIV positive, and another for members of FSW population who were HIV positive. These discussions provided an opportunity to capture the experiences, stories and opinions of the study participants in their own words. Statistics Sierra Leone (SSL) together with the Steering Committee developed and finalised the survey instruments which incorporated the globally approved questionnaire and a focus group discussion guide. A copy of the complete questionnaire and focus group discussion guides is found in the Annex.

Data Collection - Quantitative

The standard questionnaire developed by GNP+, ICW, UNAIDS and IPPF is the main tool for data collection by the People Living with HIV Stigma Index (see Annex). Prior to its use for the study, the survey questionnaire was pre-tested within the Western Area of Sierra Leone. The essence of the pre-test was to practice and deploy all survey protocols (pilot study) in an environment similar to the actual survey environment so as to determine the validity and correctness of all survey instruments and to correct all errors before the actual survey.

Once all survey instruments had been corrected and finalised on completion of the pre-test in November 2013, fieldwork staff were recruited for training for main data collection. Since the PLHIV Stigma Index Survey is unique in that it requires people living with HIV to be recruited as interviewers, NETHIPS took the lead in the recruitment of all interviewers for the study and the pilot test. The same complement of people that conducted the main survey were also involved in the pre-test so as to have had them initially trained in all survey protocols before the main training for data collection. All the interviewers were PLHIV from PLHIV networks and associations.

The training for main data collection took place during the last week of November 2013, and lasted for 3 days. 42 PLHIV (3 from each district) were trained on the tool with the understanding that only 28 (2 from each district) would be selected to conduct the survey itself. This process was used in order to build the capacity of PLHIV in conducting surveys in addition to supporting the recruitment process of selecting appropriate members as interviewers. The methodology that was used in the training involved the use of power point presentations, detailed discussion of the questionnaires, and mock interviews and exercises. The training covered a range of topics including background and objectives of the stigma index study, the meanings of key words, sampling strategy at district level, setting up interviews,



approaches to using the questionnaire, interpretation of each question, completing the questionnaire, as well as practical demonstrations and role plays. Subject specific experts were also invited to give presentations to the participants on their subjects as they related to the survey so as to guide them on best practice; such as stigma and discrimination, research, and HIV epidemiology in Sierra Leone. The training of field staff was undertaken in one central location. Once training was completed, field staff was deployed to commence field work, which lasted for the first two weeks of December 2013.

All 4 regions and 14 districts in Sierra Leone participated in this survey. Each survey team consisted of two (2) interviewers per district i.e. one (1) male and one (1) female interviewer giving a total of twenty-eight (28) interviewers. During fieldwork, there was a team of four (4) monitors from SSL, one (1) per region that undertook quality control measures. They monitored the quality of filled questionnaires and advised the field staff (interviewers) on all survey protocols so that all errors that arose were rectified in the field.

Data Collection - Qualitative

As this is the first time Sierra Leone has conducted the PLHIV Stigma Index, in-depth interviews and focus group discussions were undertaken to have a better understanding of the issues surrounding people living with HIV in relation to stigma, discrimination and their rights. Four focus group discussions (FGD) were planned: one for general PLHIV, and one for each key population of MSM, FSW and PWID. Due to lack of information regarding PLHIV within the PWID community, it was not possible to convene this group and thus it was dropped from the study. MSMs were individually interviewed using the FGD guides due to their desire to remain anonymous from a group. They were also interviewed using the PLHIV Stigma Index globally approved questionnaire to ensure that they were sufficiently covered during the survey process so that meaningful analysis could be done. Due to the hidden nature of the MSM population within Sierra Leone, this was the only method expected to adequately gather information from them.

The general PLHIV FGD had 20 participants, FSW PLHIV FGD had 20 participants, and MSM PLHIV FGD had 8 participants. Each FGD lasted approximately 3 hours; all FGD took place in the Western Urban area in mid-January 2014. Each session was recorded to aid with transcription and capturing the nuanced discussions and sentiments. Discussions were conducted in Krio, the local language; they were transcribed into summary form in English.

Quotes from the FGD have been included in this report; pseudonyms have been provided for the FGD participants for confidentiality purposes.

Data Processing and Analysis

Data processing involved data entry, data cleaning, and the submission of the clean data set. Data entry commenced in April 2014 and lasted for two weeks. Data entry personnel constituted ten (10) data entry operators, one (1) data entry supervisor and one (1) programmer; all were staff from SSL. The programmer designed the data entry programme using CSPro 5.0. The data entry operators entered data from completed questionnaires into the data entry programme (CSPro 5.0). The data entry supervisor supervisor all aspects of data



processing and cleaning. Data cleaning allowed for inconsistencies or lack of clarity in the data to be sorted, corrected and in some cases excluded from the final analysis. This process of data cleaning resulted in the number of respondents varied from one question to the other. On submission of a clean data set, the data was analysed using IBM SPSS Statistics 22 software to generate tables and charts for report writing. Once all tables and charts were generated, a draft report was prepared for validation, after which a final report was provided.

Ethical considerations

As this study required direct contact with individuals to gain their personal information, ethical approval for the study was required and obtained from the Sierra Leone Ethics and Scientific Review Committee. Application was submitted and approval received in November 2013. Informed consent was attained from each individual participating in the study prior to the start of each questionnaire and FGD, as per the Stigma Index guidelines. Confidentiality of participants' identifies was upheld during selection of participants by ensuring only NETHIPS was involved in identifying the participants. Confidentiality was upheld during the interview by conducting them at the support group meeting sites or a neutral location. Questionnaire responses were kept confidential after the interviews via use of unique identifiers. The unique identifiers ensured that data entry personnel or any other individual seeing the completed questionnaires would be unable to trace the respondents.

Limitations

The PLHIV population is a closed and small community, thus only PLHIV who are known to PLHIV support groups could be reached for the study. Sampling of PLHIV in health facilities was considered. However, because stigma in health facilities was also part of the scope of this study, it was important that PLHIV who were respondents were sampled and interviewed in a 'neutral' place. The hidden nature of key populations in Sierra Leone meant that the sample size for key populations that participated in this study was small. More insight may have been provided into the issues raised if more FSWs, MSM and any PWID were sampled. Ensuring that members from the key populations of FSW, MSM and PWID were reached in this study was a priority so as to ensure their specific vulnerabilities and concerns to be represented in the study. The Steering Committee was confident that PLHIV who identified as FSW would be found within the random sampling for the questionnaire, however as MSM and PWID are a hidden group, special efforts was required to draw them into the sample. As reported above, it was not possible to identify PWID who were HIV positive. Due to the deliberate efforts to get MSM responses for the questionnaire, the MSM proportion cannot be seen as a representative size within the PLHIV population. Rather, the information gathered from the MSM PLHIV group should be regarded with caution; it is suggested that it be viewed as case study data rather than representative of the MSM population within Sierra Leone's PLHIV population. Finally, as this is the first Stigma Index and the first time many PLHIV members have been involved with conducting surveys, errors were found in implementation of the survey, such as errors in skipping patterns. This has resulted in some questions having more respondents than expected; in some cases this has been resolved in analysis.

Findings

Demographics of respondents

This study surveyed 577 people; roughly 70 percent were female and 30 percent male, of which 1.6 percent identified as MSM and 1.2 percent as a female sex worker (FSW). It must be noted that one male identified as a sex worker, however all sex worker data for the remainder of this study focuses only on the female respondents who identified as a sex worker. Additionally, it must be emphasized that males who participated in the MSM Focus Group Discussions were also given an opportunity to answer the questionnaire in order to gather more information on MSM as it was anticipated that very few would be found in the general survey method due to the very hidden nature of the population; therefore, only one of the original 569 respondents identified as an MSM. MSM who participated in this study were compromised of individual PLHIV known to the NGP involved with MSM. For this reason, information specifically for MSM proportions should be regarded as case study data rather than representative of the MSM population within Sierra Leone's PLHIV population. It is equally important to note at this point that not all questions were answered by the respondents based on their right to decline to answer questions they are not comfortable with. Additionally, data cleaning allowed for inconsistencies or lack of clarity in the data to be sorted, corrected and in some cases excluded from the final analysis. This process explains why the number of respondents varies from one question to the other.

Table 2 outlines the demographics of the study respondents. Thirty-four percent of those surveyed were between the ages of 30 to 39; the largest portion of male respondents (36 percent) was between 40 and 49 while the largest portion of female respondents (36 percent) was between 30 and 39. Only 3 percent of respondents were under the age of 20.



Forty-six percent of respondents reported having known of their HIV status for 1 to 4 years. Many female respondents (45 percent) reported knowing of their HIV status for 1 to 4 years; similarly, male respondents (49 percent) knew of their status for the past 1 to 4 years. Thirty-eight percent of respondents have known of their HIV status for a period between 5 to 9 years, 55.7 percent have known about their status for a maximum of 4 years while 6.4 percent have known about it for at least 10 years. It must be noted that duration in this sense does not represent the time from infection since many would not know the exact time of

Figure 2: Years survey respondents have known about HIV status

infection; rather, it signifies the time from HIV diagnosis to the time of this survey.



More than half of the respondents (57 percent) reported themselves as being married or in a cohabiting relationship; the next highest grouping is the respondents who report being single (15 percent), then those who report being widowed (14 percent). Seventy-six percent of males reported being married while 8 percent reported being single. Fifty percent of females report being married while 18 percent reported being single. Within the relationships reported, 33 percent report being in the relationship for a period between 1 to 4 years; more females (37 percent) fall into this category than males (26 percent). Twenty-two percent also reported being in the current relationship for 15 or more years; more males (29 percent) report being in this category than females (18 percent). Eighty-two percent of respondents reported being sexually active; 91 percent of males and 78 percent of females report being sexually active.

	Male		Fem	nale	То	tal	FS	W	MS	SM
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Respondents	175	30.3	402	69.7	577	100.0	7	100.0	9	100.0
Age										
15 to 19	7	4.0	11	2.8	18	3.1	1	14.3	0	0.0
20 to 24	10	5.8	55	13.8	65	11.3	4	57.1	1	11.1
25 to 29	19	11.0	66	16.5	85	14.8	0	0.0	3	33.3
30 to 39	49	28.3	144	36.0	193	33.7	1	14.3	2	22.2
40 to 49	63	36.4	88	22.0	151	26.4	0	0.0	3	33.3
50+	25	14.5	36	9.0	61	10.6	1	14.3	0	0.0
Total	173	100.0	400	100.0	573	100.0	7	100.0	9	100.0
Years with HIV										
0 -1	11	6.3	44	11.0	55	9.6	0	0.0	0	0.0
1 - 4	85	48.9	180	44.9	265	46.1	3	42.9	6	66.7
5 - 9	69	39.7	149	37.2	218	37.9	1	14.3	3	33.3
10 - 14	5	2.9	18	4.5	23	4.0	3	42.9	0	0.0
15 +	4	2.3	10	2.5	14	2.4	0	0.0	0	0.0
Total	174	100.0	401	100.0	575	100.0	7	100.0	9	100.0
Relationship status										
Married /										
cohabiting, partner	121	69.5	157	39.2	278	48.3	0	0.0	3	33.3
living in household.										
Married/cohabiting,										
partner living /	11	6.3	42	10.5	53	9.2	0	0.0	2	22.2
working away.										
In a relationship,	13	7.5	23	5.7	36	6.3	0	0.0	3	33.3
not living together.	15	7.5	25	5.7	50	0.5	0	0.0	5	55.5
Single.	14	8.0	70	17.5	84	14.6	7	100.0	1	11.1
Divorced /	7	4.0	39	9.7	46	8.0	0		0	0.0
separated.	/	4.0	39	9.7	40	0.0		0.0		0.0
Widow / widower.	8	4.6	70	17.5	78	13.6	0	0.0	0	0.0
Total	174	100.0	401	100.0	575	100.0	7	100.0	9	100.0
Years in current relat	ionship									
0-1	15	10.4	30	13.1	45	12.1			1	12.5
1-4	38	26.4	84	36.7	122	32.7			2	25.0
5 – 9	27	18.8	46	20.1	73	19.6			4	50.0
10 – 14	22	15.3	29	12.7	51	13.7			0	0.0
15 +	42	29.2	40	17.5	82	22.0			1	12.5
Total	144	100.0	229	100.0	373	100.0			8	100.0
Sexually active										
Yes	157	90.8	307	77.7	464	81.7	6	85.7	9	100.0
No	16	9.2	88	22.3	104	18.3	1	14.3	0	0.0
Total	173	100.0	395	100.0	568	100.0	7	100.0	9	100.0

Table 2: Personal demographics of respondents



As a subset of the female data aforementioned, FSW who took part in the survey were spread throughout the age categories and all were single. One of the seven FSW noted that they were currently not sexually active. Similarly, as a subset of the male data aforementioned, most of the MSM interviewed were between the ages of 25 to 49, and most of them have been aware of their HIV status for a period of one to four years. Most MSM were reported to be in a relationship or married, with nearly half of them being the relationship for a period between five to nine years. All MSM respondents reported that they were sexually active.

Respondents were asked whether they had a current or past association with a specific group, which in itself might be considered by society as different or "other" – and, in some cases, deviant or morally wrong. The interviewee's membership or association with this group might very well be underlying or contributing to their experience of HIV-related stigma and discrimination. Past association with one of these categories was asked because even if someone is no longer, for example, a sex worker, the community might still stigmatize them for having been a sex worker in the past. As long as someone is seen as having belonged to a particular group – even if they are no longer a member of that group now – the attitude of the community towards that person might still reflect their past membership of a particular group rather than their current situation.

Information regarding stigma and discrimination towards PLHIV who also identify themselves as a member of a key population is important. In this study and for Sierra Leone's case, key populations refer to men who have sex with men (MSM), female sex workers (FSW), and people who inject drugs (PWID). Efforts were made to contact people who identified as a PLHIV and a PWID, however this proved to be extremely difficult as PWID are an extremely hidden sector of the population and have not disclosed to members within their cohorts whether they are HIV positive. Therefore, in addition to general PLHIV population, this study highlights findings and concerns that are specific to MSM and FSW, as seen in all the tables and finding discussions.

Table 3 outlines the association of the respondents with key and vulnerable populations. Note that respondents could identify themselves as belonging to multiple groups. Of the male respondents, most (78.9 percent) identified themselves as not belonging to a listed vulnerable group. Of those belonging to a vulnerable group, 5.1 percent identified as an MSM, 7.6 percent as internally displaced, and 4 percent as a gay person. Of the female respondents, most (85.3 percent) identified themselves as not belonging to a listed vulnerable group. Of those belonging to a vulnerable group, many identified as internally displaced (7.7 percent), a refugee / asylum seeker (3.7 percent), or a sex worker (1.7%). It is worthy to note that two individuals identified themselves as transgender, and one as a PWID.

Among the FSW, one identified herself as a refugee and another as a refugee / asylum seeker. Among the MSM, two-thirds of the population identified themselves as gay, one as a transgender, and one as a refugee / asylum seeker.



Table 3: Key and vulnerable population respondents

	Ma	ale	Female		Total		FSW		MSM	
	Number	Percent								
Category										
MSM	9	5.1	0	0.0	9	1.6	0	0.0	9	100.0
Gay or lesbian	7	4.0	0	0.0	7	1.2	0	0.0	6	66.7
Transgender	1	0.6	1	0.2	2	0.3	0	0.0	1	11.1
Sex worker	1	0.6	7	1.7	8	1.4	7	100.0	0	0.0
PWID	0	0.0	1	0.2	1	0.2	1	14.3	0	0.0
Refugee / asylum seeker	2	1.1	15	3.7	17	2.9	1	14.3	1	11.1
Internally displaced person	13	7.4	31	7.7	44	7.6	0	0.0	0	0.0
Indigenous group	6	3.4	3	0.7	9	1.6	0	0.0	0	0.0
Migrant worker	1	0.6	1	0.2	2	0.3	0	0.0	0	0.0
Prisoner	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
None	138	78.9	343	85.3	481	83.4	0	0.0	0	0.0

Table outlines 4 the personal characteristic and background of the respondents. This study showed that 14 percent of respondents had selfreported disabilities. This is much higher than the estimates of the 2004 Census which reported comparatively lower estimates and put the prevalence of disability in the general population at 2.4 percent. This is important because persons with disability in Sierra Leone face wanton discrimination in areas related to their employment, health care and education. Of those that reported disabilities and further elaborated on type, the many (20 percent) respondents reported having sight disability. Others reported having



Figure 3: Highest level of education attained by respondents

hearing problems (43 percent) and disabled limbs (29 percent). Many female respondents who reported a disability reported having hearing disability (43 percent) and disabled limbs (33 percent). Male respondents that reported a disability most commonly reported having a hearing disability (43 percent), sight disability (21 percent), and disabled limbs (21 percent).

Majority of respondents reported being employed in some capacity, most of whom report being self-employed (21 percent). More females reported being unemployed (40.4 percent) compared to their male counterparts (30.8 percent). Majority of FSW report being unemployed (66.7 percent) while nearly half of MSM (44.4 percent) report unemployment.



Half of the survey respondents reported not having any formal education; this breaks down as 58 percent of females and 30 percent of males. Twenty-four percent of respondents report having attained primary school as their highest level of education; 19 percent completed secondary school, and 7 percent completed college or university levels. A larger percentage of males within the sample size have completed some form of education compared to their female counterparts. No MSM reports having a physical disability and all MSM report having at least a secondary education. Most FSW report not having a disability and nearly half report not having a formal education.

	Ma	ale	Female		Total		FSW		MS	M
	Number	Percent								
Physical disability										
Yes	31	17.8	49	12.4	80	14.1	2	28.6	0	0.0
No	143	82.2	346	87.6	489	85.9	5	71.4	9	100.0
Total	174	100.0	395	100.0	569	100.0	7	100.0	9	100.0
Туре										
Sight	3	21.4	4	19.0	7	20.0	0	0.0		
Hearing	6	42.9	9	42.9	15	42.9	0	0.0		
Limbs	3	21.4	7	33.3	10	28.6	1	100.0		
Other	2	14.3	1	4.8	3	8.6	0	0.0		
Total	14	100.0	21	100.0	35	100.0	1	100.0		
Highest level education										
No formal education	51	30.2	233	58.4	284	50.0	3	42.9	0	0.0
Primary school	47	27.8	87	21.8	134	23.6	3	42.9	0	0.0
Secondary school	46	27.2	63	15.8	109	19.2	1	14.3	5	55.6
Technical college	25	14.8	16	4.0	41	7.2	0	0.0	4	44.4
Total	169	100.0	399	100.0	568	100.0	7	100.0	9	100.0
Employment Status										
Full time employee	37	23.3	24	6.7	61	11.8	0	0.0	3	33.3
Part time employee	14	8.8	9	2.5	23	4.4	0	0.0	1	11.1
Full time self-employed	31	19.5	76	21.2	107	20.7	1	16.7	1	11.1
Part time self-employed	28	17.6	105	29.2	133	25.7	1	16.7	0	0.0
Unemployed	49	30.8	145	40.4	193	37.3	4	66.7	4	44.4
Total	159	100.0	359	100.0	517	100.0	6	100.0	9	100.0

Table 4: Personal characteristics and background of respondents

Household characteristics of respondents

The survey explored the household settings of the respondents in order to establish the type of environment, the economic capacities, dependencies and nutritional availability. A supportive and sustainable environment is critical to ensuring that PLHIV have adequate resources to adhere to their antiretroviral therapy and maintain a healthy lifestyle.

Most respondents (69 percent) identified themselves as coming from a large town or city; this is expected as the survey sites were hosted within the regional main cities. All respondents who identified as an FSW and MSM have their house within a large town or city. Questions regarding household characteristics had a lot of non-responses. Only 154 out 175 male interviewees answered the question about the location of their household and only 335 out of 402 female interviewees answered the same question. The respondents may have considered questions on their location a sensitive question as many reiterated during the interviews the need to keep their identities confidential.



Respondents report having an average of 2.7 children between the ages of 0 to 14 living in the household, 1.4 adolescents between the ages of 15 and 19, 1 adult between the age of 20 and 24, 0.7 adults between 25 and 29 years of age. There was very little difference between male and female responses regarding number of people within households within specific age brackets. FSW and MSM respondents also report having on average the most people within the household to be between the age of 0 and 14.

Within the respondent households, it was reported that 72 percent do not have AIDS orphans. Fifteen percent reported having one AIDS orphan within the household, 8 percent have two AIDS orphans, and 5.2 percent have three or more AIDS orphans. Female respondents were more likely to report having AIDS orphans within their households than male respondents; 16 percent of females reported having one AIDS orphan, 10 percent having two AIDS orphans, and 4.5 percent with three or more AIDS orphans. In contrast, 12 percent of males reported having one AIDS orphans. In contrast, 12 percent of males reported having one AIDS orphans. In contrast, 88.9 percent of MSM and 66.7 percent of FSW respondents report not having any AIDS orphans within their households.





Variances in socioeconomic status, including disparities in the distribution of wealth, income, and access to resources, affect PLHIV. While services are largely free, patients do incur out of pocket expenses which could limit access to treatment. Respondents were requested to approximate the household income per month over the last 12 months. Sixteen percent of respondents reported making an average monthly income less than 50,000 Leones (11.11 USD), 21 percent reported an income between 50,000 to 199,999 Leones (11.11 to 44.44 USD), 34 percent reported having a monthly income between 200,000 to 499,999 Leones (44.45 to 111.11 USD), and 22 percent reported an income between 500,000 to 999,999 Leones (111.12 to 222.22 USD), and 8 percent report an income higher than one million Leones. Male respondents reported making a higher average monthly income (487,674 Leones) than

female respondents (408,215 Leones) (Figure 4). This disparity in male to female earnings, also known as the gender pay gap, is important to note because women are increasingly becoming more involved as breadwinners of the family.

Most FSW respondents report earning between 50,000 to 199,999 Leones (11.11 to 44.44 USD) a month while nearly half of MSM respondents report earning between 200,000 to 499,999 Leones (44.45 to 111.11 USD).

Adequate nutrition is an important factor to ensuring a strong immune system for PLHIV while they are receiving ART, thus respondents were asked whether members of the household had enough food to eat in the past month. Thirty percent of respondents reported that all members of their household had enough food to eat for the past month. However, 53 percent of respondents reported that at least one member of the household did not have enough food to eat for a duration between one to seven days, 12 percent reported members of household



did not have enough food to eat for a period between 8 to 14 days, 4 percent didn't have enough food for a period between 15 to 21 days, and 1 percent didn't have enough food for a period between 22 to 30 days. Males were more likely to report that they had at least one member of their household without enough food to eat within the last month. According to the report on the state of food security and nutrition in Sierra Leone in 2011, 45% of the population is food insecure. This study shows that food insecurity may be a particular issue that needs redress among PLHIV in Sierra Leone². Two-thirds of MSM respondents reported that all household members had enough to eat, while most of FSW respondents reported having at least one day in a month in which household members didn't have enough to eat.

Table 5: Household characteristics of respondents

	Male		Fen	nale	То	otal	FS	SW	M	MSM	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent	
Location of househo	old										
Rural area	15	9.7	26	7.8	41	8.4	0	0.0	0	0.0	
Small town/village	34	22.1	75	22.4	109	22.3	0	0.0	0	0.0	
Large town/city	105	68.2	234	69.9	339	69.3	5	100.0	9	100.0	
Total	154	100.0	335	100.0	489	100.0	5	100.0	9	100.0	
Average number of people living in household within specified age bracket											
0-14	2.6		2.8		2.7		1.2		1.8		
15-19	1.5		1.4		1.4		0.3		0.8		
20-24	1.0		1.0		1.0		1.2		0.7		
25-29	0.8		0.7		0.7		0.5		1.1		
30-39	0.9		1.0		1.0		0.5		0.7		
40-49	0.9		0.8		0.8		0.8		0.8		
50+	1.1		0.8		0.9		0.8		0.7		
AIDS orphans in hou	1	77.0	270	CO 4	402	71.0		CC 7	0	00.0	
0	132	77.6	270	69.4	402	71.9	4	66.7	8	88.9	
1	20	11.8	61	15.7	81	14.5	1	16.7	0	0.0	
2	9	5.3	38	9.8	47	8.4	1	16.7	1	11.1	
3+	9	5.3	18	4.6	29	5.2	0	0.0	0	0.0	
Total	170	100.0	389	100.0	559	100.0	6	100.0	9	100.0	
Average household	income in	past 12 mo	nths								
<500	7	4.1	32	8.1	39	6.9	0	0.0	2	22.2	
500-49,999	8	4.7	43	10.9	51	9.0	1	14.3	0	0.0	
50,000 - 199,999	31	18.0	87	22.0	118	20.8	4	57.1	1	11.1	
200,000 - 499,999	63	36.6	128	32.4	191	33.7	1	14.3	4	44.4	
500,000 - 999,999	46	26.7	76	19.2	122	21.5	1	14.3	0	0.0	
>1,000,000	17	9.9	29	7.3	46	8.1	0	0.0	2	22.2	
Total	172	100.0	395	100.0	567	100.0	7	100.0	9	100.0	
Days any household	member	didn't have	enough fo	od to eat							
0	46	27.4	120	30.8	166	29.7	1	16.7	6	66.7	
1 - 7	92	54.8	201	51.5	293	52.5	3	50.0	2	22.2	
8 - 14	14	8.3	55	14.1	69	12.4	1	16.7	0	0.0	
15 - 21	11	6.5	13	3.3	24	4.3	1	16.7	1	11.1	
22 - 30	5	3.0	1	0.3	6	1.1	0	0.0	0	0.0	
Total	168	100.0	390	100.0	558	100.0	6	100.0	9	100.0	
10101	100	100.0	390	100.0	550	100.0	0	100.0	9	100.0	

² The State of Food Security and Nutrition in Sierra Leone 2011



Understanding of Stigma and Discrimination

There are often nuances in definitions; therefore it is critical to have a sense of what "stigma and discrimination" means not simply because the respondents are people living with HIV, but especially because they report feeling its effects. During focus group discussions, PLHIV report stigma and discrimination as being "bad", an instance when people are pointing fingers and belittling the respondent to make them feel useless or comment about their HIV status. FSW related stigma to their profession by saying it causes them to lose customers and to behave differently.



Experience with Stigma and Discrimination from other people

Stigma and discrimination can be experienced and perceived in many different ways. During focus group discussions, participants were asked to explain some ways in which they have experienced stigma and discrimination. Stories of their experiences included relatives refusing assistance, disclosing the status to the community, branding the PLHIV as a witch and health care workers announcing the HIV status upon treatment in hospitals. Some participants, however, did mention that they do not think that they have experienced stigma and discrimination at all, though some of these individuals also correlated this to the fact that they have not disclosed their status to anybody. This association between stigma, discrimination and the effect of disclosure on these is especially important as revealed by information that this study gathered on disclosure. Sex workers also face difficulties within their group; those who are not HIV positive discriminate against the HIV positive sex workers during their attempts to "hustle". An MSM respondent reported being bullied by his peers and having suicidal thoughts due to the discrimination. Such stigma and discrimination has lasting effects as it results in PLHIV leaving their homes and family, and some resorting to living off the streets and selling sex to earn a living.

"Even people with HIV would come to pay for sex saying they don't want to use a condom	<i>"When my friends knew that I had AIDS they treated me differently. Eventually I dropped out of school and went into the streets."</i>
they wanted 'flesh to flesh' once	- Aminata, FSW FGD
you've seen the money you would spread it just to survive"	·
- Lovetta, FSW FGD	"The stigma makes us live in our own world because of the stigma we face both as FSW's and PLHIV's."
	- Alimatu, FSW FGD



Within the questionnaire, respondents were asked questions regarding their perceptions of exclusion, being gossiped about, and various means of assault, insults and harassment in the past 12 months. The focus is on the interviewee's perceptions of the causes of stigma and discrimination; the causes do not have to be objectively verified as it is more about what the interviewee perceives or feels happens rather than what actually happened.

Seven percent of respondents felt that they were being excluded from social gatherings, 1.6 percent excluded from religious activities or places of worship and 5.1 percent from family activities in the past 12 months. This needs to be seen in the context of the low level of disclosure. Indeed only 36% of men and 30% of women disclosed their status to adult family members. Of those that did feel excluded, males reported feeling exclusion from social gatherings (7.5 percent) and religious activities or places of worship (2.9 percent) more than females (7 percent



Figure 5: Respondent experience with at least one incident of exclusion

exclusion from social gatherings, and 1.1 percent exclusion from religious activities). Most of the people that felt excluded from social gatherings felt that it was due to their HIV status (78 percent); this sentiment was stronger from females (86 percent) than males (58 percent). Half of the people who felt excluded from religious activities or places of worship felt it was due to their HIV status; this was a stronger sentiment among males (67 percent) than females (25 percent). Females felt more excluded from family activities (6.3 percent) than males (2.2 percent); similarly, more females (96 percent) felt that this exclusion was due to their HIV status than males (75 percent) who felt excluded from family activities. Figure 5 illustrates the percentage of respondents who felt they were excluded at least once in the last 12 months from specific social, religious or family gatherings.

Approximately half of the FSW reported being excluded from social gatherings and family activities, for which they cited their HIV status as the main cause for their exclusion. MSM did not feel that they were excluded from any social gathering, religious activity or family gathering in the past 12 months.

Table 6: Exclusion from gatherings

	Male		Female		Total		FSW		MSM	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Exclusion from so	cial gather	ings / activ	vities in pa	st 12 mon	ths					
Never	162	92.6	374	93.0	536	92.9	3	42.9	8	88.9
Once	5	2.9	10	2.5	15	2.6	1	14.3	0	0.0
A few times	4	2.3	10	2.5	14	2.4	2	28.6	1	11.1
Often	4	2.3	8	2.0	12	2.1	1	14.3	0	0.0
Total	175	100.0	402	100.0	577	100.0	7	100.0	9	100.0
Reason for exclusi	on from s	ocial gathe	ering / activ	vities						
HIV status	7	58.3	24	85.7	31	77.5	4	100.0	0	0.0
Other reason(s)	2	16.7	3	10.7	5	12.5	0	0.0	1	100.0
HIV status and other reasons(s)	1	8.3	0	0.0	1	2.5	0	0.0	0	0.0
Not sure Why	2	16.7	1	3.6	3	7.5	0	0.0	0	0.0
Total	12	100.0	28	100.0	40	100.0	4	100.0	1	100.0
Exclusion from rel	igious acti	vities / pla	ices of woi	rship in las	t 12 montl	ıs				
Never	168	97.1	395	99.0	563	98.4	6	85.7	9	100.0
Once	3	1.7	1	0.3	4	.7	0	0.0	0	0.0
A few times	1	0.6	3	0.8	4	.7	1	14.3	0	0.0
Often	1	0.6	0	0.0	1	.2	0	0.0	0	0.0
Total	173	100.0	399	100.0	572	100.0	7	100.0	9	100.0
Reason for exclusi	on from re	eligions ac	tivities / p	laces of wo	orship					
HIV status	4	66.7	1	25.0	5	50.0	1	100.0		
Other reason(s)	1	16.7	2	50.0	3	30.0	0	0.0		
Not sure why	1	16.7	1	25.0	2	20.0	0	0.0		
Total	6	100.0	4	100.0	10	100.0	1	100.0		
Exclusion from far	nily activit	ies in the	past 12 mo	onths						
Never	171	97.7	373	93.7	544	94.9	3	42.9	9	100.0
Once	2	1.1	2	0.5	4	.7	1	14.3	0	0.0
A few times	0	0.0	11	2.8	11	1.9	2	28.6	0	0.0
Often	2	1.1	12	3.0	14	2.4	1	14.3	0	0.0
Total	175	100.0	398	100.0	573	100.0	7	100.0	9	100.0
Reason for exclusi		-					1			
HIV status	3	75.0	25	96.2	28	93.3	4	100.0		
Other reason(s)	0	0.0	1	3.8	1	3.3	0	0.0		
Not sure why	1	25.0	0	0.0	1	3.3	0	0.0		
Total	4	100.0	26	100.0	30	100.0	4	100.0		

Respondents were also asked how often they were aware of being gossiped about in the past 12 months; findings are shown in Table 7. Some respondents reported that they felt that they were gossiped about (22.7 percent), while 5.6 percent felt they were gossiped about once, 9.8 percent gossiped about a few times, and 7.3 percent gossiped about often. In general, those respondents who felt that they were gossiped about were females; 5.8 percent felt gossiped about once (males 5.2 percent), 10.5 percent felt gossiped a few times (males 8.1 percent), and 7.3 percent felt gossiped about a few times (males 7.5 percent).

Fifteen percent of respondents reported that they have been verbally insulted, harassed and / or threatened in the past 12 months. Of those that that reported experiencing this, 60.5 percent felt that it was due to their HIV status; females (68 percent) reported this causality to their status more than males (44 percent). Thirty percent of respondents felt that the insults, harassment and threats were due to other reasons apart from their HIV status, 3 percent felt unsure why they experienced the insults, harassment and threats.



Members of key populations reported being gossiped about more frequently than those from the general PLHIV group; more than half of FSW and MSM reported being the topic of gossip on more than one occasion, many of whom attribute the reason for the gossip related to their HIV status. Similarly, FSW and MSM were more likely than the general PLHIV population to report having experienced verbal insults, harassment and threats in the past year; many cited their HIV status as the reason for this experience.

	Male		Female		Total		FSW		М	SM	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent	
Awareness of bein	Awareness of being gossiped about in the past 12 months										
Never	137	79.2	306	76.5	443	77.3	1	14.3	2	22.2	
Once	9	5.2	23	5.8	32	5.6	0	0.0	0	0.0	
A few times	14	8.1	42	10.5	56	9.8	4	57.1	6	66.7	
Often	13	7.5	29	7.3	42	7.3	2	28.6	1	11.1	
Total	173	100.0	400	100.0	573	100.0	7	100.0	9	100.0	
Reason for being g	ossiped a	bout in the	e past 12 n	nonths							
HIV status	17	56.7	63	76.8	80	71.4	4	57.1	1	14.3	
Other reason(s)	7	23.3	9	11.0	16	14.3	0	0.0	3	42.9	
HIV status and other reason(s)	5	16.7	8	9.8	13	11.6	1	14.3	2	28.6	
Not sure why	1	3.3	2	2.4	3	2.7	0	0.0	1	14.3	
Total	30	100.0	82	100.0	112	100.0	5	71.4	7	100.0	
Experiences verba	l insults, h	arassmen	t and/or tl	nreats in t	he past 12	months					
Never	146	86.4	331	84.9	477	85.3	1	14.3	5	55.6	
Once	9	5.3	22	5.6	31	5.5	0	0.0	1	11.1	
A few times	11	6.5	21	5.4	32	5.7	4	57.1	3	33.3	
Often	3	1.8	16	4.1	19	3.4	2	28.6	0	0.0	
Total	169	100.0	390	100.0	559	100.0	7	100.0	9	100.0	
Reason for verbal	insult, har	assment a	nd threats	5							
HIV status	10	43.5	36	67.9	46	60.5	3	75.0	1	25.0	
Other reason(s)	9	39.1	14	26.4	23	30.3	0	0.0	2	50.0	
HIV status and other reason(s)	3	13.0	2	3.8	5	6.6	1	25.0	1	25.0	
Not sure why	1	4.3	1	1.9	2	2.6	0	0.0	0	0.0	
Total	23	100.0	53	100.0	76	100.0	4	100.0	4	100.0	

Table 7: Experience of gossip, insults, harassment and threats

Ten percent of respondents reported having experienced physical harassment and/or threats in the past 12 months (Table 8). Those that experienced physical harassment / threats reported that 4 percent experienced it once, 3 percent experienced it a few times, and 3 percent experienced it often. More females (11.7 percent) reported experiencing physical harassment than males (7.6 percent). Most respondents that experienced physical harassment and threats felt that it was due to their HIV status; more females (69 percent) reported this relation than males (47 percent).

Similarly, 10.8 percent of respondents reported having experienced physical assault in the past 12 months this, however, more females (12.2 percent) report experiencing physical assault in the past 12 months than males (7.2 percent). Of those that reported being physically assaulted, majority (67 percent) felt that it was because of their HIV status; more females (75 percent) reported this perception than males (39 percent). The person most often reported to have caused the physical assault was a person outside the household who was known to the respondent (57 percent). The second most frequently reported instigator of the physical assault was another member within the household (27 percent), and 13 percent of



respondents noted the physical assault was done by the husband / wife / partner; this is illustrated in Figure 6.

MSM respondents reported never having experienced physical harassment or threats in the past 12 months; this result must be seen within the context of the poor level of disclosure among all population groups. However, nearly half of FSW report experiencing this, many of whom believe it was related to their HIV status. Similarly, most MSM report never having experienced physical assault while half of the FSW



Figure 6: Persons who physically assaulted the respondent

report this experience; many of the FSW cite the reason for the assault to be related to their HIV status. It must be noted that there may be fewer responses than expected for some of the questions due to either the interviewer unintentionally omitting some questions or the interviewee opting to skip an answer due to comfort level.

	Male		Female		Total		FSW		MSM		
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent	
Experienced physical harassment / threats in the past 12 months											
Never	159	92.4	350	88.4	509	89.6	3	42.9	9	100.0	
Once	5	2.9	20	5.1	25	4.4	1	14.3	0	0.0	
A few times	7	4.1	11	2.8	18	3.2	2	28.6	0	0.0	
Often	1	0.6	15	3.8	16	2.8	1	14.3	0	0.0	
Total	172	100.0	396	100.0	568	100.0	7	100.0	9	100.0	
Reason for physical haras	ssment / t	hreats									
HIV status	7	46.7	33	68.8	40	63.5	2	50.0			
Other reason(s)	3	20.0	8	16.7	11	17.5	0	0.0			
Both HIV status and	4	26.7	3	6.3	7	11.1	1	25.0			
other reason(s)	4	20.7	5	0.5	/	11.1	1	25.0			
Not sure why	1	6.7	4	8.3	5	7.9	1	25.0			
Total	15	100.0	48	100.0	63	100.0	4	100.0			
Experienced physical ass	ault										
Never	154	92.8	343	87.7	497	89.2	3	42.9	8	88.9	
Once	7	4.2	22	5.6	29	5.2	1	14.3	0	0.0	
A few times	5	3.0	15	3.8	20	3.6	2	28.6	1	11.1	
Often	0	0.0	11	2.8	11	2.0	1	14.3	0	0.0	
Total	166	100.0	391	100.0	557	100.0	7	100.0	9	100.0	
Reason for physical assault											
HIV status	5	38.5	35	74.5	40	66.7	3	75.0	0	0.0	
Other reason(s)	4	30.8	7	14.9	11	18.3	0	0.0	1	100.0	
Both HIV status and	3	23.1	5	10.6	8	13.3	1	25.0	0	0.0	
other reason(s)	Э	23.1	J	10.0	0	13.3	1	25.0	U	0.0	
Not sure why	1	7.7	0	0.0	1	1.7	0	0.0	0	0.0	
Total	13	100.0	47	100.0	60	100.0	4	100.0	1	100.0	

Table 8: Experience of physical harassment, assaults and threats

	Male		Female		Total		FSW		MSM	
	Number	Percent								
Person who physically assaulted the respondent										
Husband/wife/partner	1	7.7	7	14.9	8	13.3	0	0.0	0	0.0
Another member of household	1	7.7	15	31.9	16	26.7	1	25.0	0	0.0
Person(s) outside the household known to	9	69.2	25	53.2	34	56.7	3	75.0	0	0.0
me Unknown person(s)	2	15.4	0	0.0	2	3.3	0	0.0	1	100.0
Total	13	100.0	47	100.0	60	100.0	4	100.0	1	100.0

Table 8 continued: Experience of physical harassment, assaults and threats

Family, peers, and friends are major sources of support and comfort in Sierra Leone as in other contexts. Respondents were asked whether they also experienced stigma and/or discrimination for reasons other than their HIV status. The most frequently provided answers were due to their sexual orientation (MSM, gay/lesbian/transgender) (11 percent), their status as an internally displaced person (13 percent) and other reasons (61 percent). Other reasons that were provided were due to poverty, physical appearance or disability, ordinary quarrels and family issues; some respondents also admitted not knowing the reason for the stigma and discrimination that they were experiencing. Five percent of respondents noted that they experienced stigma and discrimination due to their practice of sex work, 5 percent due to their status as refugees or asylum seekers, and 4 percent due to their membership to an indigenous group. Less than two percent of respondents noted that the stigma and discrimination that they experienced were due to their status as a person who injects drugs, as a migrant worker or as a prisoner.

Not surprisingly, nearly all MSM cited their sexual orientation as another reason for stigma and discrimination apart from HIV; all FSW cited their status as a sex worker as another reason for stigma and discrimination apart from HIV.



Figure 7: Reasons for stigma and discrimination apart from HIV



Table 9: Reasons for stigma and discrimination apart from HIV status

	Male		Female		Total		FSW		MSM	
	Number	Percent								
Reason for stigma and discrimination apart from HIV status										
Sexual orientation (MSM, gay/lesbian transgender).	17	19.8	17	7.8	34	11.2	0	0.0	8	88.9
Sex worker.	2	2.3	12	5.5	14	4.6	7	100.0	0	0.0
PWID.	0	0.0	1	0.5	1	0.3	0	0.0	0	0.0
Refugee / asylum seeker.	1	1.2	14	6.4	15	4.9	0	0.0	0	0.0
Internally displaced person.	7	8.1	33	15.1	40	13.2	0	0.0	1	11.1
Member indigenous group.	3	3.5	8	3.7	11	3.6	0	0.0	0	0.0
Migrant worker.	1	1.2	1	0.5	2	0.7	0	0.0	0	0.0
Prisoner.	0	0.0	1	0.5	1	0.3	0	0.0	0	0.0
None of above – due to other reason.	55	64.0	131	60.1	186	61.2	0	0.0	0	0.0
Total	86	100	218	100	304	100	7	100.0	9	100.0

Eight percent of respondents reported that they had experienced psychological pressure or manipulation by their husband/wife or partner in which their HIV-positive status was used against them. However, 3 percent reported that they were subjected to psychological pressure or manipulation once, 3 percent experienced this a few times, and 2 percent experienced this often. More females (9.6 percent) reported that they experienced psychological pressure and manipulation than their male counterparts (5.7 percent). Approximately half of the FSW respondents reported experiencing psychological pressure or manipulation from their partner by using their HIV status against them; MSM respondents reported never experiencing this.

Respondents were also asked whether they experienced sexual rejection due to their HIV status in the past 12 months. Seven percent reported that they had experience sexual rejection; 1.6 percent experienced this once, 1.6 percent experienced this a few times and 2.8 percent experienced this often. Roughly the same percentage (6 percent) of male and female respondents reported experiencing sexual rejection. While amongst them, MSM respondents reported never having experienced this and two-thirds of FSW respondents report this experience.

Three percent reported having experienced discrimination from other PLHIV. A larger percentage of female respondents (3.4 percent) reported having experienced discrimination from other PLHIV compared to male respondents (2.3 percent). All MSM and most FSW respondents report never having experience discrimination from other PLHIV.

Eight percent of respondents reported that their wife/husband/partner or any members of their household have experienced discrimination in the past 12 months as a result of their HIV-positive status. However, 4 percent reported that this occurred once, 3 percent a few times, and 1 percent reported that it happened often. A larger percentage of female respondents (8.8 percent reported that their husbands/partners and other household members experienced


discrimination compared to the male respondents (5.7 percent). All MSM and most FSW respondents reported that their family members have never experienced discrimination due to the respondent's HIV positive status.

	Ma	ale	Ferr	ale	То	tal	FS	W	MS	Μ
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Experienced psyc	hological	pressure /	manipula	tion by pa	rtner whil	e using HI	V status ag	gainst you		
Never	165	94.3	361	90.5	526	91.6	4	57.1	9	100.0
Once	7	4.0	12	3.0	19	3.3	0	0.0	0	0.0
A few times	2	1.1	13	3.3	15	2.6	3	42.9	0	0.0
Often	1	0.6	13	3.3	14	2.4	0	0.0	0	0.0
Total	175	100	399	100	574	100	7	100.0	9	100.0
Experienced sexual	al rejectio	n due to H	IV positive	e status						
Never	164	93.7	374	94.2	538	94.1	4	66.7	9	100.0
Once	4	2.3	5	1.3	9	1.6	0	0.0	0	0.0
A few times	4	2.3	5	1.3	9	1.6	1	16.7	0	0.0
Often	3	1.7	13	3.3	16	2.8	1	16.7	0	0.0
Total	175	100	397	100	572	100	6	100.0	9	100.0
Experienced discr	imination	from othe	r people li	ving with	HIV					
Never	170	97.7	388	96.5	558	96.9	5	71.4	9	100.0
Once	2	1.1	5	1.2	7	1.2	0	0.0	0	0.0
A few times	1	0.6	7	1.7	8	1.4	2	28.6	0	0.0
Often	1	0.6	2	0.5	3	0.5	0	0.0	0	0.0
Total	174	100	402	100	576	100	7	100.0	9	100.0
Wife/husband/pa	rtner or a	any house	hold men	nber expe	rienced d	iscriminat	ion due t	o respond	lents HIV	positive
status										
Never	165	94.3	361	91.2	526	92.1	5	71.4	9	100.0
Once	6	3.4	16	4.0	22	3.9	1	14.3	0	0.0
A few times	4	2.3	11	2.8	15	2.6	1	14.3	0	0.0
Often	0	0.0	8	2.0	8	1.4	0	0.0	0	0.0
Total	175	100	396	100	571	100	7	100.0	9	100.0

Table 10: Psychological pressure, sexual rejection and discrimination against household

Respondents were asked whether they thought they knew why they were experiencing HIVrelated stigma and/or discrimination in the last 12 months; results are shown in Table 11. Thirty-nine percent felt that it was because people were afraid of getting HIV from the respondent; more female respondents (44 percent) noted this as a reason than male respondents (27 percent). Thirty percent felt that it was because people didn't understand transmission methods of HIV and thus are afraid that the respondent will infect them with HIV through casual contact; more female respondents (33 percent) noted this as a reason than male respondents (20 percent). Twenty-three percent felt that it was because people thought that having HIV is shameful and thus they should not associate with the respondent; 25 percent of female respondents noted this as a reason in comparison to only 17 percent of male respondents. Only 5 percent of respondents felt that their HIV-related stigma and discrimination was due to religious beliefs or moral judgements, while 11 percent of respondents felt that people disapproved of the respondent's lifestyle and behaviour. Fifteen percent of respondents felt that they experienced HIV-related stigma and discrimination because the respondent looked sick with symptoms associated with HIV. Fifty-one percent of respondents were not sure of the reason for their HIV-related stigma and discrimination; this response was more frequently found among males (60 percent) than females (47 percent).



Among MSM respondents, most reported that they didn't think that they were experiencing stigma and discrimination due to people being afraid of getting infected with HIV from them, or from the fact that people didn't understand how it was transmitted and thus weren't afraid that the MSM respondent would infect them through casual contact. Similarly, many MSM respondents didn't think that they were experiencing stigma and discrimination due to people thinking having HIV was shameful, due to religious beliefs or that the respondent looked sick with symptoms associated with HIV. However, most key population respondents reported that they experienced stigma because people disapproved of their lifestyle.

Among FSW respondents, most reported that they thought that they were experiencing stigma and discrimination due to people being afraid that the respondent would get them infected with HIV, and because people didn't understand how HIV was transmitted and thus were afraid that the FSW respondent would infect them through casual contact.



Figure 8: Reasons experiencing HIV related stigma and discrimination

Table 11: Re	asons for	HIV relate	ed stigma	and discr	imination	1					
	M	ale	Fen	nale	Тс	tal	FS	W	MS	SM	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent	
People are a	afraid of ge	etting infec	ted with H	IIV from m	e						
Yes	22	27.5	93	44.1	115	39.5	7	100.0	1	14.3	
No	58	72.5	118	55.9	176	60.5	0	0.0	6	85.7	
Total	81	100.0	211	100.0	291	100.0	7	100.0	7	100.0	
People don't understand how HIV is transmitted and are afraid I will infect them with HIV through casual contact											
Yes	16	20.3	68	33.2	84	29.6	6	100.0	0	0.0	
No	63	79.7	137	66.8	200	70.4	0	0.0	7	100.0	
Total	79	100	205	100	284	100	6	100.0	7	100.0	
People thin	k that havi	ng HIV is s	hameful aı	nd they she	ould not b	e associate	d with me				
Yes	13	16.9	49	24.7	62	22.5	1	16.7	3	42.9	
No	64	83.1	149	75.3	213	77.5	5	83.3	4	57.1	
Total	77	100	198	100	275	100	6	100.0	7	100.0	
Religious be	liefs or "m	noral" judg	ements								
Yes	5	6.5	10	5.1	15	5.5	0	0.0	2	28.6	
No	72	93.5	187	94.9	259	94.5	6	100.0	5	71.4	
Total	77	100.0	197	100.0	274	100.0	6	100.0	7	100.0	
People disa	pprove of	my lifestyl	e or behav	iour							
Yes	10	13.0	20	10.3	30	11.0	1	16.7	6	85.7	
No	67	87.0	175	89.7	242	89.0	5	83.3	1	14.3	
Total	77	100.0	195	100.0	272	100.0	6	100.0	7	100.0	
I look sick w	ith sympto	oms associ	ated with	HIV							
Yes	9	11.7	31	15.9	40	14.7	1	16.7	2	28.6	
No	68	88.3	164	84.1	232	85.3	5	83.3	5	71.4	
Total	77	100.0	195	100.0	272	100.0	6	100.0	7	100.0	
I don't knov	v/I am not	sure of the	e reason(s)								

Yes

No

Total

53

35

88

60.2

39.8

100.0

Access to work, health and education services

46.5

53.5

100.0

153

150

303

50.5

49.5

100.0

0

6

6

0.0

100.0

100.0

0

7

7

0.0

100.0

100.0

100

115

215

The Stigma Index tries to ascertain whether the interviewees perceive that their access to work (and in some cases the access of members of their household) and to basic services such as health and education has been limited or reduced because of their HIV-positive status. Given that this is not confirmed with interviewee's neighbours or landlord, work colleagues or the school teachers, principals or health workers that they have interacted with, this study will not be able to find out whether any of the incidents that were perceived by the interviewee to be discriminatory because of their HIV-positive status were in fact a result of their status or not. Thus it is the interviewee's perceptions, feelings and interpretation of their experience that matters for this case.

Sixteen percent of respondents noted that they have been forced to change place of residence or were never unable to rent accommodation in the past 12 months; 10 percent replied that it has happened once, 3 percent has experienced this a few times and 3 percent experienced this often. For those respondents that had experienced this, 50 percent cite that the reason for this was their HIV status.



Roughly one-third of FSW and MSM respondents reported that they have had to change their place of residence or were unable to rent accommodation in the past 12 months; FSW respondents cited the reason for this to be related to their HIV status while MSM felt that it was not related to their HIV status.

	Ma	ale	Fen	nale	То	tal	FS	W	MS	M
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Forced to change	place of re	sidence o	r unable to	o rent acco	ommodati	on in the p	oast 12 mo	onths		
Never	150	86.7	329	82.9	479	84.0	4	57.1	6	66.7
Once	15	8.7	43	10.8	58	10.2	1	14.3	3	33.3
A few times	5	2.9	10	2.5	15	2.6	2	28.6	0	0.0
Often	3	1.7	15	3.8	18	3.2	0	0.0	0	0.0
Total	173	100	397	100	570	100	7	100.0	9	100.0
Reason for forced	change of	residence	e or inabili	ty to rent	accommo	dation ⁱ				
HIV status	20	50.0	44	49.4	64	49.6	2	66.7	0	0.0
Other reason(s)	15	37.5	32	36.0	47	36.4	0	0.0	3	100.0
HIV status and other reason(s)	1	2.5	6	6.7	7	5.4	1	33.3	0	0.0
Not sure why	4	10.0	7	7.9	11	8.5	0	0.0	0	0.0
Total	40	100	89	100	129	100	3	100.0	3	100.0

Table 12: Experience and perceived reasons for loss of accommodation Image: Commodation

Thirteen percent of respondents noted that they have lost a job or source of income in the past 12 months (Table 13). This has happened once to 9 percent of respondents, a few times to 3 percent of respondents, and often to 1 percent of respondents. For those respondents that experienced loss of job or source of income in the past 12 months, 55 percent cited that it this occurred due to reasons other than their HIV status. For those that cited that HIV status was the reason for loss of job or income, many (35 percent) noted that they felt obliged to stop working due to poor health. Some respondents (12 percent) stopped work due to the discrimination they felt from their employer or other work colleagues, and 11 percent cited both aforementioned reasons as why they lost their job.

Sixteen percent of respondents noted that they had been refused employment or a work opportunity in the past 12 months because of their HIV status; this occurred to more male (19 percent) than female (15 percent) respondents.

Respondents were also asked whether they experienced changes in job description or the nature of work, or whether they have been refused promotion, in the past 12 months as a result of your HIV status. Six percent of respondents noted that his had occurred to them; 4 percent experienced this once in the past 12 months, 1 percent experienced in a few times and 1 percent experienced it often. For those respondents that experienced a change in job description, nature of work or promotion refusal in the past 12 months, many (38 percent) cited discrimination from the employer or co-workers as the reason while others (21 percent) replied that it was the respondent's poor health that prevented them from doing certain things in the job.

MSM respondents reported that they never lost a job or source of income or experienced a change in job description or work. However one respondent reported being refused employment or work opportunities because of their HIV status.



Table 13: Stigma and discrimination related to the workplace

	Ma		Fen		То	tal	ES	W	MS	SM4
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Lost a job or other so										
Never	110	84.6	235	87.7	345	86.7	1	50.0	8	100.0
Once	13	10.0	22	8.2	35	8.8	0	0.0	0	0.0
A few times	5	3.8	8	3.0	13	3.3	1	50.0	0	0.0
Often	2	1.5	3	1.1	5	1.3	0	0.0	0	0.0
Total	130	100	268	100	398	100	2	100.0	8	100.0
Reason for lost job or		100	200	100	550	100	-	100.0	Ū	100.0
HIV status	7	28.0	13	23.6	20	25.0	0	0.0		
Other reason(s)	12	48.0	32	58.2	44	55.0	1	100.0		
HIV status and	12	40.0	52	50.2		55.0	1	100.0		
other reason(s)	2	8.0	2	3.6	4	5.0	0	0.0		
Not sure why	4	16.0	8	14.5	12	15.0	0	0.0		
•	4 25	10.0	。 55	14.5	80	100	1	100.0		
Total	-				80	100	1	100.0		
If HIV is reason, loss of	or income o	or work is	aue to '				1			
Discrimination by	2	12.0	0	12 5	11	12.4	0	0.0		
employer or co-	3	12.0	8	12.5	11	12.4	0	0.0		
workers										
Felt obliged to stop										
working due to	9	36.0	22	34.4	31	34.8	0	0.0		
poor health										
Combination of										
discrimination and	4	16.0	6	9.4	10	11.2	0	0.0		
poor health										
Other reason	9	36.0	28	43.8	37	41.6	1	100.0		
Total	25	100	64	100.0	89	100	1	100.0		
Refusal of employme	nt or work	opportun	ity due to	HIV statu	s					
Yes	21	19.1	30	14.9	51	16.3	1	50.0	1	12.5
No	89	80.9	172	85.1	261	83.7	1	50.0	7	87.5
Total	110	100	202	100	312	100	2	100.0	8	100.0
Change in job descrip	tion or nat	ture of wo	rk, or refu	sal of pro	motion due	e to HIV st	atus			
Never	113	91.1	230	95.0	343	93.7	2	100.0	8	100.0
Once	6	4.8	9	3.7	15	4.1	0	0.0	0	0.0
A few times	3	2.4	1	0.4	4	1.1	0	0.0	0	0.0
Often	2	1.6	2	0.8	4	1.1	0	0.0	0	0.0
Total	124	100	242	100	366	100	2	100.0	8	100.0
Reason for change in	job descri		ature of w		usal of pro		ie to HIV s	tatus ⁱ		
Discrimination by		-			-					
employer/co-worker	10	45.5	19	34.5	29	37.7	1	100.0		
Poor health prevented										
you from doing certain	3	13.6	13	23.6	16	20.8	0	0.0		
things										
Combination of	2				6		<u> </u>			
discrimination and	2	9.1	4	7.3	6	7.8	0	0.0		
poor health Other reason	-	21.0	10	24 5	20	22.0	0	0.0		
Total	7	31.8	19 55	34.5	26	33.8	0	0.0		
IUldi	22	100	55	100	77	100	1	100.0		

Respondents were asked whether in the last 12 months they were dismissed, suspended or prevented from attending an educational institution because of their HIV status. Nineteen percent of respondents noted that they have experienced this in the past 12 months and one percent experienced this at least once. The questionnaire also asked how often the respondent's child/children were dismissed, suspended or prevented from attending an educational institution in the last 12 months because of the respondent's HIV status. Four percent of respondents replied that this had never happened in the past 12 months.



Among MSM respondents, all reported they neither they nor their children have ever been dismissed from educational institutions due to the respondent's HIV status. In comparison, no FSW respondent reported having been denied health, family planning or sexual reproductive health services due to their HIV status. However, two FSW respondents reported having been dismissed from attending an educational institution due to HIV status.

However, a respondent has reported that they have been denied health, family planning and sexual reproductive health services due to their HIV status.

	M	ale	Eon	nale	То	tal	ES	W	MS	M
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Dismissal, susp									Rumber	rereent
Never	145	85.8	297	78.4	442	80.7	5	71.4	8	100.0
Once	3	1.8	3	0.8	6	1.1	0	0.0	0	0.0
A few times	3	1.8	3	0.8	6	1.1	1	14.3	0	0.0
Often	1	0.6	4	1.1	5	0.9	1	14.3	0	0.0
Not applicable	17	10.1	72	19.0	89	16.2	0	0.0	0	0.0
Total	169	100	379	100	548	100	7	100.0	8	100.0
Respondent's c	hild/childr	en dismiss	sed, suspe	nded or p	revented f	rom atten	ding educa	ational ins	titution	
Never	160	94.1	379	96.4	539	95.7	7	100.0	8	88.9
Once	1	0.6	1	0.3	2	0.4	0	0.0	0	0.0
A few times	1	0.6	1	0.3	2	0.4	0	0.0	0	0.0
Often	0	0.0	2	0.5	2	0.4	0	0.0	0	0.0
Not applicable	8	4.7	10	2.5	18	3.2	0	0.0	1	11.1
Total	170	100	393	100	563	100	7	100.0	9	100.0

Table 14: Stigma and Discrimination related to educational services

Two percent of respondents noted that they have been denied health services in the past 12 months due to their HIV status. When asked whether the respondent was denied family planning services in the past 12 months due to their HIV status, 12 percent responded that they had been denied; the same percentage of male and female respondents reported this (12 percent for both). Similarly, 6 percent of respondents reported that they had been denied sexual and reproductive health services in the past 12 months due to their HIV status.

Focus group discussion participants were asked whether they experienced stigma and discrimination in health facilities. Most of the participants in the general PLHIV group reported not having any issues with the health workers and their experience in the facilities, however several FSW and MSM participants expressed concern of the discrimination they faced either because of their practice of sex work or their HIV status. These participants reported deliberate delays in receiving their medication or medical attention, inability to access condoms, and having a lack of privacy in the facilities such that they don't feel comfortable to go to the ward.

"The nurses at the hospitals always delay us for several hours when we go for treatment. They do it deliberately knowing that we have been up all night. They always say "Even when you are dying, you still have sex?". They should not ask us these types of questions."

Nancy, FSW FGD

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"Government facilities treat you differently and discriminate when you go for drugs and treatment and there is no privacy. I refuse to go to the government facilities to do my CD4."	"We need supply of condoms. Some of the men that come as clients have diseased penises and they want to have unprotected sex with us because they are paying for sex. We really need protection from diseases by the government."
- Daniel, MSM FGD	- Alimatu, FSW FGD
"Tve always been treated well by health workers." - Thomas, PLHIV FGD "The place where we go to receive treatment at Connaught is so open and everybody can see us. Because of this, we no longer go there."	"When the doctor discovered that I was waiting to see him, he refused to see me. I was seen by another doctor after several hours. This has happened to me twice. Another PLHIV also made the same complaint." - Abu, MSM FGD
- Iuliana ESW EGD	

Table 15: Stigma and Discrimination related to health services

	Ma	ale	Fen	nale	To	tal	FS	W	MS	SM
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Denial of health	services,	including	dental car	e, due to I	HIV status					
Never	163	96.4	391	98.7	554	98.1	7	100.0	8	88.9
Once	3	1.8	2	0.5	5	0.9	0	0.0	1	11.1
Often	0	0.0	2	0.5	2	0.4	0	0.0	0	0.0
Not applicable	3	1.8	1	0.3	4	0.7	0	0.0	0	0.0
Total	169	100.0	396	100.0	565	100.0	7	100.0	9	100.0
Denial of family	planning	services d	ue to HIV	status						
Yes	20	12.0	46	11.6	66	11.7	0	0.0	1	11.1
No	91	54.8	287	72.5	378	67.3	5	71.4	4	44.4
Not applicable	55	33.1	63	15.9	118	21.0	2	28.6	4	44.4
Total	166	100.0	396	100.0	562	100.0	7	100.0	9	100.0
Denial of sexua	and repro	oductive h	ealth serv	ices due te	o HIV statu	IS				
Yes	12	7.2	23	5.8	35	6.2	0	0.0	1	11.1
No	155	92.8	372	94.2	527	93.8	7	100.0	8	88.9
Total	167	100.0	395	100.0	562	100.0	7	100.0	9	100.0



Internalised Stigma and Fears

According to the guidelines of the Stigma Index report, internalised 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. Internalised stigma can lead to low self-esteem, a sense of worthlessness and depression. Internalised 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. Questions on internalised stigma were asked to establish whether the respondent has anticipated or feared what other people might do or think, and this might very well have changed the way they behaved or felt, or caused them anxiety.



(43 percent). Forty-six percent of respondents shared that they felt guilty because of their HIV status; a larger portion of male respondents (49 percent) felt this way compared to female respondents (44 percent).

explored

The Stigma Index questionnaire thus

experienced certain feelings related to

internalised stigma because of their

HIV status; results are shown in Table 16. Fifty-three percent of respondents

shared that they felt ashamed because

of their HIV status; a larger percentage of females (58 percent) reported this

feeling compared to male respondents

Twenty-five percent of respondents

respondents

whether

Figure 9: Respondent reported feelings due to being HIV positive

blamed themselves for their HIV status while 8 percent blamed others. Similarly, 25 percent reported that they had low self-esteem due to their HIV status and 9 percent reported that they felt they should be punished due to their status. Six percent of respondents felt suicidal due to their HIV status.

More than half of the FSW respondents reported feeling ashamed of their HIV status, feeling guilty about it, having low self-esteem, and feeling that they should be punished for having HIV. Majority of MSM also report feeling ashamed, feeling guilty, blaming themselves and blaming others for their HIV status.

Internalised stigma was also a topic explored during the focus group discussions by asking participants to describe whether they treated themselves or felt differently after receiving results of their status. Some acknowledged that they did not treat themselves differently upon receiving the news of their status; while others shared that they became more careful about their health, such as avoiding cold nights or being more careful not to infect others. However, participants from the FSW focus group expressed sentiments of stronger isolating behaviours and decrease in self-confidence. Comments made by the FSW related to having become alone, not interacting in social gatherings, being upset, and having a decreased self-image. MSM



participants expressed sentiments of self-deprecation such as self-isolation, drinking and suicidal thoughts.

"'My child always tells me thy once I not to touch her because I m" have HIV. This makes me HIV FGD feel discouraged."	"My condition now and before I had HIV is different. I used to be nice to look at and looked healthy, unlike now that I'm a little withered. I'm always sickly now." - Jane, FSW FGD
- Yeabu, FSW FGD ' 'Even	my children, I'm ashamed to talk with them
sometin an FSU	nes because people are always telling them that I'm W. I don't go to churches or mosques anymore. I do ing on my own"
	- Rosetta, FSW FGD
"The first day that I discovered that I was HIV po. no cure. I drank so much that day without getting dr	sitive, I felt different about my life. I knew that there was unk."

- Shaka, MSM FGD

Table 16: Internalised	ciama: rocha	andant faalings	due to HIV status
Tuble 10. Internuiseu	siginu. respu	Judent Jeenings	

	Ma	ale	Fen	nale	То	tal	FS	W	MS	SM
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
I feel a	shamed									
Yes	76	43.4	232	57.7	308	53.4	4	57.1	6	66.7
No	99	56.6	170	42.3	269	46.6	3	42.9	3	33.3
Total	175	100.0	402	100.0	577	100.0	7	100.0	9	100.0
I feel g	uilty									
Yes	86	49.1	176	44.0	262	45.6	5	71.4	5	55.6
No	89	50.9	224	56.0	313	54.4	2	28.6	4	44.4
Total	175	100.0	400	100.0	575	100.0	7	100.0	9	100.0
I blame	e myself									
Yes	50	28.7	94	23.5	144	25.1	3	42.9	5	55.6
No	124	71.3	306	76.5	430	74.9	4	57.1	4	44.4
Total	174	100.0	400	100.0	574	100.0	7	100.0	9	100.0
I blame	e others									
Yes	14	8.1	32	8.0	46	8.1	0	0.0	6	66.7
No	158	91.9	366	92.0	524	91.9	7	100.0	3	33.3
Total	172	100.0	398	100.0	570	100.0	7	100.0	9	100.0
I have	low self-est	teem								
Yes	41	23.6	103	25.8	144	25.1	5	71.4	1	11.1
No	133	76.4	297	74.3	430	74.9	2	28.6	8	88.9
Total	174	100.0	400	100.0	574	100.0	7	100.0	9	100.0
I feel I	should be p	ounished								
Yes	16	9.2	33	8.3	49	8.6	4	57.1	0	0.0
No	157	90.8	366	91.7	523	91.4	3	42.9	9	100.0
Total	173	100.0	399	100.0	572	100.0	7	100.0	9	100.0
I feel s	uicidal									
Yes	11	6.4	23	5.8	34	5.9	1	14.3	2	22.2
No	162	93.6	376	94.2	538	94.1	6	85.7	7	77.8
Total	173	100.0	399	100.0	572	100.0	7	100.0	9	100.0



The Stigma Index questionnaire also explored whether in the last 12 months respondents made certain choices or behaved in specific ways because of their HIV status. Ten percent of respondents reported that they chose not to attend social gatherings because of their HIV status and 5 percent chose to isolate themselves from their family and / or friends. Female respondents (6 percent) were more likely to isolate themselves from family / friends than male respondents (2 percent). Fiver percent of respondents decided to stop working and 4 percent decided not to apply for a job or promotion because of their HIV status. Two percent of respondents shared that they withdrew from education / training or did not take up an opportunity for education and training due to their HIV status. Eight percent of respondents decided not to get married and 9 percent decided not to have sex because of their HIV status. Twenty-one percent of respondents decided not to have (more) children. Nine percent avoided going to the local clinic and 4 percent avoided going to the hospital when they needed to because of their HIV status.

Roughly two-thirds of FSW respondents report that they chose not to attend social gatherings, chose to isolate themselves from family / friends, stopped working and didn't get married due to their HIV status. Some FSW respondents also reported deciding not to have sex, have more children or seek medical attention due to their HIV status. HIV status of an MSM respondent is more likely to affect their decision in getting married, having children or seeking medical attention.



Figure 10: Reported respondent behaviour changes due to knowledge of HIV status

Table 17: Internalised sigma: respondent behaviour due to HIV status

	M	ale	Fem		Tot	tal	ES	W	MS	NA.
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
I have	chosen not				Number	reiteitt	Number	Fercent	Number	reiteitt
Yes	18	10.3	38	9.5	56	9.7	2	28.6	0	0.0
No	157	89.7	363	90.5	520	90.3	5	71.4	9	100.0
Total	175	100.0	401	100.0	576	100.0	7	100.0	9	100.0
	isolated my					100.0	,	100.0	5	100.0
Yes	4	2.3	23	5.7	27	4.7	3	42.9	0	0.0
No	171	97.7	379	94.3	550	95.3	4	57.1	9	100.0
Total	175	100.0	402	100.0	577	100.0	7	100.0	9	100.0
I took	the decisio						1			
Yes	8	4.6	18	4.5	26	4.5	2	28.6	1	11.1
No	167	95.4	383	95.5	550	95.5	5	71.4	8	88.9
Total	175	100.0	401	100.0	576	100.0	7	100.0	9	100.0
I decid	led not to a	pply for a j	ob/work or	for a pron	notion					
Yes	7	4.0	18	4.5	25	4.4	1	14.3	0	0.0
No	166	96.0	381	95.5	547	95.6	6	85.7	9	100.0
Total	173	100.0	399	100.0	572	100.0	7	100.0	9	100.0
I witho	drew from e	education/t	raining or o	did not tak	e up an opp	ortunity fo	or educatio	n/ training		
Yes	4	2.3	9	2.3	13	2.3	2	28.6	0	0.0
No	171	97.7	391	97.8	562	97.7	5	71.4	9	100.0
Total	175	100.0	400	100.0	575	100.0	7	100.0	9	100.0
I decid	ed not to g	et married								
Yes	12	6.9	36	9.0	48	8.3	2	28.6	3	33.3
No	162	93.1	366	91.0	528	91.7	5	71.4	6	66.7
Total	174	100.0	402	100.0	576	100.0	7	100.0	9	100.0
	led not to h						1			
Yes	9	5.1	41	10.3	50	8.7	1	14.3	1	11.1
No	166	94.9	358	89.7	524	91.3	6	85.7	8	88.9
Total	175	100.0	399	100.0	574	100.0	7	100.0	9	100.0
	ed not to h						1			
Yes	33	19.1	87	21.8	120	21.0	1	14.3	4	44.4
No	140	80.9	312	78.2	452	79.0	6	85.7	5	55.6
Total	173	100.0	399	100.0	572	100.0	7	100.0	9	100.0
	led going to									
Yes	14	8.0	35	8.8	49	8.5	1	14.3	3	33.3
No	160	92.0	365	91.3	525	91.5	6	85.7	6	66.7
Total	174	100.0	400	100.0	574	100.0	7	100.0	9	100.0
	led going to	-								
Yes	4	2.3	20	5.0	24	4.2	3	42.9	1	11.1
No	171	97.7	380	95.0	551	95.8	4	57.1	8	88.9
Total	175	100.0	400	100.0	575	100.0	7	100.0	9	100.0

In environments where stigma and discrimination are rife, fear and uncertainty pervades. The Stigma Index questionnaire asked respondents whether in the last 12 months they had been *fearful* of certain things happening to them, whether or not they *actually* have happened to the respondent; Table 18 shows the responses. Forty-three percent were fearful of being gossiped about, 27 percent feared being verbally insulted / harassed / threatened, 17 percent feared being physically harassed / threatened, and 17 percent feared being physically assaulted. In general, more female respondents expressed having these fears compared to male respondents. Respondents were also asked whether they feared that someone would not want to be sexually intimate with them due to their HIV status; 23 percent reported that they had this fear, with more males (25 percent) expressing this fear compared to females (22 percent).



Most FSW respondents reported being fearful of being gossiped about, being verbally insulted, and being physically harassed; half of the FSW respondents were fearful about being physically assaulted. Nearly all MSM respondents reported being fearful about being gossiped about and nearly half reported fear about being verbally insulted. Two-thirds of MSM respondents were fearful that someone would not want to be sexually intimate with them due to their HIV status.



Figure 11: Internalised Stigma - Respondent fears due to HIV status

Table 18: Internalised stigma: respondent fears

	Ma	ale	Ferr	nale	То	tal	FS	W	MS	M
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Fearful o	f any of the	e following	things hap	pening to y	ou -whethe	er or not th	ey actually	have happ	ened to you	ı
Being	gossiped at	out								
Yes	71	40.6	175	43.8	246	42.8	6	85.7	8	88.9
No	104	59.4	225	56.3	329	57.2	1	14.3	1	11.1
Total	175	100	400	100	575	100	7	100.0	9	100.0
Being	verbally ins	ulted, hara	issed and/o	or threaten	ed					
Yes	45	25.7	112	28.1	157	27.4	6	85.7	4	44.4
No	130	74.3	287	71.9	417	72.6	1	14.3	5	55.6
Total	175	100.0	399	100.0	574	100.0	7	100.0	9	100.0
Being	physically h	arassed an	d/or threa	tened						
Yes	25	14.4	73	18.4	98	17.2	5	71.4	1	11.1
No	149	85.6	324	81.6	473	82.8	2	28.6	8	88.9
Total	174	100.0	397	100.0	571	100.0	7	100.0	9	100.0
Being	physically a	ssaulted								
Yes	23	13.1	74	18.6	97	16.9	3	42.9	1	11.1
No	151	86.9	324	81.4	476	83.1	4	57.1	8	88.9
Total	175	100.0	398	100.0	573	100.0	7	100.0	9	100.0
Fear that	someone	would not	want to be	sexually in	timate due	to HIV-pos	itive status	i i		
Yes	43	25.1	84	21.5	127	22.6	0	0.0	6	66.7
No	128	74.9	307	78.5	435	77.4	7	100.0	3	33.3
Total	171	100.0	391	100.0	562	100.0	7	100.0	9	100.0



Rights, laws and policies

It is important for rights and laws regarding HIV and PLHIV to be well known and understood by all people, not just PLHIV. The Stigma Index questionnaire therefore asked respondents whether they were aware about key policies that have a great effect on their rights as PLHIV.

Respondents were asked whether they ever heard about the Declaration of Commitments on HIV/AIDS. In the Declaration of Commitment on HIV/AIDS, governments affirmed that the realization of human rights and fundamental freedoms for all is essential to reduce vulnerability to HIV, and that respect for the rights of people living with HIV drives an effective response. (The full text of the Declaration of Commitment on HIV/AIDS is available at www.ohchr.org/english/law/hiv.htm). Seventy-five percent of respondents answered that they had heard of the declaration and 58 percent have read and discussed the content. Male respondents (81 percent) were more likely to have heard about the Declaration than the female respondents (73 percent).



Figure 12: Awareness of respondents to International and National HIV legal frameworks

Respondents were also asked whether they had heard about the National HIV and AIDS Commission Act of 2011; Table 19 shows the responses. This Act contains penalties for discriminatory acts against those infected and affected by HIV and AIDS. Seventy-two percent of respondents had heard of the National HIV and AIDS Commission Act of 2011, and 61 percent had read and discussed its contents. Male respondents (81 percent) were more likely

to have heard of the Act than female respondents (68 percent).

Many of the MSM respondents report having heard about the international Declaration of Commitment as well as the National HIV and AIDS Act, however of those that have heard of these frameworks, very few have had the chance to read or discuss the content. Less than half of the FSW respondents have heard of the international and national frameworks, however of those that have, roughly half of them have had a chance to read and discuss these contents.

Focus group discussions also revealed the extent of knowledge of the PLHIV regarding their rights. When asked regarding their awareness of rights and policies that guarantee PLHIV rights, they quoted specifically their understanding of laws against stigma as well as criminalization of deliberate HIV infection of non-infected people. Unfortunately, the FSW group discussion did not express awareness of specific PLHIV rights, while most MSM participants seemed aware that they exist but did not know what it entailed.



Table 19: Respondent awareness of global and national legal frameworks

	Ma	ale	Ferr	ale	To	tal	FS	W	MS	M
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Heard of	the Declara	ation of Co	mmitment	on HIV/AIC	DS					
Yes	141	81.0	293	72.9	434	75.3	3	42.9	6	66.7
No	33	19.0	109	27.1	142	24.7	4	57.1	3	33.3
Total	174	100.0	402	100.0	576	100.0	7	100.0	9	100.0
If yes, ha	ve you read	d or discuss	ed the cont	tent ⁱⁱ						
Yes	83	58.9	159	57.0	242	57.6	2	66.7	2	33.3
No	58	41.1	120	43.0	178	42.4	1	33.3	4	66.7
Total	141	100.0	279	100.0	420	100.0	3	100.0	6	100.0
Heard of	the Nation	al HIV and	AIDS Comm	nission Act	2011					
Yes	139	80.8	274	68.3	413	72.1	3	42.9	8	88.9
No	33	19.2	127	31.7	160	27.9	4	57.1	1	11.1
Total	172	100.0	401	100.0	573	100.0	7	100.0	9	100.0
If yes, ha	ve you read	d or discuss	ed the cont	tent "						
Yes	90	65.2	151	59.0	241	61.2	2	66.7	2	25.0
No	48	34.8	105	41.0	153	38.8	1	33.3	6	75.0
Total	138	100.0	256	100.0	394	100.0	3	100.0	8	100.0

Respondents were asked whether in the last 12 months they had experienced certain things because of their HIV status; see Table 20 for range of activities requested. Seven percent of respondents report being forced to submit to a medical or health procedure (including an HIV test); 10 percent of males reported this in comparison to 5 percent of female respondents. Two percent of respondents were denied health insurance or life insurance because of their HIV status, however it must be noted that health and life insurance is only a burgeoning service in Sierra Leone. Less than 1 percent of respondents were arrested or taken to court on a charge related to their HIV status, however this occurred more frequently to males (2 percent) than to females (0.3 percent). One percent of respondents were made to disclose their HIV status in order to apply for residence or nationality. Two percent of respondents reported being detained, quarantined, isolated or segregated due to their HIV status; this was three times more likely to occur to males (4 percent) than female (1 percent) respondents. Fortunately, majority of respondents to the questionnaire reported that none of the aforementioned incidents happened to them (93 percent).



No members of the MSM population surveyed reported having their rights violated, however some FSW respondents reported that they were forced to submit to medical procedures and were detained or quarantined. Additionally, some FSW have reported being harassed and taken advantage of by police.

Focus group discussions also explore the topic of PLHIV right violations; participants were asked to share whether they had ever experienced any abuse of their rights. Although the general PLHIV group didn't express any concerns regarding violation of rights, participants from the FSW and MSM focus group discussions reported several instances, such as being prevented to sell or buy goods, police harassment, and prevention of access to health. There are some differences between questionnaire responses and FGD responses on rights violations. This could be due to possible anxiety about discussing such topics in the open despite the private location of the FGDs.

"Even the police harass us for free sex sometimes." - Jane, FSW FGD	"The behaviour of the doctor when I go for treatment in refusing to see me constitutes a violation of my rights." - Thomas, MSM FGD
'My rights have been seized so many times. Because th Leone, the police always harass me."	hey know that I'm the chairman for FSW's in Sierra
	- Lovetta, FSW FGD
"They only arrest us the women and leave the hustling in the streets."	the male prostitutes to continue their - Alimatu, FSW FGD
"When my father died, I received none of the properties that he had. The surviving children prevented me from getting my share because I was HIV positive." - Abu, PLHIV FGD	"I was prevented from going to sell at the market because of my HIV status. I'm also prevented from going inside shops to buy things."
L	- Rosetta, PLHIV FGD



Figure 13: Respondents with rights violated due to HIV status

Table 20: Rights violations against respondents

	М	ale	Fen	nale	Тс	otal	FS	W	M	SM
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Forced to s	ubmit to a	medical or	health pro	cedure (inc	luding HIV	testing)				
Yes	13	10.0	16	5.1	29	6.5	1	14.3	0	0.0
No	117	90.0	300	94.9	417	93.5	6	85.7	9	100.0
Total	130	100	316	100	446	100	7	100.0	9	100.0
I was denied health insurance or life insurance because of my HIV st										
Yes	1	0.8	7	2.2	8	1.8	0	0.0	0	0.0
No	126	99.2	306	97.8	432	98.2	7	100.0	9	100.0
Total	127	100	313	100	440	100	7	100.0	9	100.0
Arrested or	r taken to o	court on a c	harge relat	ed to my H	IV status					
Yes	2	1.6	1	0.3	3	0.7	0	0.0	0	0.0
No	124	98.4	309	99.7	433	99.3	7	100.0	9	100.0
Total	126	100	310	100	436	100	7	100.0	9	100.0
Had to disc	lose my HI	V status in	order to en	ter anothe	r country					
Yes	4	3.2	2	0.6	6	1.4	0	0.0	0	0.0
No	122	96.8	306	99.4	428	98.6	7	100.0	9	100.0
Total	126	100	308	100	434	100	7	100.0	9	100.0
I had to dis	close my H	IIV status to	apply for	residence o	or national	ity				
Yes	1	0.8	2	0.7	3	0.7	0	0.0	0	0.0
No	125	99.2	303	99.3	428	99.3	7	100.0	9	100.0
Total	126	100	305	100	431	100	7	100.0	9	100.0
Detained, o	quarantine	d, isolated	or segregat	ed						
Yes	5	3.9	3	1.0	8	1.8	1	14.3	0	0.0
No	123	96.1	302	99.0	425	98.2	6	85.7	9	100.0
Total	128	100.0	305	100.0	433	100.0	7	100.0	9	100.0
None of the	ese things	happened t	o me							
Yes	139	89.7%	352	94.4%	491	93.0%	5	71.4	9	100.0
No	16	10.3%	21	5.6%	37	7.0%	2	28.6	0	0.0
Total	155	100.0%	373	100.0%	528	100.0%	7	100.0	9	100.0



Figure 14: Percentage of respondents to report abuse of PLHIV rights

Thirteen percent of respondents said that they had experienced an abuse of their rights as a PLHIV in the past 12 months (Table 21). Of those that had experienced an abuse of their rights as a PLHIV, 38 percent sought redress for the abuse; more females (42 percent) than males (29 percent) sought redress. Of those that sought redress, 74 percent had begun the process in the past 12 months, of which 59 percent had completed the process by the time of the survey, 15 percent still had the matter in process, and 26 percent found that nothing was

done to deal with the redress process. For those who had not sought legal redress, the most common reasons for not doing so was insufficient financial

resources to take action (54 percent) and feelings of intimidation or fear to take action (25 percent). Some were advised by others not to take action (20 percent), while others felt the process of taking on the problem was too bureaucratic (3 percent) or they had no confidence that a successful outcome would take place (3 percent).

All FSW respondents in the survey reported that their rights as a PLHIV were abused in the past 12 months; less than half of them sought legal redress. For those FSW PLHIV whose rights were abused and did not seek legal redress, they cited lack of financial resources as the reason for not doing so. Only one MSM reported having his rights abused as a PLHIV; he chose not to seek legal redress as he felt intimidated to take action.

	Μ	ale	Fen	nale	То	tal	FS	W	MSM	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Abuse of rights as a PL	HIV in pas	t 12 mont	hs							
Yes	19	11.6	51	13.4	70	12.8	7	100.0	1	11.1
No	135	82.3	321	84.0	456	83.5	0	0.0	5	55.6
Not sure	10	6.1	10	2.6	20	3.7	0	0.0	3	33.3
Total	164	100	382	100	546	100	7	100.0	9	100.0
If yes, legal redress sou	ight for ar	iy abuse o	f PLHIV rig	ghts ⁱⁱⁱ						
Yes	6	28.6	22	41.5	28	37.8	3	42.9	0	0.0
No	15	71.4	31	58.5	46	62.2	4	57.1	1	100.0
Total	21	100.0	53	100.0	74	100	7	100.0	1	100.0
Process begun in the last 12 months										
Yes	4	66.7	16	76.2	20	74.1	3	100.0		
No	2	33.3	5	23.8	7	25.9	0	0.0		
Total	6	100.0	21	100.0	27	100.0	3	100.0		
Result of process										
The matter has been dealt with	6	66.7	17	56.7	23	59.0	0	0.0		
The matter is still in the process of being dealt with	1	11.1	5	16.7	6	15.4	2	66.7		
Nothing happened/the matter was not dealt with	2	22.2	8	26.7	10	25.6	1	33.3		
Total	9	100	30	100	39	100	3	100.0		

Table 21: Abuse of PLHIV rights and legal redress



Male Female Percent Number Percent Reason for not seeking legal redress Insufficient financial 30.0 resources to take 3 16 64.0 19 54.3 4 80.0 0 0.0 action. Process of addressing the problem 0.0 0.0 0 0.0 3.0 0 0 1 11.1 1 appeared too bureaucratic. Felt intimidated or 3 33.3 6 22.2 9 25.0 1 20.0 1 100.0 scared to take action. Advised against taking action by 2 22.2 5 19.2 7 20.0 0 0.0 0 0.0 someone else. No/little confidence that the outcome 0 0.0 1 4.0 1 2.9 0 0.0 0 0.0 would be successful. None of the above. 0 0.0 0 0.0 0.0 1 3.7 1 2.8 0

Table 21 continued: Abuse of PLHIV rights and legal redress

Twenty-one percent of respondents report that they tried to get a government employee to take action against an abuse of their rights as a PLHIV; females were more likely to seek this support than males. Of those that sought this support, 84 percent reported that it occurred in the past 12 months and 47 percent reported that the issue had been resolved. Fifteen percent of respondents tried to get a local or national politician to take action against the abuse of their rights; male respondents were more likely to seek this support than females. Of those that sought the support of politicians, 68 percent reported that it occurred in the past 12 months and 50 percent reported that the issue had been resolved.

Some FSW respondents tried to get a government employee or politician to take action against an abuse of their rights as a PLHIV, however the matter has not yet been resolved. No MSM reported attempting to get a government employee or politician involved.

	Ma	ale	Fen	nale	То	tal	FS	W	MSM	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Get government employee	Get government employee(s) to take action against an abuse of your rights as a PLHIV									
Yes	3	13.0	15	24.6	18	21.4	2	28.6	0	0
No	20	87.0	46	75.4	66	78.6	5	71.4	1	100.0
Total	23	100	61	100	84	100	7	100.0	1	100.0
Did this happen in the last										
Yes	3	100.0	13	81.3	16	84.2	1	50.0		
No	0	0.0	3	18.8	3	15.8	1	50.0		
Total	3	100	16	100	19	100	2	100.0		
The result										
Matter been dealt with	1	33.3	8	50.0	9	47.4	0	0.0		
Matter still in the process of being dealt with	0	0.0	3	18.8	3	15.8	1	50.0		

Table 22: Involvement of authorities in rights abuse issue

Northing/happened/the matter was not dealt with	2	66.7	5	31.3	7	36.8	1	50.0		
Total	3	100	16	100	19	100	2	100.0		
Tried to get local or national politician to take action against an abuse of your rights as a PLHIV										
Yes	4	17.4	8	14.5	12	15.4	2	28.6	0	0
No	19	82.6	47	85.5	66	84.6	5	71.4	1	100.0
Total	23	100	55	100	78	100	7	100.0	1	100.0
This happen in the last 12	months									
Yes	4	100	8	57.1	12	66.7	2	100.0		
No	0	0.0	6	42.9	6	33.3	0	0.0		
Total	4	100	14	100	18	100	2	100.0		
The result										
Matter been dealt with	1	33.3	6	54.5	7	50.0	0	0.0		
Matter still in the process of being dealt with	0	0.0	3	27.3	3	21.4	1	50.0		
Nothing happened/the matter was not dealt with	2	66.7	2	18.2	4	28.6	1	50.0		
Total	3	100	11	100	14	100	2	100.0		

Effecting Change

Despite stigma and discrimination, some PLHIV feel empowered enough to take action and do something to bring about a positive change. Twenty-three percent of respondents report having confronted, challenged or educated someone who was stigmatizing or discrimination against them in the past 12 months. Seventy-eight percent of respondents are also aware of organizations that are able to support PLHIV through experiences of stigma and discrimination, with the most frequently cited organizations being the PLHIV support groups and NETHIPS. Apart from the list noted in Table 23, respondents also mentioned hospitals, chiefs, HIV counselors and police as groups that they could turn to for support regarding stigma and discrimination. Twenty-six percent of respondents have turned to the known organizations for support on resolving stigma and discrimination issues.

Focus group discussions also revealed PLHIV expressing efforts to change the circumstances of stigma and discrimination around them by addressing their aggressor or reporting the event to a supervisor of the aggressor. In some instances, the participant reported being able to resolve the outcome to their favor, however some also expressed resignation in the matter in order not to upset the balance within the family or community.

"I did not feel good after my experience with stigma and discrimination. I conveyed my feelings to the nurse who informed the doctor. It was only then that the doctor tried to improve his behaviour towards	"I reported my brother after he paraded my papers along the street and they wanted to have him arrested but I said no, the family would not like that." - Musu, PLHIV FGD
me."	"One day I took the male sex workers to go and
- Jonathan, MSM FGD	address the people that always offend us and cursed



Figure 15: Support groups known by respondents to help during experiences of stigma and discrimination

Most FSW respondents have not confronted, challenged or educated someone who was stigmatizing them, nor are most FSW aware of organizations that could help them if they experienced stigma or discrimination. Almost half the MSM respondents reported that they confronted, challenged or educated someone who was stigmatizing them, and most MSM report being aware of an organization that could help them if they experienced stigma and discrimination. Less than a quarter of the MSM and FSW respondents sought help from any organization to resolve stigma and discrimination issues.

Table 23: Confronting stigma and discrimination

	M	ale	Fen	nale	Тс	otal	FS	SW	M	SM
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Confronted, challenge	ed or educ	ated some	eone who	was stign	natizing ar	nd/or discr	iminating	against y	bu	
Yes	41	23.7	91	23.0	132	23.2	2	28.6	4	44.4
No	132	76.3	305	77.0	437	76.8	5	71.4	5	55.6
Total	173	100	396	100	569	100	7	100.0	9	100.0
Awareness of any organizations / groups that can help if you experience stigma or discrimination										
Yes	141	82.9	290	75.9	431	78.1	2	28.6	8	88.9
No	29	17.1	92	24.1	121	21.9	5	71.4	1	11.1
Total	170	100.0	382	100.0	552	100.0	7	100.0	9	100.0
If yes, which organiza	tions / gr	oups do yo	ou know a	bout						
PLHIV support group	122	85.9	259	88.7	381	87.8	2	28.6	3	33.3
NETHIPS	96	68.1	196	68.1	292	68.1	2	28.6	4	44.4
Local NGO	18	15.9	29	11.2	47	12.6	1	14.3	4	44.4
Faith-based organization	20	16.0	47	17.1	67	16.8	4	57.1	1	11.1
A legal practice	14	12.5	21	8.4	35	9.7	4	57.1	3	33.3
Human rights organization	40	34.5%	79	29.9%	119	31.3%	1	14.3	7	77.8
National NGO	12	10.9	41	16.3	53	14.7	1	14.3	3	33.3
NAC / NAS	33	28.9	69	26.7	102	27.4	1	14.3	1	11.1
International NGO	25	21.2	57	21.8	82	21.6	4	57.1	2	22.2
UN	24	20.5	59	23.1	83	22.3	4	57.1	2	22.2
Other	12	11.3	13	5.3	25	7.2	4	57.1	8	88.9
Sought help from any	organizat	tions / gro	ups to res	olve stign	na or discr	imination	issues			
Yes	42	26.9	94	25.4	136	25.9	2	28.6	2	22.2
No	114	73.1	276	74.6	390	74.1	5	71.4	7	77.8
Total	156	100	370	100	526	100	7	100.0	9	100.0



Seventy-one percent of respondents have supported other PLHIV in the past 12 months through means of emotional support (86 percent), physical support (51 percent) and referral to other services (41 percent). Most respondents (83 percent) reported being current members of PLHIV support groups or networks and some (32 percent) are involved as volunteers or employees in programmes providing assistance to PLHIV. Twenty-one percent of respondents are also involved in efforts to develop legislation, policies or guidelines related to HIV. Most respondents do not feel that they have the power to influence decisions related to legislations, policies or project directions. According to the respondents of the questionnaire, the most important thing that organizations should do in order to address stigma and discrimination is to advocate for the rights of PLHIV and to provide emotional, physical and referral support to PLHIV.



Figure 16: Percentage of respondents currently belonging in HIV support groups MSM respondents were more likely to support other PLHIV than FSW respondents, citing emotional support as the type most likely to be provided. Roughly one-third of the key population groups are current members of a PLHIV network or are involved as a volunteer in a programme to provide assistance to PLHIV. No MSM reported being involved in efforts to develop legislation, policies or guidelines related to HIV; however one FSW reported being involved in such activities. Many FSW respondents reported that they felt that they had the power to influence decisions in legal matters related to PLHIV, while MSM were

more likely to report that they felt power to influence local projects intended to benefit

PLHIV. Both key population groups reported that the top two activities that an organization could do to address stigma and discrimination were (1) advocate for the rights of PLHIV, and (2) provide emotional, physical and referral support to PLHIV.



Table 24: Support mediums for stigma and discrimination

		ale		nale		otal	E	SW	М	SM
	Number	Percent	Number	Percent	Number	Percent	Number		Number	Percent
Respondent supported oth	er PLHIV									
Yes	130	76.5	269	68.8	399	71.1	2	28.6	7	77.8
No	40	23.5	122	31.2	162	28.9	5	71.4	2	22.2
Total	170	100	391	100	561	100	7	100.0	9	100.0
Types of support provided										
Emotional support	104	87.4	224	85.2	328	85.9	1	14.3	6	85.7
Physical support	53	52.5	111	50.7	164	51.3	1	14.3	2	33.3
Referral to other services	40	41.7%	86	41.1%	126	41.3%	1	14.3	1	14.3
Current member of a PLHIV										
Yes	140	83.3	323	82.8	463	83.0	2	28.6	3	33.3
No	28	16.7	67	17.2	95	17.0	5	71.4	6	66.7
Total	168	100	390	100	558	100	7	100.0	9	100.0
Involved as volunteer or er	nployee ii	n any progi	ramme /	project pro	viding as	sistance to	PLHIV			
Yes	58	35.6	119	30.9	177	32.3	1	14.3	3	33.3
No	105	64.4	266	69.1	371	67.7	6	85.7	6	66.7
Total	163	100.0	385	100.0	548	100.0	7	100.0	9	100.0
Involved in efforts to devel	1						4	14.2	0	0.0
Yes No	38 122	23.8 76.3	74 290	20.3 79.7	112 412	21.4 78.6	1 6	14.3 85.7	0 9	0.0 100.0
Total	160	100.0	364	100.0	524	100.0	7	100.0	9	100.0
Feel that you have the pow						10010		20010	5	10010
Legal/rights matters affecting PLHIV.	66	48.9	115	34.8	181	38.9	5	71.4	4	44.4
Local government policies affecting PLHIV.	25	19.2	31	9.8	56	12.6	1	14.3	2	22.2
Local projects intended to benefit PLHIV.	31	24.4	29	9.5	60	13.9	2	28.6	5	55.6
National government policies affecting PLHIV.	23	18.5	27	8.8	50	11.6	0	0	2	22.2
National programmes to benefit PLHIV.	21	16.9	13	4.2	34	7.9	0	0	3	33.3
International agreements/treaties.	3	2.4	8	2.6	11	2.5	0	0	0	0
None of these things.	63	47.4	204	62.8	267	58.3	0	0	3	33.3
Most important thing to do	o as an org	ganization	to addres	s stigma aı	nd discrim	nination	l			
Advocating for the rights of all PLHIV.	88	56.1	239	63.1	327	61.0	6	85.7	4	44.4
Providing emotional, physical and referral support to PLHIV.	45	28.7	104	27.4	149	27.8	1	14.3	2	22.2
Advocating for the rights and/or providing support to particular marginalized groups.	6	3.8	7	1.8	13	2.4	0	0.0	3	33.3
Educating PLHIV about living with HIV(including treatment literacy).	11	7.0	20	5.3	31	5.8	0	0.0	0	0.0
Raising the awareness and knowledge of the public about AIDS.	7	4.5	9	2.4	16	3.0	0	0.0	0	0.0
Total	157	100	379	100	536	100	7	100.0	9	100.0
	I									



Participants in the focus groups were asked to provide advice on what needed to be done to address stigma and discrimination. Some suggestions provided are already in place, such as sensitization in newspapers and radio, meetings with community authorities regarding stigma, sensitization of law makers and health workers regarding stigma and PLHIV, providing alternative livelihood projects for sex workers, and general blood test days for the public. The reiteration of these activities as needs simply underlines the scale up that is needed as well as the promotion provided regarding these activities. Other suggestions that are not currently being done in Sierra Leone include provision of living areas for HIV people, documentaries on TV showing PLHIV to sensitize the public, legalization of sex work, CSOs to support key populations in carrying out their trade safely, football programs that bring PLHIV and non-PLHIV together to dispel stigma myths, and have HIV facilities specific for key populations.

Testing and Diagnosis

HIV testing is an important entry point for both the prevention of HIV and for the early uptake of appropriate services for those who need them. It is important to encourage people to be tested for HIV in order to improve understanding of the national epidemic and to enable PLHIV to gain access to treatment in order to limit disease progression and transmission. According to the 2013 DHS, Sierra Leone has a very low HIV testing rate; 50 percent have ever been tested and only 13.6 percent have been tested and received their results in the past 12 months. Respondents to the Stigma Index questionnaire cited the most frequent reasons for getting tested for HIV were personal interest in knowing their status (33 percent) and referral to the testing center based on suspected HIV related symptoms (28 percent). Most reported that the decision to be tested for HIV was a personal decision (86 percent), however it is concerning to note that 4 percent were pressured into getting tested, 6 percent were coerced into getting tested, and 5 percent were tested without their knowledge. Seventy-seven percent of respondents also received pre and post HIV test counseling.



Figure 17: Respondent reasons for getting an HIV test



Nearly half of the members from the key populations of FSW and MSM reported the reason for getting an HIV test as "wanting to know" their status. Some FSW also cite HIV testing reasons due to pregnancy, referral due to suspected HIV related symptoms and a family member tested positive for HIV. MSM also cited reasons for HIV testing due to referral from STI clinics and referral due to suspected HIV related symptoms. Most FSW and MSM respondents took the decision to be tested on their own, while others decided to be tested on their own but with pressure from others. All FSW respondents reported receiving pre and post HIV test counseling while almost all MSM received pre and post HIV test counseling.

Table 25: HIV testing among respondents										
	Ma	ale	Ferr	nale	То	tal	FS	w	MS	M
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Why were you tested for HIV										
Employment	9	6.4	9	2.7	18	3.8	0	0	0	0
Pregnancy	6	4.6	95	28.1	101	21.6	2	28.6	0	0
Prepare for										
marriage/sexual relationship	3	2.3	8	2.5	11	2.4	0	0	0	0
Referred by clinic for STI	15	11.4	16	5.0	31	6.9	0	0	1	11.1
Referred due to suspected HIV-related symptoms (e.g. TB)	46	34.6	83	25.7	129	28.3	1	14.3	3	33.3
Husband/wife/partner/fami ly member tested positive	14	10.9	20	6.3	34	7.7	1	14.3	0	0
Illness/death of husband/wife/partner/fami ly member	29	22.0	74	23.1	103	22.7	0	0	0	0
I just wanted to know	56	39.2	100	30.6	156	33.2	3	42.9	5	55.6
Other	5	3.9	8	2.6	13	3.0	0	0	0	0
Decision to be tested for HIV up to you										
Yes, I took the decision myself to be tested(i.e. it was voluntary)	156	91.8	320	82.7	476	85.5	6	85.7	8	88.9
I took the decision to be tested, but it was under pressure from others	5	2.9	15	3.9	20	3.6	1	14.3	1	11.1
I was made to take an HIV test (coercion)	3	1.8	32	8.3	35	6.3	0	0	0	0
Tested without knowledge - only found out after the test	6	3.5	20	5.2	26	4.7	0	0	0	0
Total	170	100	387	100	557	100	7	100.0	9	100.0
Received counselling when to	ested for I	liv								
I receive both pre-and post HIV test counselling	147	86.5	283	72.8	430	76.9	7	100.0	8	88.9
I only received pre-test HIV counselling	2	1.2	11	2.8	13	2.3	0	0	0	0
I only received post-test HIV counselling	14	8.2	75	19.3	89	15.9	0	0	1	11.1
I did not receive any counselling when I had an HIV test	7	4.1	20	5.1	27	4.8	0	0	0	0
Total	170	100	389	100	559	100	7	100.0	9	100.0

Table 25: HIV testing among respondents



Information received from the questionnaire was also reflected within the responses from the focus group discussions. Participants often shared stories regarding their decision to test due to recurring / prolonged illness or due to the death of a spouse (often cases the husband) who died of AIDS. Some women reported that they found out about their HIV status during their visits for antenatal care, while another found out while undergoing the blood donation procedures. An NGO that provides support to the MSM network was also reported to offer testing and counseling specific to its members as they are a reticent and hidden group.

"I was sick and even unable to pick up a five gallon rubber full of water. I went to the hospital to do a test and was told that I had HIV."

Juliana, PLHIV FGD

"The organisation that I work for offered testing and counselling for MSM's, and so I volunteered as I thought it was necessary to know my status. The results showed that I was positive."

- Edward, MSM FGD

Disclosure and Confidentiality

A large barrier to receiving an HIV test and thus treatment relates to the discrimination, confidentiality and privacy that are associated with the knowledge and disclosure of the results. It is also important to note disclosure as it may influence internalised stigma and fears of stigma and discrimination.

Table 26 outlines the groups with whom respondents disclosed their HIV status. Respondents reported most frequently having disclosed their status to other PLHIV (77.8 percent), health care workers (56.4 percent) and social workers (67.5 percent); these trends are the same for both males and females. Figure 18 also illustrates these observations. Although much less in number, respondents also most frequently provided consent to someone to disclose their HIV status to the same groups (Table 27). Eight percent of respondents consented for someone to disclose their HIV status to health care workers and other PLHIV. Respondents reported that their friends and neighbours were most likely to be told their HIV status without their consent (9.4 percent). Interestingly, respondents also noted that the groups that are not aware of their HIV status are their friends / neighbours (76.6 percent), community leaders (72.5 percent), and religious leaders (68.4 percent).

Male respondents reported to be more likely to disclose their HIV status to their wives / partners (54.0 percent) than female respondents (35 percent). However, women were more likely to disclose their HIV status to their children (39.2 percent) than male respondents (27.7 percent). Apart from family and health care workers, very few respondents report disclosing their HIV status to other members within their community.

FSW and MSM respondents were also more likely to disclose their status to health care workers, however FSW were more willing to disclose HIV status to social workers / counsellors than MSM respondents.



	M	ale	Ferr	nale	То	tal	FS	W	MS	SM
	Number	Percent								
Respondent told specific	group									
Your husband/wife/partner	74	54.0	117	35.3	191	40.8	1	14.3	2	22.2
Other adult family members	49	35.8	96	29.1	145	31.0	3	42.9	2	22.2
Children in your family	38	27.7	130	39.2	168	35.8	2	28.6	1	11.1
Your friends/neighbours	12	9.2	22	6.7	34	7.4	1	14.3	5	55.6
Other PLHIV	106	77.4	255	78.0	361	77.8	4	57.1	7	77.8
Your co-workers	14	10.1	21	6.3	35	7.4	1	14.3	2	22.2
Your employer	5	3.7	12	3.6	17	3.7	1	14.3	0	0.0
Your clients	17	12.5	34	10.4	51	11.0	0	0.0	0	0.0
Injecting drug partners	1	0.7	3	0.9	4	0.9	0	0.0	0	0.0
Religious leaders	4	2.9	17	5.1	21	4.5	1	14.3	0	0.0
Community leaders	4	2.9	14	4.3	18	3.9	1	14.3	1	11.1
Health care workers	73	52.9	191	57.9	264	56.4	6	85.7	7	77.8
Social workers/counsellors	97	70.8	218	66.1	315	67.5	7	100.0	5	55.6
Teachers	9	6.5	8	2.4	17	3.7	0	0.0	0	0.0
Government officials	11	8.0	25	7.5	36	7.7	0	0.0	0	0.0
The media	1	0.7	5	1.5	6	1.3	1	14.3	0	0.0



Figure 18: Percentage of respondents that disclosed their HIV status to someone



Someone else told the group Someone else told the group Group does not know Number Percent Number Percent Percen Someone else told the group with respondent consent 29.1 Your husband/wife/partner 25 5.3 18 3.8 136 Other adult family members 51.4 30 6.4 30 6.4 240 Children in your family 20 4.3 249 53.1 10 2.1 Your friends/neighbours 76.6 10 2.2 43 9.4 350 Other PLHIV 37 6.7 6.9 8.0 31 32 Your co-workers 5 3.4 45.1 1.1 16 212 2.2 29.0 Your employer 1 0.2 10 135 Your clients 2 0.4 22 4.7 162 34.9 Injecting drug partners 2 3 59 12.7 0.4 0.6 2 **Religious leaders** 0.4 9 1.9 321 68.4 **Community leaders** 2 0.4 16 3.4 337 72.5 Health care workers 38 22.4 8.1 34 7.3 105 Social workers/counsellors 26 5.6 38 8.1 57 12.2 Teachers 2 0.4 6 1.3 205 44.1 9 Government officials 1.9 17 3.6 217 46.3 The media 0 0.0 15 3.2 220 46.9

Table 27: Means of respondent HIV status disclosure to family and community groups

* Table 27 has not been disaggregated by gender and key population as the difference of the value / trend with total population was negligible.

Focus group discussion participants shared stories regarding their experience with disclosure on their HIV status with friends and family. Some participants were ostracized by their family members and shunned, while others shared stories of reaffirmed acceptance by their husband. Some participants reported that disclosing their status to their religious leader resulted in disclosure to the religious group that there was an HIV positive person in the room and they should pray for them.

"I disclosed my status to my sister but she der	nied the existence of HIV."
 	- Yeabu, PLHIV FGD
"When I told my husband I asked him for us to part ways. He said no, he married me when I was well and sickness would not cause us to part. I was not treated differently by anyone."	'I felt relief after disclosure." - Jonathan, MSM FGD
- Mariama, PLHIV FGD	"I was so embarrassed when my brother took my documents and walked up and down the street shouting that his sister has HIV."
people that I disclosed to t the end of my life. None o	sed my status to made me feel good and gave me courage. The were also positive and they told me to keep cool as this was not f my family members know about my status."
63 Stigma Index	- James, MSM FGD

"When I disclosed my HIV status to my Imam, he went to the mosque and told the people to pray for me because I had contracted HIV." - Aminata, FSW FGD



Figure 19: Percentage of respondents receiving pressure about disclosing HIV status

Fifteen percent of respondents have been pressured by other PLHIV or PLHIV groups to disclose their HIV status and 11.4 percent have felt pressure from people who are not living with HIV to disclose their status. Key population respondents are more likely than the general PLHIV population to be pressured by others living with HIV or other PLHIV groups to disclose their HIV status. Similarly,

FSW and MSM respondents were more likely to report feeling pressure from others not living with HIV to disclose their HIV status.

	Male		Fen	Female		tal	FSW		MS	M
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Pressure from others living with HIV or from groups/networks of PLHIV to disclose HIV status										
Often	14	8.2	21	5.5	35	6.4	1	14.3	0	0.0
A few times	11	6.4	15	4.0	26	4.7	0	0.0	3	33.3
Once	9	5.3	11	2.9	20	3.6	0	0.0	0	0.0
Never	137	80.1	332	87.6	469	85.3	6	85.7	6	66.7
Total	171	100	379	100	550	100	7	100.0	9	100.0
Feel pressure fr	om others	not living	with HIV	to disclose	e your HIV	status				
Often	12	7.1	17	4.5	29	5.3	1	14.3	4	44.4
A few times	6	3.6	20	5.3	26	4.8	1	14.3	0	0.0
Once	2	1.2	5	1.3	7	1.3	0	0.0	1	11.1
Never	149	88.2	335	88.9	484	88.6	5	71.4	4	44.4
Total	169	100	377	100	546	100	7	100.0	9	100.0

Table 28: Pressure of disclosure



Figure 20: Percentage of respondents that believe health care professionals disclosed their HIV status without consent

As PLHIV rely on health services and its personnel to provide adequate treatment, care and support, it is important that PLHIV are able to trust the staff to treat their information with utmost confidentiality. Eight percent of respondents noted а health care professional has disclosed their HIV status without their consent, 62.7 percent believe that that their health care professional didn't disclose their status, while 29 percent are not sure if this has happened. Most (62.5 percent) do feel that their medical records are kept confidential.

Similarly, about a quarter of FSW report that their health care professional had disclosed their HIV status without their consent; most FSW respondents report that they do think that health care professionals disclosed their status. Half of FSW respondents report that they are sure that their records are kept confidential. Roughly two-thirds of MSM are not sure if their health care professional had disclosed their HIV status without their consent, and most MSM think that their records are not being kept confidential.

	Male		Fen	Female		Total		W	MSM	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Health care professional disclosed respondent's HIV status without your consent										
Yes	10	5.8	36	9.5	46	8.4	2	28.6	1	11.1
No	110	64.0	235	62.2	345	62.7	5	71.4	2	22.2
Not sure	52	30.2	107	28.3	159	28.9	0	0.0	6	66.7
Total	172	100	378	100	550	100	7	100.0	9	100.0
Confidence in confidentia	ality of res	pondent's	medical r	ecords						
Sure that records kept confidential	57	59.4	155	63.8	212	62.5	3	50.0	0	0.0
Don't know if records kept confidential	36	37.5	63	25.9	99	29.2	3	50.0	8	88.9
Records are not kept confidential	3	3.1	25	10.3	28	8.3	0	0.0	1	11.1
Total	96	100	243	100	339	100	6	100.0	9	100.0

The willingness to disclose HIV status may also be influenced by the reaction received upon disclosure. In general, respondents have found a supportive reaction from those that they have disclosed their HIV status; a supportive reaction (Table 30) is more frequently reported to be from other PLHIV (68.7 percent), spouses / partners (44 percent), health care workers (49.5 percent) and social workers / counsellors (60.7 percent). Male respondents tended to report more supportive reactions from groups regarding disclosure of their HIV status than the female respondents.



Some discriminatory reactions are more prevalent among women than men; women most often reported that their husbands / partners reacted discriminately (6.7 percent) than men (1.5 percent). Men however have received a more discriminatory reaction from their co-workers (5.8 percent) and clients (3 percent) than women (2.4 percent and 1.2 percent respectively). The only group for which respondents reported a more discriminatory reaction than supportive is the media; for all respondents, 10.9 percent reported discriminatory reaction and 4.3 percent reported a supportive reaction. The two most frequently reported groups to react in a discriminate manner towards respondents were their neighbours and friends (7 percent) and the media (10.9 percent).

A high proportion of FSW and MSM respondents reported receiving discriminatory reactions from health care workers, social workers / counsellors and other PLHIV. It is interesting to note that these respondents also reported high frequency of supportive reactions regarding HIV status disclosure from their employers, clients, religious and community leaders.

	Ma	ale	Female		Total		FSW		MSM	
	Number	Percent								
Discriminatory	1						1			
Your husband / wife / partner	2	1.5	22	6.7	24	5.2	1	14.3	3	33.3
Other adult family members	6	4.4	21	6.4	27	5.8	3	42.9	2	22.2
Children in your family	3	2.2	16	4.8	19	4.1	2	28.6	1	11.1
Your friends/neighbours	8	6.0	24	7.4	32	7.0	2	28.6	5	55.6
Other PLHIV	4	2.9	7	2.1	11	2.3	5	71.4	7	77.8
Your co-workers	8	5.8	8	2.4	16	3.4	1	14.3	4	44.4
Your employer	4	2.9	8	2.4	12	2.6	1	14.3	0	0.0
Your clients	4	3.0	4	1.2	8	1.7	0	0.0	0	0.0
Injecting drug partners	1	0.7	2	0.6	3	0.6	1	14.3	0	0.0
Religious leaders	1	0.7	4	1.2	5	1.1	1	14.3	0	0.0
Community leaders	3	2.2	5	1.6	8	1.8	1	14.3	1	11.1
Health care workers	2	1.5	7	2.1	9	2.0	6	85.7	8	88.9
Social workers/counsellors	1	0.7	4	1.2	5	1.1	7	100.0	6	66.7
Teachers	1	0.7	3	0.9	4	0.9	0	0.0	0	0.0
Government officials	1	0.7	2	0.6	3	0.6	0	0.0	0	0.0
The media	0	0.0	2	0.6	2	10.9	1	14.3	0	0.0

Table 30: Reactions to disclosure

Table 30 continued: R	eactions to disclosure
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	Male		Ferr	ale	То	Total		W	MSM	
	Number	Percent								
Supportive										
Your husband / wife / partner	79	58.1	126	38.2	205	44.0	3	42.9	5	55.6
Other adult family members	50	36.8	118	35.8	168	36.1	4	57.1	7	77.8
Children in your family	46	34.3	152	46.1	198	42.7	4	57.1	7	77.8
Your friends/neighbours	18	13.4	33	10.1	51	11.1	4	57.1	2	22.2
Other PLHIV	101	73.7	221	66.6	322	68.7	2	28.6	2	22.2
Your co-workers	17	12.4	19	5.8	36	7.8	6	85.7	4	44.4
Your employer	10	7.3	16	4.9	26	5.6	6	85.7	7	77.8
Your clients	15	11.1	40	12.3	55	11.9	7	100.0	9	100.0
Injecting drug partners	3	2.2	9	2.7	12	2.6	6	85.7	9	100.0
Religious leaders	14	10.4	32	9.8	46	10.0	6	85.7	9	100.0
Community leaders	9	6.7	24	7.5	33	7.2	5	71.4	8	88.9
Health care workers	62	46.3	166	50.8	228	49.5	1	14.3	1	11.1
Social workers/counsellors	83	60.6	201	60.7	284	60.7	0	0.0	3	33.3
Teachers	9	6.6	10	3.0	19	4.1	7	100.0	9	100.0
Government officials	22	16.1	36	10.9	58	12.4	7	100.0	8	88.9
The media	11	8.0	9	2.7	20	4.3	6	85.7	9	100.0







Figure 22: Percentage of respondents that found disclosure to be an empowering experience

Disclosure of one's HIV status can be seen as an empowering experience as it allows one to live openly, however respondents of this survey were divided on this experience (Table 31). Forty-two percent of respondents found disclosure to be an empowering experience while 38 percent did not. FSW and MSM respondents felt otherwise; roughly three-quarters of FSW and MSM respondents found disclosure to an empowering experience. be As mentioned above, only a small number of focus group discussion participants felt empowered or relieved in disclosing their status with others; worthy to note is that

those who felt empowered were also members of the MSM group and found encouragement from the NGO providing support to MSM.

Table 31: Disclosure as an empowering experience

	Ma	Male		Female		Total		FSW		SM
	Number	Percent								
Yes	76	46.3	149	40.6	225	42.4	5	71.4	7	77.8
No	50	30.5	150	40.9	200	37.7	2	28.6	1	11.1
Not applicable	38	23.2	68	18.5	106	20.0	0	0.0	1	11.1
Total	164	100	367	100	531	100	7	100.0	9	100.0

Treatment

Most of the respondents felt that they were in good health at the time of the questionnaire, as shown in Figure 23. Nearly all reported that they were currently taking ARVs (98 percent) and had access to ART even if they were not currently taking it (95 percent). Many also reported that they were currently taking medication to prevent or treat opportunistic infections (OI) (76 percent) and that could access OI medication (72 percent). The high percentage of respondents taking ARV could be attributed to the fact that respondents were identified via support groups and therefore would be more likely to require treatment or seek support for their health. Most respondents also noted that they have had constructive discussions with health care professionals regarding HIV related treatment options (66 percent) and regarding other topics (57 percent) such as sexual reproductive health (SRH), sexual relationships, emotional well-being and drug use. It is encouraging to note that in terms of the aforementioned aspects related to treatment, there is near parity between female and male respondents.

Among the FSW respondents, almost half reported feeling "fair" or "poor", while majority of MSM reported feeling "good", "very good" or "excellent". Roughly half of FSW respondents reported that they were currently taking ARV and OI drugs, and only half said that they had access to ARV and OI even if not currently taking it. Most FSW reported that they do not have constructive discussions with health care professionals regarding HIV related treatment, SRH,

sexual relationships, emotional well-being and drug use. All MSM reported that they were currently taking ARV drugs and could access it even if not currently taking it. Most MSM also noted that they were currently taking medication to prevent OIs and could access these drugs even if not currently taking it. Roughly two-thirds of MSM reported that they have had constructive conversations with health care professionals about HIV related treatment, SRH, sexual relationships, emotional well-being and drug use.



Figure 23: Respondents' health at the moment of the survey

	Ma	le	Ferr	nale	То	tal	FS	W	M	SM
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Health at the	e moment									
Excellent	17	9.8	25	6.3	42	7.3	0	0.0	1	11.1
Very good	45	26.0	111	27.8	156	27.2	1	14.3	2	22.2
Good	90	52.0	206	51.5	296	51.7	3	42.9	5	55.6
Fair	19	11.0	46	11.5	65	11.3	2	28.6	1	11.1
Poor	2	1.2	12	3.0	14	2.4	1	14.3	0	0.0
Total	173	100	400	100	573	100	7	100.0	9	100.0
Currently tal	king ARV									
Yes	171	99.4	388	97.5	559	98.1	4	57.1	9	100.0
No	1	0.6	10	2.5	11	1.9	3	42.9	0	0.0
Total	172	100	398	100	570	100	7	100.0	9	100.0
Access to AR	T even if n	ot current	ly taking it							
Yes	164	95.3	379	95.0	543	95.1	4	57.1	9	100.0
No	7	4.1	19	4.8	26	4.6	3	42.9	0	0.0
Don't	1	0.6	1	0.3	2	0.4	0	0.0	0	0.0
know	T	0.6	T	0.3	Z	0.4	0	0.0	0	0.0
Total	172	100	399	100	571	100	7	100.0	9	100.0
Taking medie	cation to p	revent / ti	reat Ols							
Yes	129	75.0	303	76.7	432	76.2	4	57.1	7	77.8
No	43	25.0	92	23.3	135	23.8	3	42.9	2	22.2
Total	172	100	395	100	567	100	7	100.0	9	100.0
Access to OI	medication	n, even if I	not current	ly taking i	t					
Yes	124	72.5	280	71.2	404	71.6	4	57.1	7	77.8
No	33	19.3	88	22.4	121	21.5	2	28.6	1	11.1
Don't	14	8.2	25	6.4	39	6.9	1	14.3	1	11.1
know							_			
Total	171	100	393	100	564	100	7	100.0	9	100.0
Constructive	1								-	
Yes	113	65.7	264	66.5	377	66.3	1	14.3	4	44.4
No	59	34.3	133	33.5	192	33.7	6	85.7	5	55.6
Total	172	100	397	100	569	100	7	100.0	9	100.0
Constructive		n with he	alth care	profession	al(s) on S	RH, sexual	relations	nıp(s), em	otional w	ell-being,
drug use, etc										
Yes	93	54.1	234	58.4	327	57.1	1	14.3	3	33.3
No	79	45.9	167	41.6	246	42.9	6	85.7	6	66.7
Total	172	100	401	100	573	100	7	100.0	9	100.0

Table 32: Health and treatment experience of respondents



Focus group discussions explored challenges in HIV testing and treatment that were experienced by the participants. Often times, participants expressed frustration with the CD4 machines as they were reported to be unavailable, broken or extremely backlogged. Additionally, there are countless reports of insufficient supplies and drugs in the HIV service facilities; this is a major concern for many as transport to the health facility is already a difficult and expensive task for some.



Having Children

Most respondents currently have children (93 percent) and 17 percent of those that do have HIV positive children. Since being diagnosed as HIV positive, 58 percent reported having ever received counseling on their reproductive options; however, 12 percent of respondents reported having at some point being advised by a health care professional not to have a child and 4 percent have been coerced by a health care professional to be sterilized. Twenty-two percent of respondents also noted that their ability to obtain ART is conditional on the use of certain forms of contraception.



Roughly half of FSW respondents reported having children; of those with children, one-third reported having an HIV positive child. Since being diagnosed as

Figure 24: Percentage of respondents with children who are HIV positive

HIV positive, half of the respondents reported having ever received counseling on their reproductive options, and a third of respondents reported having at some point being advised by a health care professional not to have a child. No FSW respondent reported having been coerced by a health care professional to be sterilized, but a third of respondents also noted that their ability to obtain ART is conditional on the use of certain forms of contraception.



Two-thirds of MSM respondents reported having children; of those with children, only one reported having an HIV positive child. Since being diagnosed as HIV positive, less than a quarter of the respondents reported having ever received counseling on their reproductive options, and a no MSM respondent reported having at some point being advised by a health care professional not to have a child. No MSM respondent reported having been coerced by a health care professional to be sterilized, but a third of respondents also noted that their ability to obtain ART is conditional on the use of certain forms of contraception.

	Ma	ale	Fen	nale	То	tal	FS	W	MSM	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Have a child/ch	ildren									
Yes	162	92.6	376	93.8	538	93.4	3	42.9	6	66.7
No	13	7.4	25	6.2	38	6.6	4	57.1	3	33.3
Total	175	100	401	100	576	100	7	100.0	9	100.0
If Yes, any child	ren knowi	n to be HI\	/-positive							
Yes	20	12.4	73	19.4	93	17.3	1	33.3	1	16.7
No	141	87.6	304	80.6	445	82.7	2	66.7	5	83.3
Total	161	100.0	377	100.0	538	100.0	3	100.0	6	100.0
Since being diag	gnosed as	HIV-positi	ve, have y	ou						
ever received	l counselli	ng about y	our repro	ductive op	tions					
Yes	89	51.1	237	61.2	326	58.1	4	57.1	2	22.2
No	62	35.6	114	29.5	176	31.4	3	42.9	7	77.8
Not	22	12.2	20	0.2	50	10 5	0	0.0	0	0.0
applicable	23	13.2	36	9.3	59	10.5	0	0.0	0	0.0
Total	174	100.0	387	100.0	561	100.0	7	100.0	9	100.0
been advised	by a healt	th care pro	ofessional	not to hav	e a child					
Yes	15	8.7	52	13.1	67	11.8	2	28.6	0	0.0
No	153	88.4	303	76.5	456	80.1	3	42.9	9	100.0
Not	5	2.9	41	10.4	46	8.1	2	28.6	0	0.0
applicable	5	2.9	41	10.4	40	0.1	2	20.0	0	0.0
Total	173	100.0	396	100.0	569	100.0	7	100.0	9	100.0
been coerced	l by a heal	th care pro	ofessional	into being	sterilized					
Yes	7	4.0	14	3.5	21	3.7	0	0.0	0	0.0
No	159	91.4	337	85.3	496	87.2	6	85.7	9	100.0
Not	8	4.6	44	11.1	52	9.1	1	14.3	0	0.0
applicable	0	4.0	44	11.1	52	9.1	T	14.5	0	0.0
Total	174	100.0	395	100.0	569	100.0	7	100.0	9	100.0
Ability to obtain	n antiretro	viral treat	ment con	ditional or	the use o	of certain f	orms of co	ntraceptio	on	
Yes	36	21.1	88	22.2	124	21.8	2	28.6	3	33.3
No	97	56.7	244	61.5	341	60.0	4	57.1	5	55.6
Not	17	9.9	31	7.8	48	8.5	1	14.2	1	11.1
applicable	1/	9.9	31	7.8	4ð	ð.3	1	14.3	T	11.1
I don't know	21	12.3	34	8.6	55	9.7	0	0.0	0	0.0
Total	171	100.0	397	100.0	568	100.0	7	100.0	9	100.0

Table 33: HIV and family planning options

Focus group participants expressed concern regarding their ability (or their wife's) to have children. They were concerned about the strength of the woman to undergo labor and whether the child could possibly be HIV positive or not. Interestingly, a participant expressed that his wife's pregnancy would provide him the opportunity to disclose his HIV status to his wife.



Female respondents were also asked questions specific to their health and pregnancy. Due to the respondent's HIV status, respondents reported that health care professional coerced them to terminate their pregnancy (2 percent), to select a specific birthing method (16 percent), and to use a specific infant feeding practice (27 percent). The PMTCT program in Sierra Leone started in since 2005. Although PMTCT services are free for all pregnant women in Sierra Leone, only 56 percent of respondents noted that they had received ART to prevent HIV transmission to their child and 12.5 percent of female respondents did not know about, could not access or were refused treatment. Note that 32 percent of female respondents were not HIV positive at the time of their last pregnancy. Of those that received ART for PMTCT, 88 percent were given information about healthy pregnancies and motherhood.

Similarly, FSW respondents reported that they have been coerced to terminate their pregnancy (14.3 percent), to use a specific method of birth (16.7 percent), and to use specific infant feeding practices (33.3 percent). One-third of FSW respondents reported having received ART for PMTCT; all of whom also indicated that they were given information regarding healthy pregnancies and motherhood as part of HIV PMTCT.


Table 34: Health and pregnancy

	Female		FSW		
	Number	Percent	Number	Percent	
Coerced by health care professional in relation to any of the following because of HIV status					
Termination of pregnancy					
Yes	8	2.1	1	14.3	
No	306	78.7	6	85.7	
Not applicable	75	19.3	0	0.0	
Total	389	100	7	100.0	
Method of giving birth					
Yes	61	15.9	1	16.7	
No	249	65.0	5	83.3	
Not applicable	73	19.1	0	0.0	
Total	383	100	6	100.0	
Infant feeding practices					
Yes	104	27.1	2	33.3	
No	205	53.4	4	66.7	
Not applicable	75	19.5	0	0.0	
Total	384	100	6	100.0	
Given ART to prevent mother-to-child transmission of HIV during pregnancy					
Yes - received treatment	212	55.8	2	28.6	
No - did not know treatment exist	27	7.1	2	28.6	
No - refused treatment	5	1.3	0	0.0	
No - did not access to treatment	16	4.2	1	14.3	
No - not HIV+ when pregnant	120	31.6	2	28.6	
Total	380	100	7	100.0	
If yes, were you given information about healthy pregnancy and motherhood as part of HIV PMTCT					
Yes	207	88.1	2	100.0	
No	28	11.9	0	0.0	
Total	235	100	2	100.0	

Analysis

This section summarizes key observations and inferences that can be made from the findings of the PLHIV Stigma Index and the complementary Focus Group Discussions.

PLHIV stigma and discrimination exists

This is the first comprehensive study that documents the extent and types of stigma and discrimination that exists in Sierra Leone, thus it is important to highlight that this survey provides qualitative and quantitative evidence that PLHIV experience obstacles and challenges from and within the community. This study provides evidence of the existence of stigma and discrimination in different forms and at varying degrees in the Sierra Leonean context including but not limited to loss of income, exclusion from social, religious and family gatherings as well as through threats and harassments.

Self-stigma is very high among PLHIV

This study revealed a low level of disclosure among PLHIV. Despite low reports of social exclusion (Table 6 and Figure 5), many PLHIV reported making a personal choice to isolate themselves (Table 17 and Figure 12) and felt greater personal insecurities and inferiorities (Table 16 and Figure 10). This is further supported by sentiments expressed in the focus group discussions of keeping away from social circles and making the choice to live on their own. This evidence shows that internalised stigma is high amongst the respondents, and thus amongst the general PLHIV community. Internalised stigma can result in a cascade of negative consequences on the health of PLHIV and on their care-seeking behaviours.

Fears of stigma and community reaction to HIV status is high

Respondents reported that few of them felt excluded from social gatherings, family events or religious activities (Figure 5 and Table 6), but respondents more frequently reported that they feared that this exclusion would happen to them (Figure 13 and Table 18). This suggests that there is great apprehension amongst PLHIV regarding community reaction to their status. This heightened stress and paranoia is not conducive for a healthy lifestyle or for the encouragement of health or support seeking behavior. This is interpreted as further evidence for internalised stigma.

Supportive environment is not enough to encourage disclosure of HIV status

As only 40% have reported disclosing their HIV status to non-health related members of the community (Figure 21), and the general reaction regarding disclosure is more supportive than discriminatory (Figure 24), it can be inferred that there is general fear regarding disclosure and apprehension about public reaction despite the reported supportive environment. Other factors must be explored in order to increase the comfort level of PLHIV regarding disclosure of HIV status. It must be noted that the reported supportive environment may also be a result of this environment not being aware of HIV positive people within the group.

Key populations are hidden and silent even among PLHIV network and support groups

Despite only 18 respondents identifying as an MSM, gay, lesbian or transgender, 34 respondents reported that their sexual orientation was the cause for their stigma apart from



HIV (Table 9). This supports the widely held belief that key populations are an incredibly hidden group within Sierra Leone, including in the PLHIV community. It is possible to infer that there could be more members of key populations within the PLHIV respondents of the survey, even more than those that already reported. Their reticent and hidden nature makes them more vulnerable to inability to access appropriate care and support for practices that leave them more at risk for HIV transmission and further stigma and discrimination.

Key populations are especially vulnerable due to specific stigma and discrimination related to their practices

Reports of rights abuse, inability to access care and experiences of stigma and discrimination were more frequently reported by MSM and FSW respondents than the general PLHIV group. This is evidence that they require specific interventions that will target their behaviors and practices in addition to reducing the harm and risk that they encounter through the daily challenges they face. Targeted interventions for key populations should empower them to seek legal redress for rights abuses as they are afforded human rights as with everyone in the population, therefore harassment and abuse should not be tolerated.

Health service access and quality needs improvement and consistency in delivery

Although respondents indicated having low denial of access to health services (Table 15) and only few reported lack of confidence in health workers regarding confidentiality (Table 28), participants from the Focus Group Discussions frequently brought up concerns regarding access to treatment and discrimination from health workers. This raises concerns regarding the quality of treatment that PLHIV receive in the facilities and the general confidence and competence of health workers regarding HIV, confidentiality and sensitization to stigma and discrimination. Health facilities and workers are the first and recurring line of contact for PLHIV, therefore this connection must be strengthened for quality patient care, support, and trust.

Patient confidentiality is not respected and upheld

Almost one-third of respondents reported being unsure about the confidentiality of their HIV status within the health care setting. The symbiotic relationship between the health facility and the populations is critical to the success of HIV programs. People need to feel absolute trust and confidence that should they decide to get tested, their status will be kept in complete trust and confidentiality. Disclosure or non-disclosure is an important fundamental right of PLHIV and this must be upheld. Perceptions such as these have the possibility of negatively affecting the health seeking behaviours.

Abuse of rights by authority figures pose security and health risk for PLHIV

PLHIV have reported both in the survey (Table 20) and during focus group discussions that police and health workers are not trusted and are abusing their rights, leading to matter such as illegal imprisonment and lack of access to confidential health care. Police have been reported by focus group discussion participants to take advantage of PLHIV, especially sex workers, and abuse their power to subject women to unsafe sex practices. Health workers pose a health risk to the respondents when they deny or discriminate against PLHIV which results in lack of care and treatment. PLHIV also turn to religious leaders, but instances have been shared in the discussion groups that resulted in greater stigma for the PLHIV.



Respondents report having knowledge about legal frameworks regarding HIV, stigma and discrimination (Figure 14 and Table 19), however this study clearly shows that instances of policy and law violations are taking place. Although the frameworks have been made, their enforcement and complete understanding of authority figures and PLHIV are weak. Moreover, focus group discussion participants' requests for interventions that are already in place displays the need for scaling up these interventions, increasing communication regarding their availability, and further enforcement of the laws and policies. This may empower PLHIV to demand for their rights and seek legal redress when these are violated.

PLHIV support groups and NETHIPS must be further capitalized as an entry point and communication and conduit

Survey respondents report being more likely to be aware about the HIV support groups and NETHIPS as organizations to receive support on HIV related stigma and discrimination (Figure 18 and Table 23). These existing structures should be capitalized as entry points for other organizations to ensure best contact with the PLHIV beneficiaries. Using these groups as means to disseminate valuable information and resources to PLHIV would result in faster and more efficient means of communication and delivery points.

Stronger messaging regarding HIV and pregnancies and children are needed

Concerns regarding keeping pregnancy and children safe from HIV transmission were frequently raised by survey respondents (Table 31) and Focus Group Discussion participants. Although these topics are addressed during post-test counseling and PMTCT support, there is a clear need to ensure that all PLHIV are aware of the correct information.

Discordant couples are at high risk of HIV transmission

Most respondents have reported being in a relationship and being sexually active, therefore it is critical to address topics and interventions related to discordancy. Apart from mitigating HIV transmission to the uninfected partner, fear of disclosing HIV status to the partner was often expressed by focus group discussion participants; this leads to further internalised stigma. Interventions that support PLHIV in disclosure methods would assuage any conflicts or obstacles that may arise between partners.

Needs of male sex workers have to be considered

It is interesting to note that although only one person identified as a male sex worker within the survey respondents, there were several anecdotal stories regarding male sex workers made during the focus group discussions. This group is often not addressed when discussing sex work as they are considered not to be present; this study proves otherwise.

The role of the media in the HIV response needs to be emphasized

The perception of the media by PLHIV respondents was not always positive according to the findings of this study. The media in all its forms and types have a critical role to play in the HIV response, particularly as it relates to PLHIV directed stigma and discrimination.

HIV related stigma in the workplace is prevalent

Up to 16% reported refusal of employment or work opportunity due to their HIV status. This is an important finding that needs to be addressed with targeted workplace interventions that



ensures that PLHIVs are able to fend and tap into legitimate economic opportunities as a right rather than as a privilege.

PLHIV support groups could be an entry point for targeted PLHIV interventions

83% reported being current members of PLHIV support groups or networks while up to a third of the key population groups living with HIV identified themselves as belonging to one support group or another. As these support groups have activities and meetings, they could be veritable avenues and entry points for reaching hidden key populations and other PLHIV in the general population.



As a result of the study analysis and lessons outlined above, several recommendations are proposed to address the most critical areas that can mitigate the effects and experiences related to PLHIV stigma and discrimination. A more details breakdown and suggestion of activities and responsibilities is presented in the Annex.

Strengthen psychological and social support to PLHIV from HIV facilities

The high reports of internalised stigma need to be addressed in order to mitigate further experiences of stigma and discrimination. Improving psychological support during post-test counseling and patient care during regular ARV visits can initiate this process as support for mental health in Sierra Leone is limited.

Provide informational sessions to PLHIV regarding stigma and discrimination

PLHIV are aware of stigma and discrimination, however they are not often provided with the tools to address it in their daily lives. Support and sessions on mechanisms of handling stigma and discrimination, both from their communities and themselves, are needed in order to build their capacity to demand for their rights, ensure their safety and build confidence in themselves. This could include sessions targeted towards raising their self-esteem; encourage positive living, and positive prevention.

Stigma and discrimination sensitization sessions for health workers and authority figures

Although stigma and discrimination sensitization has been done in the country, a more targeted approach is needed for health workers and people in positions of authority, such as the police. They are involved in specific types of interaction with PLHIV and key populations, and therefore the sensitization and communication that is provided to them must address this.

Stronger counseling needed for disclosure and discordant couples

Methods of disclosure with partners need to be taught to PLHIV such that they are empowered by the process and are able to find means to disclose in a safe and respectful manner. Additionally, as this infers a discordant relationship, greater support must be provided to discordant couples to ensure that HIV transmission is mitigated and that there is clear understanding about safe practices during the relationship and family planning.

Regular HIV radio program to be broadcasted

The media and civil society groups need to be at the forefront of efforts towards standing against stigma and discrimination. Innovative information, education and communication (IEC) approaches to increase awareness, dispel misconceptions and to engage and involve communities are necessary. Sensitization on general HIV information, and PLHIV stigma and discrimination is still greatly needed. An efficient means could be via regular radio broadcast shows that educate the public regarding HIV, safe sex practices and mitigation of stigma and discrimination practices.



Strengthen family planning sessions provided to HIV support groups

Although communication and resources regarding family planning can be offered in health facilities, dialogue with PLHIV and key populations is critical to ensuring that they receive the correct information about HIV and children / pregnancy. A family planning session within support groups will not only allow a conduit to share this correct information, but would also allow a forum of support as PLHIV embark on the decision to start a family.

Mainstream stigma and discrimination

In order for HIV programs and the wider health system to respond adequately to problems caused by stigma and discrimination, it is necessary to consider adding a stigma and discrimination at all levels of HIV project development. Due to the negative effects of stigma in HIV programming at different levels, all health policies and programs must consider stigma and discrimination from the planning stages all through to implementation and evaluation. As seen in the results on workplace discrimination, workplace policies needs to be inculcate and absorb HIV related interventions and activities

Further integrate and utilize PLHIV networks and support groups in interventions

Support groups are strong and confidential networks that can reach beneficiaries directly and effectively. Organizations seeking to support PLHIV and key populations must include them in programming and implementation in order to strengthen the support group's capacity and build greater trust with the beneficiaries. The frontline participation of PLHIV in the successful conduct of this study is clear evidence for greater advocacy for the increased and greater involvement of PLHIV in programs and projects that affect them

Provide training and sensitization sessions regarding legal rights of PLHIV and key populations

Sensitization campaigns need to be done to improve the awareness of PLHIV on their legal rights. Targeted groups to be trained include PLHIV, families of PLHIV, HIV support groups, health care workers and authority figures. These campaigns also need to go further and needs to be done at institutional, organisational, community and individual levels on the rights of PLHIV as guaranteed by the law.

Local evidence base needs to be strengthened through iterative research

This stigma index leads the way in providing evidence regarding HIV related stigma and discrimination and possible interventions to address these concerns. However, in order to keep abreast of progress and changes in stigma and discrimination in Sierra Leone, it will be necessary to conduct this stigma index every 3 years. This will enable programs to respond to a constant changing environment, especially due to the ever evolving nature of stigma and discrimination. Additionally, a Knowledge, Attitude and Practice (KAP) survey is suggested in order to assess how best to improve the behaviors and attitudes of health workers towards PLHIV and key populations.

Strengthen the functional capacities of PLHIV networks and support groups

A key finding of this study is that PLHIV networks are the main support networks for PLHIV when they experience situations of stigma and discrimination. PLHIV networks and their affiliate support groups need to be strengthened functionally and structurally in order to respond adequately to the responsibilities of supporting a vulnerable population. Their capacities need to be built to fulfil their roles as change agents and gate keepers.

Annex

List of Steering Committee Members

<u>Name</u> **Organization** Idrissa Songo **NETHIPS** Martin P. Ellie **NETHIPS** Patricia Ongpin UNAIDS Wole Ameyan (Dr.) SOLTHIS Sonnia Bu-Buakai Jabbie Statistics Sierra Leone Miata Jambawai AHF Nathalie Daries UNICEF **Edmond Makiu** UNICEF Umu Nabieu NAS Hudson Tucker **Dignity Association** Flora Cole VOW Semion Saffa-Turay **Christian Aid Daniel Siaffa SLANGO** Mathew M. Kanneh FDID Sylvia Deen CWI

Focus Group Discussion Guidelines

Focus Group Discussion Protocol

Target Audience: Adolescents & young adults living with HIV **Topics:** Stigma and discrimination in relation to PLHIV's

Introduction

(Statement of purpose, goals, informed consent, rapport building time.) Introduce self, observers and each other. We're doing this as part of a study investigating the issues relating to stigma against people living with HIV. Researchers from NETHIPS, and Statistics Sierra Leone, are conducting the study.

Introduce format of focus group:

We want to find out what you think about various issues relating to the stigma and discrimination PLHIV's face, so we can understand the extent and forms of stigma and discrimination faced by people living with HIV. Your participation is very important because what you say will help to improve care, support and treatment interventions as well as the participation of PLHIV in the society. We want everyone to feel free to say exactly what he or she thinks (no matter how silly or crazy it might seem). EVERYTHING you say here will be kept confidential and anonymous - no one will ever know what you personally said (only what everybody's combined responses are). Please speak up if you disagree with what's being said - we want lots of different ideas and opinions. What I'll do is begin by asking some general questions to get the discussion going, I will be writing down what you say (with no names of course! This is totally anonymous), and just in case we can't get everything down on paper we're tape recording this session. Any questions before we start?

Go to the interview guide.

Interview Guide

1. What does stigma and discrimination mean to you? -

{This will be an open ended question that sets the scene. Moderator should allow different opinions to come in while he preps up for the other questions}.

2. In what ways have you experienced stigma and discrimination?

{Moderator should allow opinions to form before using the probes. Probes should be used if certain areas of the discussion are being left out} PROBE

- What has been your experience of stigma and/or discrimination in looking for a job (employment)? Have you ever been fired or refused employment because of your HIV status?
- What has been your experience of stigma and discrimination when travelling within or outside Sierra Leone (travelling documents etc)
- Are there any differences in your experiences (living condition, health condition, employment status and life generally) before and after you became positive?

3. How did you first find out that you were positive?



- 5. What has been your experience of stigma and/or discrimination in health facilities? How have you found the attitude of health workers towards you in terms of privacy, confidentiality, friendly or unfriendly behavior?
- 6. How did you feel or what were your feelings like after having experienced some form of stigma or discrimination? {*Let them give varying reactions and give their examples in their own words*}
- 7. Have you ever tried to react or respond to stigma and/or discrimination?

PROBE

- In what ways have you tried to do this (respond to stigma)? Share an experience of a time when you reacted to perceived stigma towards you. What were the circumstances?
- 8. What has been your experience with regards to disclosure

{Please be sure to let the discussion flow and make sure to use the probes to elicit more reactions and move on the debate}

PROBE

- Probe about experiences on disclosure to wife, family members, neighbours, Pastor/Imam
- How did they react when you told them? Elicit experiences on reactions of the above people to disclosure
- What has been the reaction of other PLHIV when you tell them that you have disclosed?
- Is disclosure more difficult for women or men in relationships? What are your views on this?
- Are there any stories or experiences on disclosure without your consent? What were the consequences of this?
- Have you found disclosure empowering or not? Why?
- 9. What problems and challenges have you had in terms of testing and diagnosis, confidentiality, antiretroviral treatment and having children?
- 10. Have you suffered any abuse of your rights?
- 11. Are you aware of laws and policies that guarantee the rights of people living with HIV?

PROBES

- Which ones are you aware of? How did you become aware of this?
- What are your views on the general awareness of PLHIV of these laws and policies?
- 12. Have you suffered abuse from any persons or groups including police or law enforcement agencies? What were the circumstances?

PROBE

• Is the abuse of rights due to your HIV status? Due to your involvement with key populations?



13. What are the things that should be done to address stigma and discrimination?

PROBE

- What should the community be doing?
- What should CSOs be doing?
- What should health workers be doing?
- What should government be doing?
- What should we (as individuals) be doing?
- What type of support do you think people within this key population need to address HIV and AIDS?
- 14. What other issues would you like to raise or speak about?

End the session

End the session. Thank everyone for attending. Reiterate that everything said will be kept confidential and anonymous.



Recommended Activities and Stakeholders

Recommendation 1: Strengthen psychological and social support to PLHIV from HIV facili	ties				
Activity	Responsible				
Training and supervision of HIV counsellors on adherence and psychosocial support delivery	NACP, Solthis				
Training and supervision of support group members on psychosocial support delivery	NETHIPS, NACP				
Create pamphlets regarding FAQ for psychosocial needs and support to be distributed at service delivery areas	NACP, NAS, NETHIPS				
Recommendation 2: Provide informational sessions to PLHIV regarding stigma and discrimination					
Activity	Responsible				
Conduct and supervise support group meetings specifically targeted towards discussing stigma and discrimination	NETHIPS				
Develop and implement support group meeting manual for stigma and discrimination	NETHIPS, Solthis, UNAIDS				
Train support group leaders on meeting manual	NETHIPS				
Recommendation 3: Stigma and discrimination sensitization sessions for health workers and authority figures					
Activity	Responsible				
Annual sensitization workshops for health workers, police, armed forces, teachers, journalists, and religious leaders	NAS, NACP, NETHIPS				
Place media adverts to sensitize the public on the public health hazards of stigma and discrimination	Media, NETHIPS				
Recommendation 4: Stronger counseling needed for disclosure and discordant couples					
Activity	Responsible				
Develop national guideline on HIV-disclosure counselling for health workers, including couples counselling on disclosure	NACP, Solthis				
Training for HIV counsellors on counselling related to and disclosure	NACP, Solthis				
Conduct research on the impact of internalized stigma and disclosure and its effects on realizing and fulfilling human rights	NAS, NETHIPS, Global Fund, Solthis, UNAIDS				
Recommendation 5: Regular HIV radio program to be broadcasted					
Activity	Responsible				
Develop and implement a monthly one hour radio and television programs addressing HIV concerns and HIV related stigma and discrimination	NAS, NETHIPS				



Engage media and CSO on IEC approaches to increase awareness,	NAS, NETHIPS, Media			
dispel misconceptions on HIV and to engage and involve communities				
Recommendation 6: Further integrate and utilize PLHIV networks and support groups in i	interventions			
Activity	Responsible			
Advocate for the inclusion of PLHIV support groups and key				
populations in national and district programming and implementation				
Recommendation 7: Mainstream stigma and discrimination				
Activity	Responsible			
Advocate for the increased mainstreaming of needs and policies against stigma and discrimination related to HIV in all HIV related public policies and strategies	NACP, NAS, NETHIPS, Solthis, UNAIDS			
Update, review and implement Sierra Leone Work Place Policy on HIV/AIDS	NAS, Minister of Labour, Social Security and Industrial Relations			
Include indicators to capture HIV-related stigma and discrimination as part of the national AIDS response M & E systems to monitor and evaluate progress over time	MoHS, NAS, UNAIDS			
Recommendation 8: Mainstream stigma and discrimination				
Activity	Responsible			
Advocate for the increased mainstreaming of needs and policies against stigma and discrimination related to HIV in all HIV related public policies and strategies	NACP, NAS, NETHIPS, Solthis, UNAIDS			
Update, review and implement Sierra Leone Work Place Policy on HIV/AIDS	NAS, Minister of Labour, Social Security and Industrial Relations			
Recommendation 9: Further integrate, utilize and strengthen the functional capacities of PLHIV networks and support groups				
Activity	Responsible			
Trainings for NETHIPS on leadership, coordination, management, advocacy, resource mobilization, capacity building, human rights, treatment education to enhance their participation in decision making processes.	Solthis, UNAIDS			
Trainings and workshops on relevant topics for support group members and leaders (management and leadership, counselling, adherence, rights, positive living, referral, basic HIV, side effects)	Solthis, UNAIDS			
Continued advocacy for the increased involvement of NETHIPS in the planning, implementation, monitoring and evaluation of the national HIV program	NETHIPS, NACP, Solthis, NAS, UNAIDS			



Recommendation 10: Provide training and sensitization sessions regarding legal rights of PLHIVs and key populations				
Activity	Responsible			
Bi-annual sensitization workshops for PLHIV and other stakeholders like families of PLHIV, HIV support groups, health care workers, authority figures, and key populations on legal rights and responsibilities of and regarding PLHIV	NAS, NETHIPS,			
Recommendation 11:				
Local evidence base needs to be strengthened through iterative research				
Activity	Responsible			
Improve linkage between M&E department of the national HIV program and M&E of NETHIPS	NAS, NETHIPS, UNAIDS			
Conduct the national Stigma Index in Sierra Leone every 3 years	NETHIPS, UNAIDS			
Conduct KAP among health care workers regarding behaviours and attitudes towards PLHIV and key populations on a biannual basis	NACP, NAS			

ⁱ It is recognized that respondents provided multiple responses to this question rather than the one requested. The data has therefore been displayed as received due to lack of clarity of priority response.

ⁱⁱ Respondents who replied "no" to previous question within the general PLHIV group were mistakenly categorized by enumerators as "no" for this question as well. This error has been adjusted in analysis and this table presentation.

ⁱⁱⁱ Some respondents who were unsure whether their rights as a PLHIV were abused in the past 12 months also sought legal redress