

LIBERIA PLHIV STIGMA INDEX REPORT



THE PEOPLE LIVING WITH HIV STIGMA INDEX

Liberia

November 2013



LIBNEP+



**National
AIDS
Commission**



Liberia



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Acronyms

ANC	Antenatal Care
ART	Antiretroviral Therapy
EPP	Estimates Projection Package
FGD	Focus Group Discussion
GNP+	Global Network of People Living with HIV and AIDS
HIV	Human Immune Virus
ICW	International Community of Women Living with HIV and AIDS
IPPF	International Plan Parenthood Federation
LDHS	Liberia Demographic Health Survey
LIBNEP+	Liberia Network of People Living with HIV
LISGIS	Liberia Institute for Statistics and Geo-Information Services
MSM	Men who have sex with men
NAC	National AIDS Commission
NACP	National AIDS Control Program
PLHIV	People Living with Human Immune Virus
PMTCT	Prevention of Mother to Child Transmission
UL-PIRE	University of Liberia – Pacific Institute for Research and Evaluation
UNAIDS	United Nations Joint Program on HIV and AIDS
UNICEF	United Nations International Children Endowment Fund

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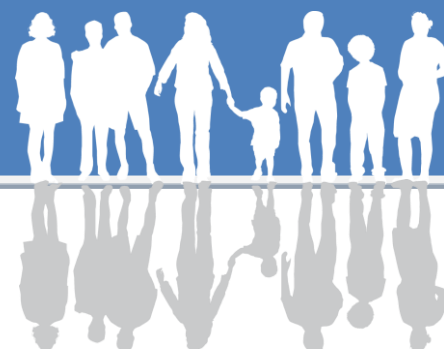
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Executive Summary

PLHIV Stigma Index is a tool that measures and detects changing trends in relation to stigma and discrimination as experienced by people living with HIV. It is a joint initiative involving the Global Network of People Living with HIV and AIDS (GNP+), the International Community of Women Living with HIV and AIDS (ICW), the International Planned Parenthood Federation (IPPF) and UNAIDS. The Index is an empowering research tool for developing evidence-based advocacy by and for people living HIV. In the Liberian context, this stigma index is an eye opener for all partners in the national response especially the Liberia Network of People Living with HIV (LIBNEP+) and National AIDS Commission. As the first Stigma Index study in Liberia, it provided learning opportunity and enriched participating agencies with key experiences and lessons.

According to the Liberia Demographic and Health Survey (LDHS 2007), a composite indicator on stigma towards HIV positive people shows that only 13% of women and 22% of men expressed accepting attitudes toward persons living with HIV. This composite indicator is somewhat higher among women and men with secondary education and among those in the higher wealth quintiles. It is also higher in urban than rural areas, especially among men. A study to identify the drivers and context in which HIV-related stigma and discrimination occurs in Liberia is important in designing and implementing effective programs and targeting HIV prevention and control, hence this PLHIV stigma index study.

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

The specific objectives of the stigma index project are to:

- Document the various experiences of PLHIV within their communities regarding HIV-related stigma and discrimination on an individual level, family level, community level, and national level;
- Measure changes over a period of time as they relate to changing attitudes;
- Generate an evidence base on HIV-related stigma for policy change and programmatic interventions;
- Increase the evidence base for policies and programs to reduce HIV-related stigma and discrimination and
- Ensure that the greater involvement of people living with HIV and AIDS is enshrined in global, regional and national HIV responses.

Methodology

The Liberia roll-out of the stigma index was based on the methodology developed by the People Living with HIV Stigma Index project. The study targeted people living with HIV in the country. The minimum age requirement for participation was 18 years. Five hundred and thirty (530) persons responded to interview questions in the following categories: 500 PLHIV were interviewed using the adapted questionnaire developed by the stigma index project. However, the data cleaning process found 483 respondents composed of 361 female and 122 males to contain usable data. Most of the respondents (over 50%), on account of knowledge of their status, have lived with HIV from 1 to 4 years, followed by those who lived with the virus from 5 to 9 years (28%). Twenty (20) persons participated in focus group discussion and 10 persons took part in the key informant interview. Discussants and participants of focus group discussion and key informant interview were mixture of PLHIV and staff of partners within the national response. Participants in the study were selected based on regional proportion of PLHIV in the country.

Table 1: Number of respondents by sex and age group

Age group	Male	% of male	Female	% of female	Transgender	% of transgender	Total	% total
Youth aged 18-19 ¹	1	0.82%	12	3.32%	0	0%	13	3%
Adult aged 20-24 years	8	6.56%	49	13.57%	0	0%	57	12%
Adult aged 25-29 years	18	14.75%	85	23.55%	0	0%	103	21%
Adult aged 30-39 years	40	32.79%	128	35.46%	0	0%	168	35%
Adult aged 40-49 years	47	38.52%	77	21.33%	0	0%	124	26%
Adult 50+ years	8	6.56%	10	2.77%	0	0%	18	4%
Total	122	100.00%	361	100.00%	0	0%	483	100%

Key Findings

Most of the respondents representing 80% on average have never experienced stigma and discrimination from other people. However 29.81% of them said they were verbally insulted, 21% has been physically assaulted, 20% subjected to psychological pressure of manipulation by sexual partners and 48% said they were aware of being gossiped about. Interestingly 28 (representing 5%) respondents have indicated that they have experience stigma and discrimination from other PLHIV. Responses are shown in the table below.

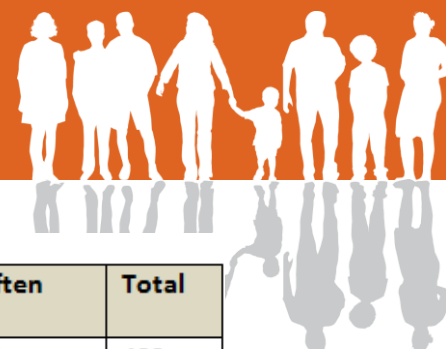


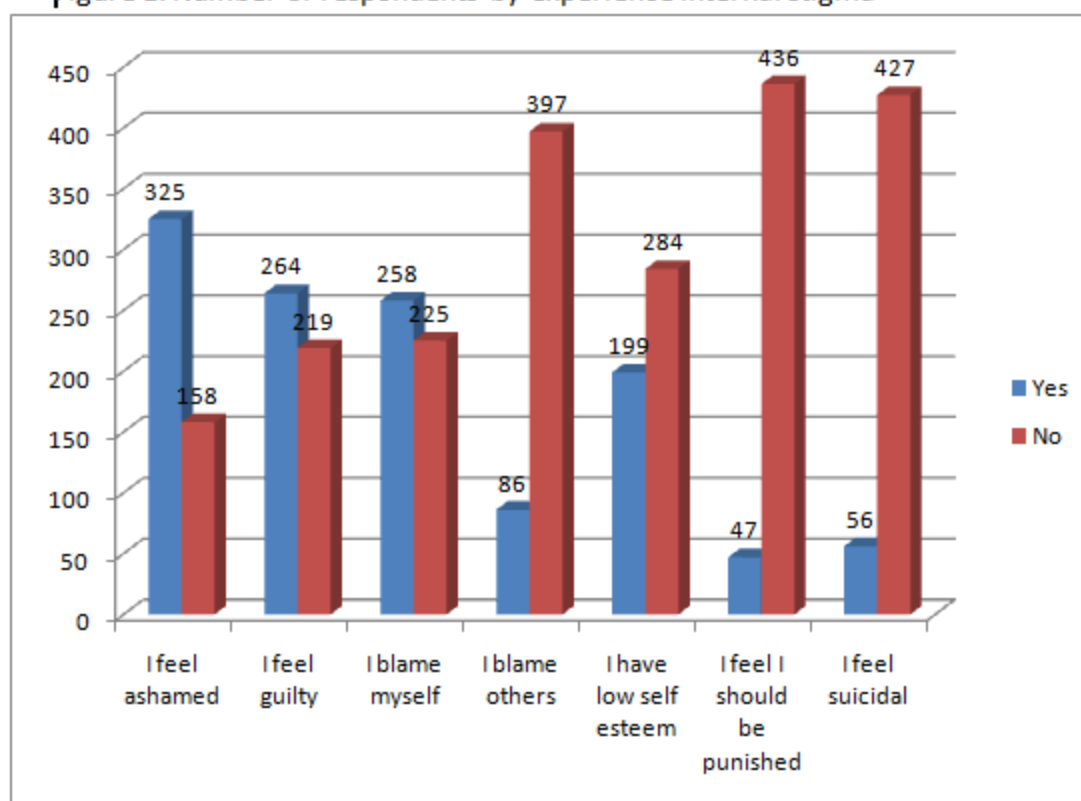
Table 2: Number of respondents by experience of external stigma

Type of stigma and discrimination	Never	Once	A few times	Often	Total
Excluded from social gathering	416	22	27	18	483
Excluded from religious activities/place of worship	448	14	14	7	483
Excluded from families activities	405	30	25	23	483
Aware of being gossiped about	252	52	89	90	483
Verbally insulted	329	72	48	34	483
Physically harassed/threatened	402	42	21	18	483
Physically assaulted	381	56	28	18	483
Subjected to psychological pressure of manipulation by partner	386	52	23	22	483
Experienced sexual rejection	398	35	26	24	483
Discriminated against by PLHIV	455	13	12	3	483
Other in household experience stigma/discrimination	390	42	34	17	483

- i. Twenty-six percent of respondents identified the reason for stigma and discrimination, to be fear of people for getting infected by them. Another 27% believes that those who stigmatize them do not understanding the modes of HIV transmission. 11% of respondents noted that “people feel being HIV infected is shameful so they do not want to associate with people living with HIV”.
- ii. About 22% of respondents said they were forced to change residence due to their HIV status; 12% of them have lost their jobs or other sources of income because of HIV status, while 6% experienced change of job description or refused promotion because of their HIV status. Approximately 7% said they were dismissed, prevented or suspended from attending educational institution because of HIV status; whereas 2% reported that their children were thrown out of school on account of HIV related stigma and discrimination against members of their family. Over 6% of respondents asserted that they have been denied health or dental service due to their HIV status.
- iii. Internal stigma seemed to be the most common type of stigma experienced by respondents. There were 67% of respondents who feel ashamed of themselves because their HIV status is known to others. Fifty-five percent (55%) of respondents feel guilty for being HIV positive regardless of the HIV mode of transmission. Additionally, 53% of respondents blame

themselves for being HIV positive, while 41% felt that they experience low self-esteem because of their HIV status. Areas of lower but significant prevalence were the questions of isolation, suicidal ideation and deserving punishment. Eighteen percent (18%) of them reported isolating themselves from family and friends, 12% have felt suicidal and 10% have felt that they deserved to be punished.

Figure 1: Number of respondents by experience internal stigma



iv. The results indicate that some PLHIV take discriminatory actions against themselves. Of the total number of 483 respondents, 94 persons representing 19% said that they have chosen not to attend social gathering(s) and not to have sex. Eighty-nine persons accounting for 18% reported that they have isolated themselves from family and/or friends, as well as not to get married. More than half of the respondents (250 persons/52%) said they have decided not to bear child(ren) as a result of their condition.

v. There was an attempt to dichotomize between just hearing of the existence of laws and policies and being able to read and discuss the contents of the



laws in order to make maximum use of one's rights under such laws. United Nations Declaration of Commitment on HIV and AIDS of April 2001 has been heard of by 61% of respondents but only 28% read or discussed its contents. Various countries have their HIV laws and policies recorded on international network. Liberia's HIV and AIDS law commonly referred to as the 'Model Law' has been read or discussed by 141 out of 483 respondents.

- vi. Respondents' ability to effect change was followed. This is whether or not they confronted or educated someone who tried to stigmatize or discriminate against them. Their knowledge of the existence of organizations or support groups that could defend them in case of stigma and discrimination was also assessed. The results show that not many PLHIV muster the courage to confront, challenge or educate those who stigmatize or discriminate against them. Of the number that responded to this inquiry (483 persons), only 174 asserted that they have taken steps to change the attitude of people who stigmatize or discriminate against them.
- vii. In the face of stigma and discrimination, PLHIV reserve the right to choice in determining where to seek redress. Organization such as support groups, PLHIV associations and network, legal and human rights platforms, faith-based organizations and the National AIDS Commission have responsibility to support PLHIV when they are stigmatized and discriminated against. The extent to which individual PLHIV uses the services of these organizations was followed during the study. Many of the respondents declared that they have knowledge of organizations from whom to seek help in case of such experience. Three hundred and fifty-eight individuals corresponding to 74% mentioned PLHIV support groups as their source of redress or refuge. Eighty-seven respondents accounting for 18% named PLHIV network (LIBNEP+) as an organization they could seek help from when confronted with issue of stigma and discrimination. Faith-based organizations including churches, mosques and non-governmental organizations are other organizations some claimed to seek help from when needed.
- viii. Approximately 134 respondents, representing 28%, have said that they were tested due to suspected HIV related symptoms. Another 24% has said that test was done upon the illness or death of spouse, while 14% was tested during antenatal care.

- ix. Contrary to the principle of confidentiality, PLHIV get disappointed when their status gets known to people within their community or place of work. Breach of confidentiality was also assessed in the experiences of respondents. Interestingly, 15% of respondents have said that they were aware their status was revealed by social workers and medical practitioners. It was also interesting to know whether participants were aware of their medical records being kept confidential. Fifty-five percent (55%) of respondents believed that their medical records are kept confidential. 35% had a contrary view that their records were not confidentially kept while 10% was not sure if their medical records are kept in confidence. About 61% of respondents said they find the disclosure of their HIV status as an empowering experience. Twenty-three percent (23%) did not think that the disclosure of their status empowers them in any way. Fourteen percent (14%) do not feel that disclosure of HIV status has any bearing on their lives.
- x. Most PLHIV respondents (89%) have asserted that they are taking antiretroviral treatment. 86% has said that they are taking medication against opportunistic infections. These responses are similar to those given by respondents who described the health as good, very good or excellent. However, the data shows that access to opportunistic infection treatment was a challenge to 15% of respondents.
- xi. The survey shows that 86% have children as opposed to 14% that did not have children. Only 21% has released their HIV status to their children. Post diagnostic reproductive health counselling is an issue of interest in the PLHIV stigma index roll out. Sixty-five percent (65%) of respondents have said they have received reproductive health counselling since they were diagnosed. Nineteen percent (19%) said they have been advised not to have children; while 14% have admitted of being coerced by health professionals to be sterilized. Seventeen percent (17%) declared that they can only obtain antiretroviral treatment when they agree to use suggested contraceptive(s).
- xii. Approximately 156 women representing 43% of total female participants in the study have said that they have received PMTCT. However, 35% said they gave birth to their children before being diagnosed of HIV.

In view of the findings the following recommendations were made:



1. Implementing the establishment of an empowerment scheme for PLHIV. This could include academic program and vocational training, business, etc. depending on individual need and context.
2. Re-strategize awareness raising methodologies to enhance knowledge of the general population on the nature of HIV, particularly on the mode of transmission and the need to support and care for people living with and affected by HIV/AIDS. Many people still seem apprehensive about HIV and appear not to understand the mode of transmission for which they fear getting infected through casual contact. This could involve specifically including HIV in school curriculum, working with religious leaders, working with families, etc.
3. Build the capacity of PLHIV over time to enable them take initiatives on their own and breach the capacity gaps prevalent among PLHIV. This should be done through a diversified approach that will recognize all sectors of the PLHIV population. It could be through mentorship, apprenticeship, skills training, professional placement, etc.
4. Provide supplementary feeding to PLHIV on treatment to enable them cope with the strength of the medication and encourage them follow the treatment procedure.
5. Provide supplementary feeding, incentive and support to HIV+ mothers and their babies during pregnancy and continue support for the child until completion of primary education.
6. Encourage and support PLHIV into the medical field so that they can be actively involved in the provision of care and support to colleagues.
7. Actively involve PLHIV to the extent possible and necessary in all activities affecting them for ownership and sustainability.
8. Expand testing and treatment centers to more locations across the country to increase access to as many PLHIV as possible, particularly in the rural areas.
9. Seek means to improve the current types of ART to reduce the side effects of the medication which may be a contributing factor for loss to follow-up and the failure to follow treatment procedure.

10. Increase the number of CD4 count machines around the country to enable people know their status level and make some key decisions in their lives such as bearing of children.
11. Reduce the HIV Law into simple English and disseminate it. Put in place a program to educate PLHIV on key documents that protect their rights.
12. Provide continuous training for health care providers and social workers on how to care for and support PLHIV, including respecting the principle of confidentiality.
13. Advocate for the rights of PLHIV through their network, civil society organizations and government institutions such as NAC and NACP. This should also be a part of the empowerment process for PLHIV to enable them advocate for themselves rather than people continuously advocating for them.
14. Establish a complaint and response mechanism to get information from and provide feedback to PLHIV on services provided to them. This will help improve the way people work with them through their involvement and participation in issues that affect them.



1.0 INTRODUCTION

1.1 Background

HIV-related stigma and discrimination is pervasive in all regions of the world and a major factor that fuel the transmission of HIV infection. Stigma and discrimination occurs in varied contexts and represents major challenges faced by countries in their national HIV responses.

Fear of becoming victims of stigma and discrimination can adversely affect people's willingness to be tested and engage in safe sex practices. Anecdotal evidence shows that stigma and discrimination against PLHIV is prominent even among the health care providers, preventing PLHIV from seeking care and treatment at health facilities. This results in a significant number of patients not adhering to the antiviral therapy and being lost to follow up for further interventions.

PLHIV Stigma Index is a tool that measures and detects changing trends in relation to stigma and discrimination as experienced by people living with HIV. It is a joint initiative involving the Global Network of People Living with HIV and AIDS (GNP+), the International Community of Women Living with HIV and AIDS (ICW), the International Planned Parenthood Federation (IPPF) and UNAIDS. The Index is an empowering research tool for developing evidence-based advocacy by and for people living HIV.

The results of the 2008 Population and Housing Census indicate that Liberia has a population of approximately 3.5 million¹. Liberia, with an annual growth rate of 2.1%, has a young population. The population aged 5-14 years is frequently referred to as a "window of hope", and will require concerted effort to ensure that they remain uninfected. 2008 National Population and Housing Census results document that young people aged 5-14 years account for 26.7% of the population while the proportion of the population aged 15-19 years is about 10.8%.

According to the Liberia Demographic and Health Survey (LDHS 2007), a composite indicator on stigma towards HIV positive people showed that only 13% of women and 22% of men expressed accepting attitudes toward persons living with HIV. This composite indicator is somewhat higher among women and men with secondary education and among those in the higher wealth quintiles. It is also higher in urban than rural areas, especially among men. A study to identify the drivers and context in which HIV related stigma and discrimination occurs in Liberia is important in designing and implementing effective programs and targeting HIV prevention and control.

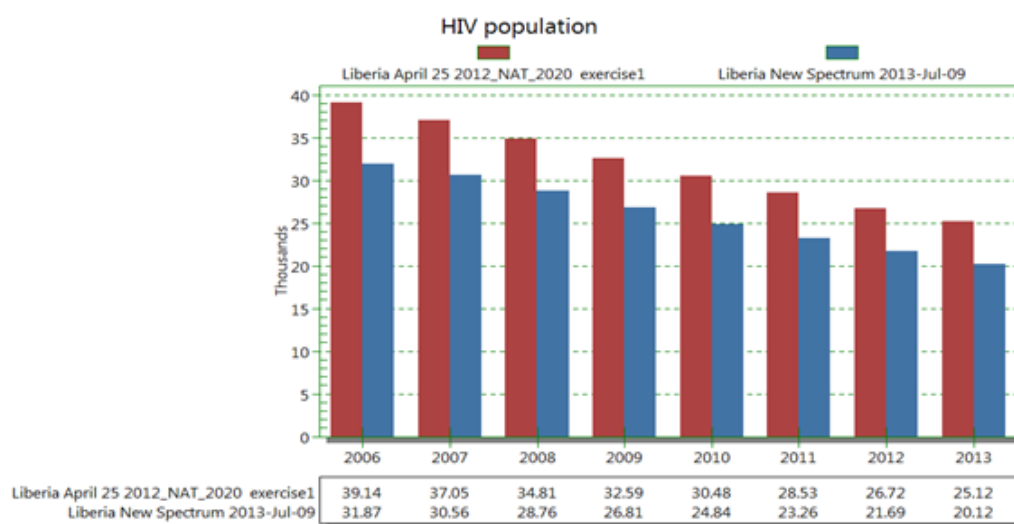
¹ Population and Housing Census, 2008

1.2 HIV and AIDS in Liberia

The first case of HIV in Liberia was diagnosed in 1986. Since then HIV has spread to all parts of the country and into all strata of society. The prevalence is higher in women than men and in urban areas than in rural areas. The most recent report on HIV prevalence among the general population shows a prevalence rate of 1.5%² among persons aged 15–49 years, indicating a low-level, generalized epidemic. It also revealed significant differences between urban and rural settings, with the primary urban area, Monrovia, exhibiting rates of between 2.5% and 2.9% and rural areas having rates of 0.8%.

There is anecdotal evidence that HIV prevalence is higher than the national average among sex workers, men who have sex with men (MSM), injecting drug users, and persons in incarceration. Socio-economic and cultural practices and the resulting gender inequalities are among the major drivers of the epidemic. Data from the Estimates and Projection Package and Spectrum (EPP/Spectrum) model indicate more than 90,000 AIDS-related deaths have occurred since the epidemic started³. Liberia's spectrum projection (July 2013) estimates 20,120 people living with the virus, indicating 20% decrease compare to April 2012 projection. The projection package also puts estimate people needing ART at 13,740, representing 69% of adults living with HIV in Liberia⁴.

Figure 2: HIV projection in Liberia



Though substantial gains have been made in the national response to HIV & AIDS, the epidemic remains a major developmental challenge in Liberia. This is predicated

² 2007 LDHS and Analytic Summary on Liberia published by African Health Observatory and World Health Organization

³ Midterm Review of the National Response, 2013

⁴ EPP/Spectrum, 2013



on many factors, including stigma and discrimination, demographic movements, high illiteracy rate, and some socio-economic factors like poverty, unemployment, etc.

1.3 Stigma and Discrimination

People living with HIV often face stigma and discrimination. Many do not know what their rights are and how they can help to change things for the better. There are a number of organizations that are campaigning against stigma and discrimination and fighting for improved rights for people living with HIV. This initiative started since 2005.

HIV-related stigma and discrimination undermines HIV prevention efforts by making people afraid to seek out information about how to reduce their risk of exposure to HIV and to adapt safer behaviour, in case this inquiry raises suspicion about their HIV status. Fear of stigma and discrimination does not only discourage PLHIV from disclosing their status even to family members and sexual partners but also undermines their ability to adhere to treatment. In Botswana, a survey of patients receiving ART found 40 percent delay getting tested for HIV, mostly due to stigma⁵. Thus stigma and discrimination weaken the ability of individuals and communities to protect themselves from HIV and to stay healthy if HIV positive.

Moreover, stigma and discrimination affect men and women differently. Women and girls in many countries face discrimination that makes them more vulnerable to HIV. HIV-related stigma and discrimination also affect children and young people in specific ways⁶. In some settings, orphaned or abandoned children of HIV positive mothers are placed in specialized orphanages for HIV positive children, segregated from the outside world. In addition, some educational institutions may refuse to accept a child who is HIV positive or whose parents are HIV positive.

Stigma is the most severe deterrent to utilization of ART services in Liberia. Whilst many people are frightened and fearful of having an HIV test, most PLHIV on treatment are horrified, scared, and shamed by the stigma they endure on a daily basis from family and friends who should love and support them. In the community and workplace, fear of loss of respect and dignity from colleagues and health care providers (despite oath to privacy and confidentiality of information about patients) continues to incessantly weaken the determination of ordinary people and PLHIV to seek counsel and treatment, thus worsening their condition. Trust is evaded as service providers leak private information with impunity. By and large, the very programs designed to care for, treat, and support PLHIV remain vertical and un-integrated into routine health care and other social protection services. The scourge of stigma against PLHIV must therefore be exorcised by all, through accepting attitudes and respect; empathy and understanding; and ensuring support and empowerment of PLHIV. Some, including PLHIV, believe stigma is reducing, albeit slowly. Many PLHIV

⁵ Wolfe, W., et al. (2006), *Effects of HIV-related stigma among an early sample of patients receiving antiretroviral therapy in Botswana*. AIDS Care, 2006. 18(8): p. 931-933

⁶ UNAIDS(2010) *Non-discrimination in HIV responses*, 26th Meeting of UNAIDS programme Coordinating Board

testify to and some non-HIV infected people recount witnessing the pain and suffering endured by people infected and affected by HIV and AIDS as a result of stigmatization. These have made it difficult for patients to adhere to treatment and some even drop out completely!⁷

1.4 LIBNEP+

The Government of Liberia along with its partners has been making significant efforts in the fight against HIV. The Government has participated in a number of international conferences and become a signatory to many international instruments that seek the protection and promotion of the rights of people living with HIV, as well as to counter the spread of the virus. Predicated upon these desires the Government formulated two institutions, the National AIDS Control Program (NACP) and the National AIDS Commission (NAC), to foster the wellbeing of people living with, and affected by HIV. Further, the Government of Liberia in 2010 amended the Public Health Law of 1976, Title 33, Liberian Code of Laws Revised to create a new Chapter 18 providing for the “Control of Human Immunodeficiency Syndrome (AIDS). This new law, among other things, prohibits discrimination and vilification on the basis of actual or perceived HIV status. Additionally, a study was commissioned by UNAIDS-Liberia in partnership with the National AIDS Commission (NAC) and the Global Fund on HIV AND AIDS, Tuberculosis and Malaria (GFATM) to assess the capacity needs of PLHIV associations and support groups that gave birth to LIBNEP+, an umbrella organization for PLHIV that coordinates their activities, represents their interests and advocates for their common good. Liberia Network of Positive People (LIBNEP+) was established in 2011. LIBNEP+ presently has five PLHIV associations in its membership.

LIBNEP+ played a significant role in the conduct of this stigma index. The network chaired the steering committee for the implementation of the study, and coordinated key aspects including recruitment of data collectors and data entry clerks. The network collaborated with other partners in developing the study work plan and budget.

1.5 The PLHIV Stigma Index

The Stigma Index was developed to collect information on stigma, discrimination and rights of people living with HIV to help in advocacy efforts. It is a project that has been developed and implemented by and for people living with HIV. It aims to collect information on the experiences of people living with HIV related to stigma, discrimination and their rights. The information obtained will enable documentation of various experiences of people living with HIV within a particular community or country regarding HIV related stigma and discrimination; comparison in country and between countries, measure change over time and will inform programming and

⁷Midterm Review of the National Response, 2013



policy change. The People Living with HIV Stigma Index is a joint initiative of the Global Network of People Living with HIV and AIDS (GNP+); the International Community of Women Living with HIV and AIDS (ICW); the International Plan Parenthood Federation (IPPF); and the Joint United Nations Program on HIV and AIDS (UNAIDS).

1.6 Objective

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

The specific objectives of the stigma index project are to:

- Document the various experiences of PLHIV within their communities regarding HIV-related stigma and discrimination on an individual level, family level, community level, and national level;
- Measure changes over a period of time as they relate to changing attitudes;
- Generate an evidence base on HIV-related stigma for policy change and programmatic interventions;
- Increase the evidence base for policies and programs to reduce HIV-related stigma and discrimination and
- Ensure that the greater involvement of people living with HIV and AIDS is enshrined in global, regional and national HIV responses.

2.0 METHODOLOGY

2.1 The study design

The Liberia Stigma Index Rollout Study was conducted in a participatory manner with PLHIV highly involved throughout the entire process. Their umbrella organization, LIBNEP+ was at the centre of the study, with technical support from NAC, UNAIDS, the consultant institution and other partners. The interviewers, interviewees and data entry clerks were PLHIV identified and recruited by LIBNEP+.

The study is a part of global efforts to establish a baseline for the extent of stigma and discrimination in countries around the world. The idea was borne and crafted by four major global forerunners in the fight against HIV/AIDS: GNP+, IPPF, UNAIDS and ICW. As an integral part of these efforts, the study is a rollout of the PLHIV stigma index documents that were designed as the principal tools for the conduct of this study around the world. Accordingly, the design for this study is a blend of formal research and the HIV stigma rollout template so as to maintain some level of consistency in the rollouts around the world while at the same time applying basic concepts and principles of general formal research.

The study employed three methods of data collections including questionnaire, focus group discussion (FGD) and key informant interview (KII) so as to triangulate the process. The questionnaire, though quantitative for the most part, contained some open ended questions in the problem and challenges section that gave respondents the opportunity to freely express themselves on the subject matter in question.

Twenty (20) PLHIV were recruited as interviewers by LIBNEP+. These interviewers were trained in data collection techniques and interview skills. The data was collected from five regions of the country, with the data collectors being recruited and resident in these regions. The data was collected from 530 persons in the following categories: 500 for questionnaire, 20 for the focus group discussion and 10 for key informant interview. The data collection lasted for 15 days using the questionnaire, followed by a separate one week for the focus group discussion and key informant interview.

Data from the questionnaire was entered into a database using the EPI Info data analysis software for analysis while the data from the focus group discussion and the key informant interview was analyzed manually. Four trained data entry clerks were used to enter the data.

2.2 Ethical Considerations

The issue of ethical consideration was treated with due diligence. Deliberate efforts were made to target participants of legal age that can provide informed consent. Each interviewee was made to provide and sign an informed consent form before going into the interview to ensure that he/she voluntarily participated in the process. All



members of the research team were made to sign a confidentiality form for the protection of respondents' information. Access to the informed consent and interviewees' contact list was limited to the interviewers and team leader, with the interviewers' access actually ending to the point of delivery to the team leader. The data collected were kept in locked cabinet, with the informed consent and interviewees' contact list kept separately from the rest of the data. Moreover, the questionnaires bear a 14-digit code for the interviewees and carry **NO NAME** of the interviewees. In addition, ethical clearance was sought from UL-PIRE through an Ethical Review Committee.

2.3 The study population

The study targets people living with HIV in the country. The minimum age requirement for participation was 18 years. Five hundred and thirty (530) persons responded to interview questions in the following categories: 500 for the questionnaire, 20 for the focus group discussion and 10 for key informant interview.

2.4 Sampling Frame and Sample Size

Table 3: Number of PLHIV seeking treatment at treatment centers

COUNTY	ON AND NOT ON ART					ON ART				
	Children	Male > 14 yrs	Female >= 15 yrs	Pregnant females	Total	Children	Male > 14 yrs	Female > 15 yrs	Pregnant females	Total
Bomi	23	18	61	18	120	1	11	46	11	69
Bong	35	29	108	14	186	7	24	61	2	94
Gbarpolu	16	20	0	2	38	2	1	6	2	11
Grand Bassa	33	53	142	8	236	30	59	186	6	281
Cape Mount	3	12	37	0	52	2	7	17	0	26
G.Gedeh	71	43	315	27	456	13	62	218	2	295
Grand Kru	1	9	18	0	28	0	1	6	0	7
Lofa	68	61	237	31	397	19	45	133	4	201
Margibi	26	84	257	6	373	16	106	132	2	256
Maryland	55	59	191	14	319	10	36	108	3	157
Montserrado	688	1479	3208	249	5624	281	1149	2100	78	3608
Nimba	108	120	416	49	693	20	74	238	8	340
River Gee	92	107	21	13	233	28	19	6	9	62
Rivercess	0	10	13	2	25	0	6	5	1	12
Sinoe	8	20	66	1	95	1	18	40	0	59
Grand Total	1227	2124	5090	434	8875	430	1618	3302	128	5478

Legend: Region 1: green ; Region 2: red; Region 3: yellow; Region 4: purple; Region 5: blue

The PLHIV population as per Spectrum projection for 2013 is 25, 120. This figure is inclusive of children and youths below the age of 18 years and do not qualify for the study as per the age criteria. The figure was therefore less by the number of children

and youths below the age of 18 years (8,441) using the NACP data for PLHIV seeking treatment across the various treatment centers around the country. This brought the sample frame to 16, 679. Applying the recommended 3% of the PLHIV population for the sample size according to the HIV-related stigma index rollout study guide, we derived at 500 as the sample size for the study.

The country was divided into five regions as they exist under the decentralization approach used by LIBNEP+ and partners, and data was collected from each of these regions proportionate to the number of PLHIV within the area. Efforts were made to make the sample size representative of the disaggregated PLHIV population throughout the country.

2.5 Limitations of the study

The study was challenged by several limitations occasioned by its peculiar nature that made it a little bit distinct from conventional research. It was made by and for a special population, the PLHIV. Some of these include:

1. The questionnaire: a tailor-made questionnaire which is not to be changed or adapted by country rollout team thereby making it difficult to amend the tool to reflect country context.
2. Question structure: the structuring of some of the questions that made it difficult to get the full understanding of them. For example, the question on sex that includes transgender and the one on the association with setting groups/association, as well as length of stay with the virus.
3. The age category: the questionnaire contains an age grouping that includes ages below 18, which in many countries including Liberia is not of legal age and do not provide informed consent (except through their parents or guardians) which is required before such an interview is conducted.
4. The design of this study leaves out those people living with HIV who do not know their status; even if they know their diagnosis, they may not openly live with HIV.

2.6 Data Collection Methods/Tools

The data collection method was triangulated using the questionnaire, focus group discussion and key informant interview. The questionnaire used was developed by GNP+, IFPP, ICW and UNAIDS, specifically designed to be used for the conduct of the rollout study. The questionnaires were administered through a face-to-face means where the interviewer sits side by side with the interviewee to ask the questions. The focus group discussion and key informant interviews were held using semi-structured questions and in a privately conducive environment respecting the principle of respect and confidentiality.



2.7 Data Collection

The data was collected by PLHIV recruited by LIBNEP+. Twenty (20) data collectors from the five regions were recruited and trained in the administration of the questionnaire and the conduct of the focus group discussion and key informant interview including the content of the questionnaire, basic interview skills and the procedure to follow during the data collection process. The training of data collectors lasted for three days while the data collection on the field lasted for fifteen (15) days. The questionnaires were administered between the 10th and the 27th of May 2013.

2.8 Data Cleaning and Validation

This procedure involved a tedious process of checking hard copy of completed questionnaires against records in the database to ensure data accuracy and integrity. This was followed by re-entry process that complemented the preceding process. At the end of the data cleaning process, 483 corresponding to 96.6 % of the completed questionnaires were judged to contain usable data for analysis while the remaining 17 completed questionnaires representing 3.4% were rejected on the basis of not containing usable data. It is worth noting here that though 483 completed questionnaires were found useful, the number of persons who responded to the questions may vary from question to question as interviewees had the choice to decline answering any of the question coupled with the fact that some questions were not actually applicable to certain people.

2.9 Data Analysis

The data was analyzed using the recommended data analysis software for the stigma index rollout study, the EPI Info. As a descriptive study, the data was analyzed using simple data analysis techniques or statistics, particularly tables, listing and frequencies, with confidence level of 95%. The qualitative components (the challenge and problem section in the questionnaire and the focus group discussion and key informant interviews) were analyzed manually through the identification of common themes and coding.

2.10 What is in this Report?

You will see in this report (in the findings section) the following which mainly follow the content of the questionnaire. They are as follows:

- i. General information about the respondent and his/her household;
- ii. Experience of HIV-related stigma and discrimination by PLHIV respondents (external & internal); respondents' access to work, health and educational

- services; and the rights, and laws and policies that protect the rights of PLHIV; effecting change
- iii. Information on testing and diagnosis, disclosure and confidentiality, ARV treatment and having children when HIV positive and the challenges and problems PLHIV face relative to them;
 - iv. Discussion of the findings and
 - v. Conclusion and recommendations based on the findings



3.0 FINDINGS

3.1 Demographic Information of Respondents

In spite of the fact that stigma index study is designed for special population, it does not ignore the sex and age groupings of respondents since HIV cuts across these lines. This aspect of demographic data as illustrated in the table below has been drawn from responses to questionnaire collated from EPI Info software database designed for the study. Five hundred persons (identified by LIBNEP+) were followed through the stigma index rollout questionnaire. Out of the 500 questionnaires, 483 respondents corresponding to 96.6% of completed questionnaires were judged to contain usable data for analysis while 17 respondents representing 3.4% were found not to contain useful information. The table below shows the number of persons (male or female) in each specified age category based on 483 realistic data.

Table 1: Number of respondents by sex and age group

Age group	Male	% of male	Female	% of female	Transgender	% of transgender	Total	% total
Youth aged 18-19 ⁹	1	0.82%	12	3.32%	0	0%	13	3%
Adult aged 20-24 years	8	6.56%	49	13.57%	0	0%	57	12%
Adult aged 25-29 years	18	14.75%	85	23.55%	0	0%	103	21%
Adult aged 30-39 years	40	32.79%	128	35.46%	0	0%	168	35%
Adult aged 40-49 years	47	38.52%	77	21.33%	0	0%	124	26%
Adult 50+ years	8	6.56%	10	2.77%	0	0%	18	4%
Total	122	100.00%	361	100.00%	0	0%	483	100%

As indicated in the table above, adult aged 30-39 years constitutes the highest number of respondents followed by adult aged 40-49, with female dominance representing 74% of sum total. Vertical view of the table also shows that females in all six age categories represent 74% of total respondents, which is anecdotal evidence that PLHIV support groups are female dominant and that HIV has more burden on women and girls than their male counterparts.

3.2 Years of knowledge of HIV status

Respondents were followed as to how long they have known to be living with the virus. As shown in the table above, a total of 483 (361 females and 122 males) responded to this question. Of this number 246 representing more than half of the respondents said that they have lived with the virus between 1-4 years, followed by 140 representing 28.99% who said that they have lived with virus between 5 to 9 years since they knew their status. Another category accounting for 15.32% has lived with the virus from 0-1yr while 21 persons corresponding to 4.35% said they have lived with the virus between 10 and 14 yrs. Only 0.41% of the PLHIV respondents have lived with the virus for over 15yrs.

**Table 4: Years of knowledge of HIV status**

Years					Total	
	M	%	F	%	#	%
0-1 yr	17	13.93%	57	15.79%	74	15.32%
1-4 yrs	61	50.00%	185	51.25%	246	50.93%
5-9 yrs	37	30.33%	103	28.53%	140	28.99%
10-14 yrs	5	4.10%	16	4.43%	21	4.35%
15+ yrs	2	1.64%	0	0.00%	2	0.41%
Total	122	100.00%	361	100.00%	483	100.00%

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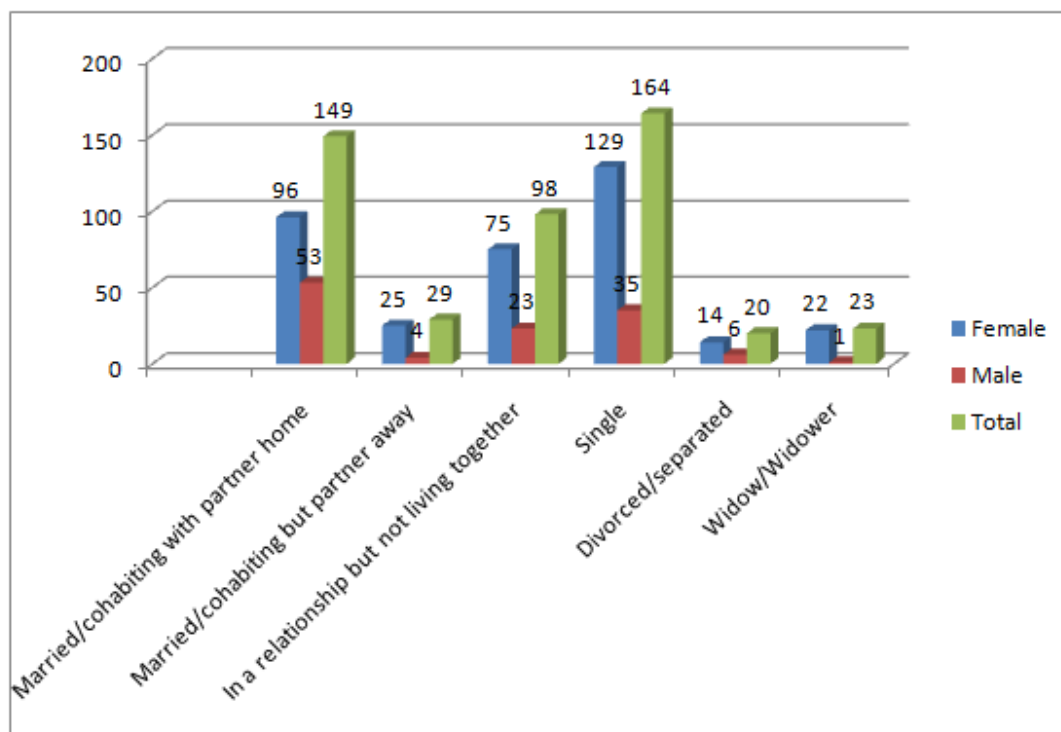
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3.3 Relationship Status

Respondents' social relationship status was also taken into consideration. By this we tried to investigate the impact of HIV status (especially in the face of status disclosure) on social or marital relations. The stigma index questionnaire considers six categories of relationship status. They include respondents married or cohabiting currently in one household, those temporarily cohabiting, those married or cohabiting but spouse living away from the household, those in relationship but not living together, those who are single, others who divorced or separated and those whose spouse died. The results reveal that one out of every three PLHIV is single and women constitute approximately 78.7% of this total. Ninety-eight persons representing 20% reported being in relationship but not living together while 29 respondents accounting for 6% reported being in relationship but their partners are away. Additionally, 20 persons (4%) of the respondents said that they are either divorced or separated while 23 individuals (5%) indicated that they are one of a widow or widower. However, 149 respondents corresponding to 31% said they are married/cohabiting with partners in the home. Overall, 69% of the respondents are without partners at one point in time or the other.



Figure 3: Respondents' relationship status



3.4 Sexual activity

Respondents were followed as to whether they are sexually active. Of the 478 (357 females and 121 males) PLHIV that responded to this question, 366 (268 female and 98 male) respondents representing 76.57% reported that they are sexually active while 112 (89 female and 23 male) accounting for 23.43% indicated the opposite. A cross tabulation of the result shows that men within the age bracket of 40-49 are most sexually active (38.84%) followed by those in the age bracket of 30-39 (32.23%). On the other hand, female in the age category of 30-39 were the most sexually active (35.29%) followed by those in the 25-29 age bracket (23.53%) and 40-49 age bracket (21.57%).

3.5 Categories of PLHIV respondents by most at risk population status

Respondents were asked to indicate their sexual and behavioural orientations. Two percent of respondents said they are MSM, 1% identified themselves as transgender, 2% as sex workers and another 1% said they are injecting drug users. By trend of behaviour, respondents were analyzed in relation to sexual practice as indicated in the table below. Currently, there is no respondent who is a transgender. However, 3 respondents hinted that they had belonged to that category in the past.

Table 5: Number of respondents by categories/associations

Categories	Male	%	Female	%	Total	% of total
Men who have sex with men	12	9.02%	0	0.28%	12	2.5%
Gay or lesbian	1	0.82%			1	0.2%
Transgender ¹⁰	0	0	3	0.83%	3	0.6%
Sex worker	2	1.64%	10	2.77%	12	2.5%
Injecting drug user	3	2.46%			3	0.6%
Refugee or asylum seeker	9	7.38%	32	8.86%	41	8.5%
Internally displaced person	17	13.93%	47	13.02%	64	13.3%
Member of an indigenous group	9	7.38%	44	12.19%	53	11%
Migrant worker	1	0.82%	1	0.28%	2	0.4%
Prisoner					0	0%
None	69	56.56%	223	61.77%	292	60.4%
Total	122	100.00%	361	100.00%	483	100%

3.6 Educational Level and Employment

Table 6: Number of respondents by level of education

Level of education	Male	% of male	Female	% of female	Total	% of total
No formal education	10	8.20%	105	29.09%	115	24%
Primary school	33	27.05%	118	32.69%	151	31%
Secondary school	45	36.89%	120	33.24%	165	34%
Technical college/university	34	27.87%	18	4.99%	52	11%
Total	122	100.00%	361	100.00%	483	100%

Consistent with the overall educational level of the country, the level of education among PLHIV respondents is generally low, particularly technical and higher education. It can be seen from the table above and graph below, that 24% of respondents do not have formal education and just 31% has acquired primary education and 37% secondary education. And only a negligible 11% has acquired technical college/university education. It is keen to note that women are three times more than their male counterpart not to have acquired any form of formal education. Out of the 115 who have acquired no formal education women constitute more than 90%. It can be deduced here that the burden of HIV is heavier on the female than the male as more women than men are likely to find it difficult to get any substantial source of income because of their limited skills and low level of education which play pivotal roles in employment opportunities.

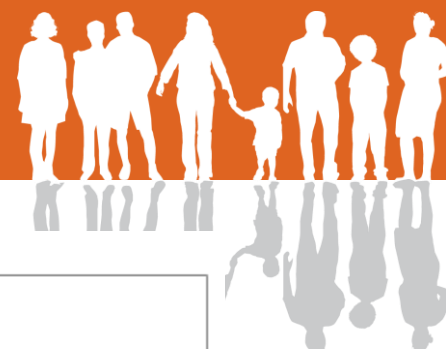
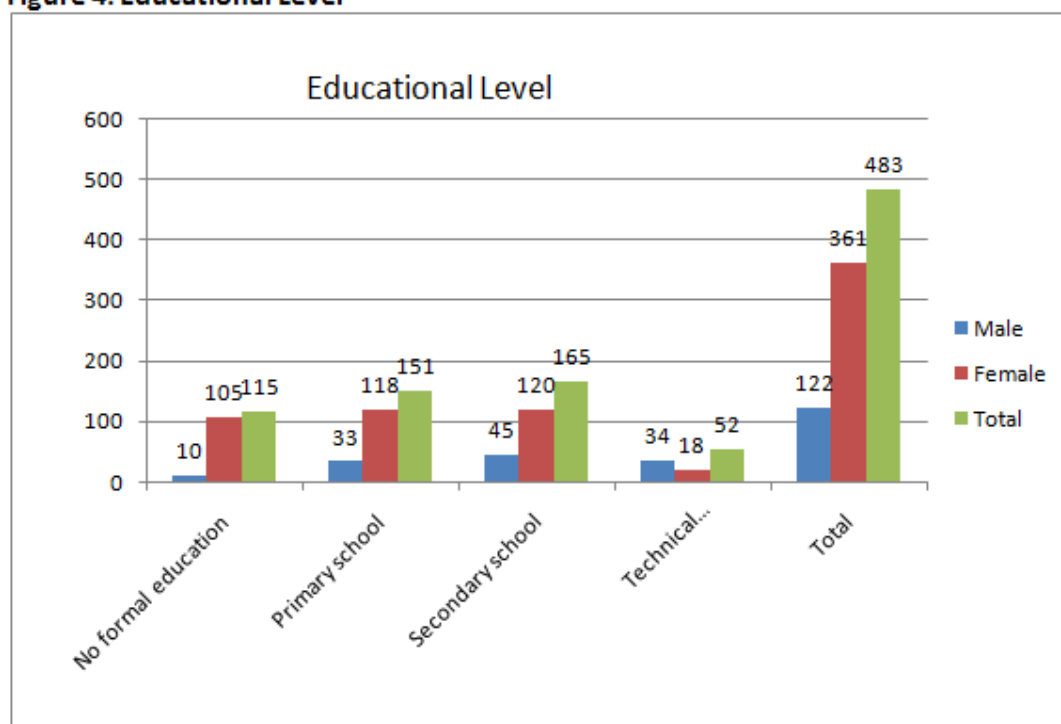


Figure 4: Educational Level



The correlation between education level and employment status cannot be debated. In low income countries like Liberia, employment opportunities are limited. Most available jobs are obtained on the basis of education level. The table below shows the number of respondents in various employment categories (whether as full time employee, part time employee, full time self-employment, casual self-employed or not employed at all).

Table 7: Number of respondents by employment status

Employment status	Male	% of male	Female	% of female	Total	% of total
In full-time employment/employee	15	12.30%	24	6.65%	39	8.07%
In part-time employment/employee	12	9.84%	19	5.26%	31	6.42%
Working full-time not as employee/self employed	18	14.75%	34	9.42%	52	10.77%
Casual worker/self employed	36	29.51%	66	18.28%	102	21.12%
Unemployed and not working at all	41	33.61%	218	60.39%	259	53.62%
Total	122	100.00%	361	100.00%	483	100.00%

As shown in the table, approximately 53.62% of respondents are not employed; 21.12% are in casual self-employment and 10.77 % are in full time self-employment. Only 8%of the respondents are in full time employment, while another 6.4% are part time employees. While HIV status could be a reason for the low level of employment

as indicated in the responses, educational level and the country's economic condition remain another set of unimpeachable reasons for the low level of employment.

3.7 Experiences of Stigma and Discrimination from other People

The experience of stigma and discrimination is one of the greatest impediments to the fight against HIV/AIDS. These social menaces have the propensity to deter people from knowing their status and practicing safe and healthy behaviors to counter the spread of the disease. On that account for an HIV prevention and response program to maximize results it must understand the extent of this problem to enable them develop strategies that will make the program more effective and efficient. Accordingly, respondents were asked as to their experience of stigma and discrimination from other people as shown in the table below. Most of the respondents representing 80% on average reported that they have never experienced stigma and discrimination from other people. However it is worth noting that 144 of them said they were verbally insulted, 21% has been physically assaulted, 20% subjected to psychological pressure of manipulation by sexual partners and 48% said they were aware of being gossiped about. Interestingly 28 respondents have indicated that they have experienced stigma and discrimination from other PLHIV. The table also indicates that respondents experienced other forms of stigma and discrimination including sexual rejection and household discrimination.

3.8 Perceived Reason(s) for Stigma and Discrimination

Stigma and discrimination have many faces anchored on a number of root causes and contributing factors. Just as the knowledge of the extent of stigma and discrimination is vital so is the knowledge of the reasons (perceived or real) for these unhealthy behaviours and attitudes. Knowledge of these reasons will help to adequately inform program and policy formulation for better results. Respondents were followed as to the reason(s) why they are being stigmatized or discriminated against. Twenty six percent of respondents have identified the reasons for stigma and discrimination against them to be fear of people for getting infected by them. Another 27% believes that those who stigmatize them do not understanding the modes of HIV transmission. 11% of respondents noted that "people feel being HIV infected is shameful so they do not want to associate with people living with HIV". The table below shows respondents' perceived reasons for being stigmatized and discriminated.

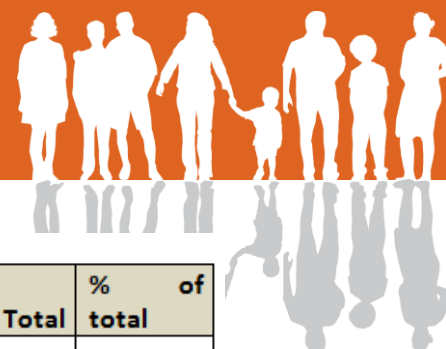


Table 8: Number of responses by reason of stigma & discrimination

	Male	% of male	Female	% of female	Total	% of total
People are afraid of getting infected with HIV from me	28	26.21%	98	32.21%	126	26%
People don't understand how HIV is transmitted and are afraid I will infect them with HIV through casual contact	24	14.56%	106	21.48%	130	27%
People think that having HIV is shameful and they show not be associated with me	12	10.68%	40	9.06%	52	11%
Religious beliefs or moral judgment	4	1.94%	4	0.67%	8	2%
People disapprove of my lifestyle or judgment	7	3.88%	7	2.35%	14	3%
I look sick with symptoms associated HIV	6	3.88%	17	4.36%	23	5%
I don't know/I am not sure of the reason	41	38.83%	89	29.87%	130	27%
Total	122	100.00%	361	100.00%	483	100%

3.9 Access to Work, Health and Educational Services

Respondents' social economic status was followed. They provided responses in terms of access to work, health and education. About 22% of respondents said they were forced to change residence due to their HIV status; 12% of them have lost their jobs or other sources of income because of HIV status, while 6% experienced change of job description or refused promotion because of their HIV status.

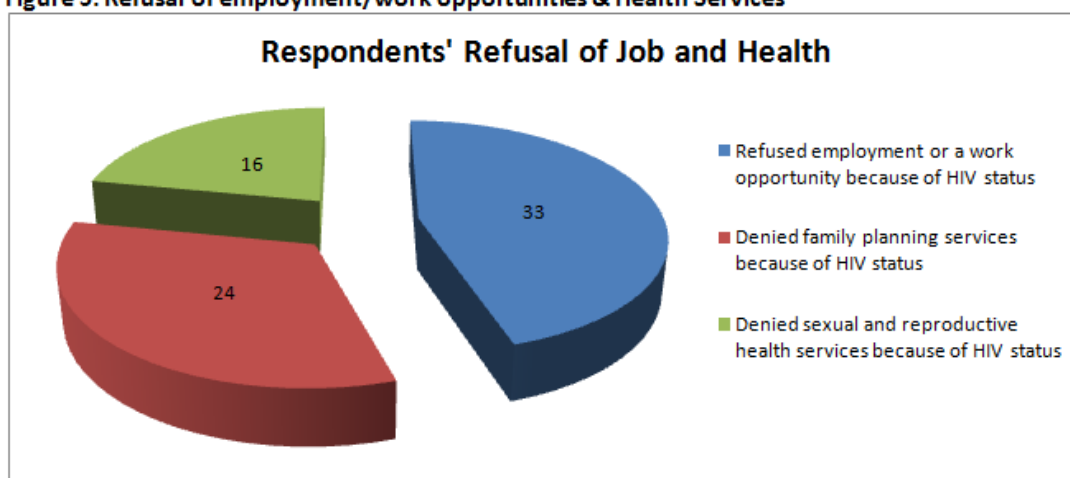
Approximate 1.24% said they were dismissed, prevented or suspended from attending educational institution because of HIV status; whereas 2.07% reported that their children were thrown out of school on account of HIV related stigma and discrimination against members of their family. Similarly, 2.48% of respondents asserted that they have been denied health or dental service due to their HIV status. The following table shows respondents by access to work, health and education.

Table 9: Number of respondents by access to work, health and education

Level of access	Never	Once	A few times	Often	Total
Forced to change resident/unable to rent accommodation because of HIV status	377	85	14	7	483
Lost a job or another source of income because of HIV status	426	46	10	1	483
Change of job description or nature of work, or refused promotion because of your HIV status	456	22	2	3	483

Refusal of employment opportunity and denial of family planning or reproductive health services was noted to also be caused by HIV status. Thirty three respondents said they have been refused employment opportunity, 24 of them have experienced denial of family planning services, while another 16 said they were denied sexual and reproductive health services because of HIV status.

Figure 5: Refusal of employment/work opportunities & Health Services



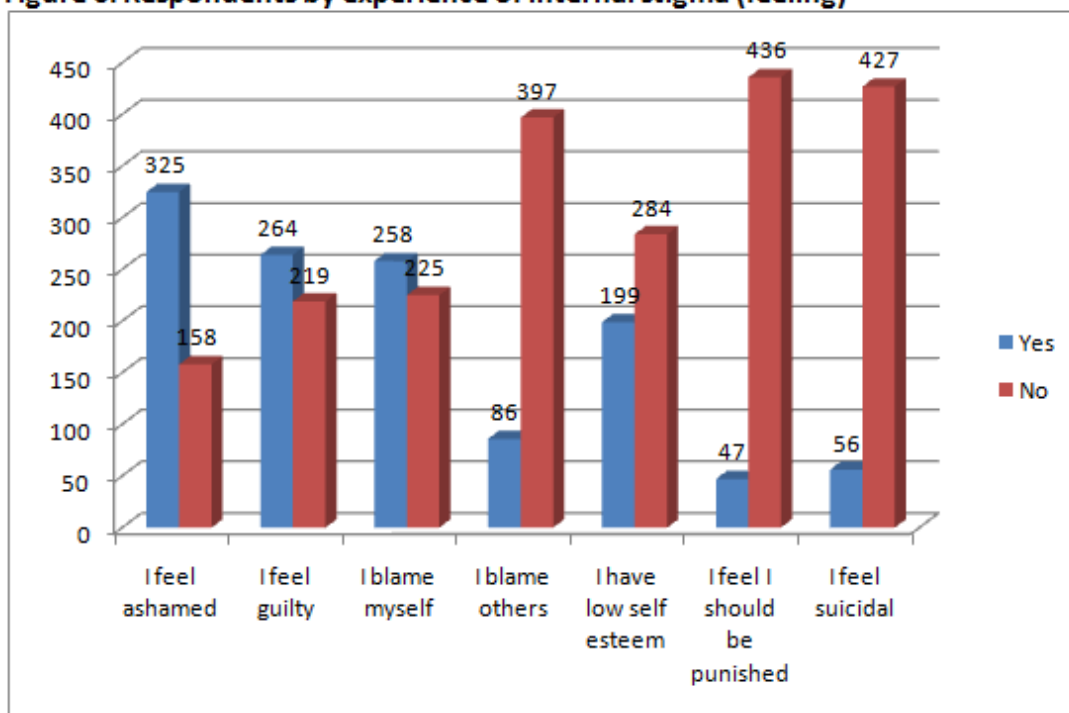
However, educational level is critical to employment opportunity. It is subjective to out rightly say that the respondents were denied employment on account of their HIV status. Respondents were therefore followed on the basis of their level of education. The results show that there is less university/technical education among PLHIV respondents. As seen from this analysis, only 52 persons representing 11% have attained university/technical education. Under the current Liberian economy where there is scarcity of jobs, there is strong association between education and employment. Even people who are favoured for job opportunities for one reasons or the other are often judged by their academic credential, or they must at least exhibit their academic and professional capabilities to be able to maintain the job.



3.10 Experiences of Internal Stigma and Fears

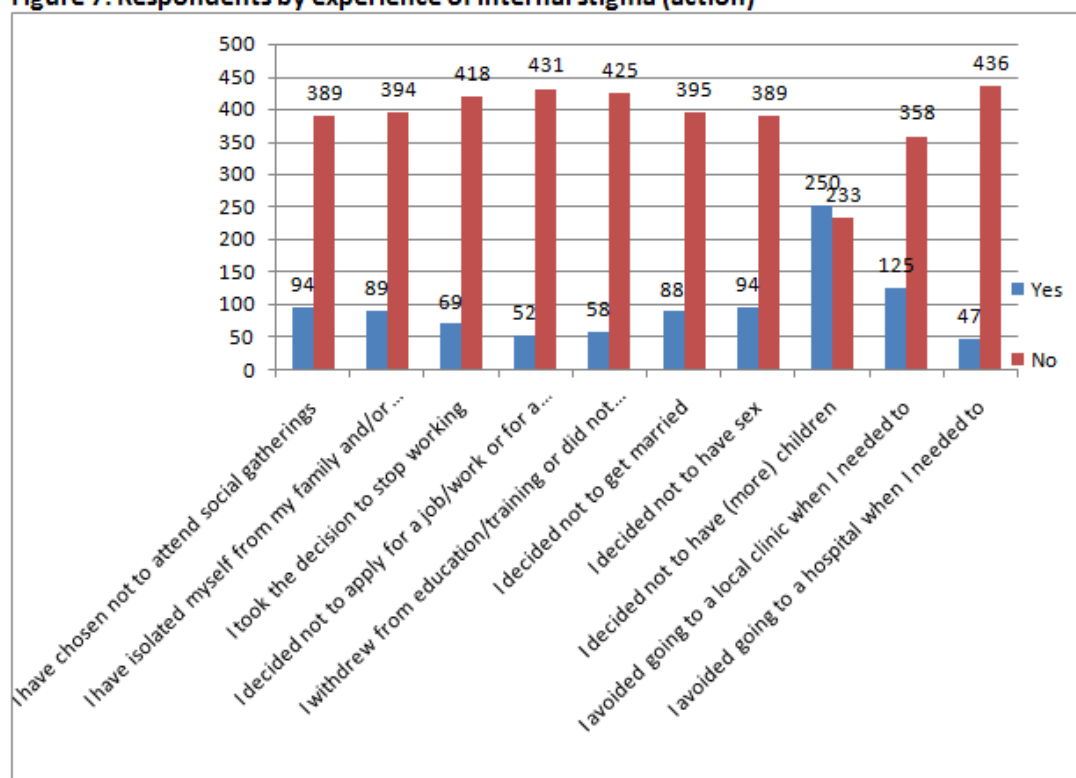
Stigma and discrimination can be internalized by the individual person. Like an intra-personal conflict, stigma can be preconceived. This universal phenomenon does not excuse PLHIV as shown by the graph below. Out of 483 persons who responded to questions relating to internal stigma, about 67% of respondents feel ashamed of themselves whether or not their HIV status is known to others. Fifty-five percent (55%) of respondents feel guilty for being HIV positive regardless of their HIV mode of transmission. Additionally, 53% of respondents blame themselves for being HIV positive, while 41% felt that they experience low self-esteem because of their HIV status. Areas of lower yes responses yet of significance were the questions of isolation, suicidal ideation and deserving punishment. Eighteen percent (18%) of them reported of isolating themselves from family and friends, 12% has felt suicidal and 10% has felt that they deserved to be punished. These results show that while efforts are needed to combat external stigma and discrimination an equally significant focus must also be directed towards fighting internal stigma that is more common among the PLHIV. This type of stigma has the potential to pose more danger to the health and survivability of PLHIV since it is within them, and they are left alone to struggle with it on grounds that it is not easily evident to others that could be of help. This could lead to more psychological and socio-economic problems that could potentially accelerate the deterioration of their health.

Figure 6: Respondents by experience of internal stigma (feeling)



The experience of internal stigma is multidimensional. The experience of feeling as named above certainly has the ability to influence the behaviour of people to take certain actions against themselves. In view of this, the stigma index study also explores some of the self-defeating actions PLHIV may likely take against themselves as a result of their conditions. The results indicate that some PLHIV take discriminatory actions against themselves. Of the total number of 483 respondents, 94 persons representing 19% said that they have chosen not to attend social gathering and not to have sex. Eighty-nine persons accounting for 18% reported that they have isolated themselves from family and/or friend, as well as not to get married. More than half of the respondents (250 persons/52%) said they have decided not to bear child(ren) as a result of their condition. As further depicted in the graph below, PLHIV at any given time have taken one form of discriminatory actions or the other against themselves. There might be the need for further study to establish in a more empirical terms the correlation between external stigma and internal stigma. But as it stands, internal stigma and discrimination is a critical issue among PLHIV population that needs to be seriously considered in the formulation of strategic direction and action plans against the silent enemy of the fight against HIV pandemic.

Figure 7: Respondents by experience of internal stigma (action)

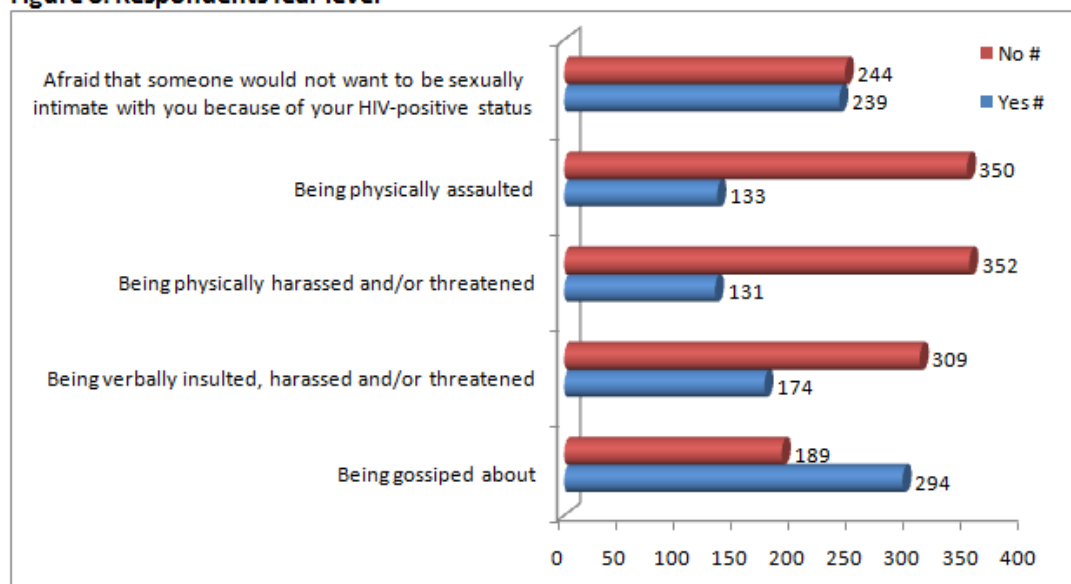


Fear is another cardinal issue for PLHIV and one of the drivers that have the propensity to deter this population from testing, disclosure and seeking support. Cognizant of this, the stigma index study seeks to understand the fear level of respondent by soliciting response to the following questions: feeling of being gossiped about, being verbally insulted/harassed or threatened being physically



harassed and/or threatened; being physically assaulted and fear of people not wanting to be sexually intimate with them because of HIV status. As shown in the graph below, 294 persons representing 61% of the total respondents of 483 reported that they have fear of being gossiped about. Another 239 representing 49% indicated that they are afraid that someone would not want to be sexually intimate with them because of their status. Even acts that someone might least expect to happen on account of HIV status (e.g. physical assault), they still serve as corridors of fear for PLHIV. While it is true that the fear level varies across the parameters it however shows that many PLHIV conceive fear of one form or the other. This also points to an issue closely related to internal stigma that needs to be addressed concomitantly if the fight against the pandemic must emerge victorious.

Figure 8: Respondents fear level



3.11 Rights, Laws and Policies

PLHIV's awareness of existing laws and policies that protect their rights in country was also followed. There was an attempt to dichotomize between just hearing of the existence of laws and policies and being able to read and discuss the contents of the laws in order to make maximum use of one's rights under such laws. United Nations Declaration of Commitment on HIV and AIDS of April 2001 has been heard of by 61% of respondents but only 28% read or discussed its contents. Various countries have their HIV laws and policies recorded on international network; Liberia is one of few countries that are exception. Liberia's HIV and AIDS law commonly referred to as the 'Model Law' has been read or discussed by 141 out of 483 respondents. The table below indicates awareness of respondents' rights under various laws and policies disaggregated by sex.

Table 10: Number of respondents by Knowledge of their rights, laws and policies

Knowledge	Response								Total			
	Yes				No				Yes		No	
	M	%	F	%	M	%	F	%	#	%	#	%
Have you heard of the Declaration of Commitment on HIV/AIDS	81	66.39%	216	59.83%	41	33.61%	145	40.17%	297	61%	186	39%
If yes have you ever read or discussed the content of this Declaration	34	27.87%	103	28.53%	88	72.13%	258	71.47%	137	28%	346	72%
Have you heard of the HIV/AIDS law	64	52.46%	226	62.60%	58	47.54%	135	37.40%	290	60%	193	40%
If yes, have you read or discussed the content of the HIV/AIDS law?	32	26.23%	109	30.19%	90	73.77%	252	69.81%	141	29%	342	71%

The Declaration of Commitment on HIV and AIDS notes with grave concern that Africa, in particular sub-Saharan Africa, is currently the worst affected region where HIV/AIDS is considered as a state of emergency, which threatens development, social cohesion, political stability, food security and life expectancy and imposes a devastating economic burden and that the dramatic situation on the continent needs urgent and exceptional national, regional and international action. Under the Declaration of Commitment, countries have pledged to set a target of allocating at least 15 per cent of their annual national budgets for the improvement of the health sector to help address the HIV/AIDS epidemic; and recognizing that action to reach this target, by those countries whose resources are limited, will need to be complemented by increased international assistance⁸.

3.12 Effecting Change

Respondents' ability to effect change was followed. This is whether or not they confronted or educated someone who tried to stigmatize or discriminate against them. Their knowledge of the existence of organizations or support groups that could defend them in case of stigma and discrimination was also assessed. The results show that not many of the PLHIV respondents have mustered the courage to confront, challenge or educate those who stigmatize or discriminate against them. Of the number that

⁸ Declaration of Commitment on HIV and AIDS, April 2001

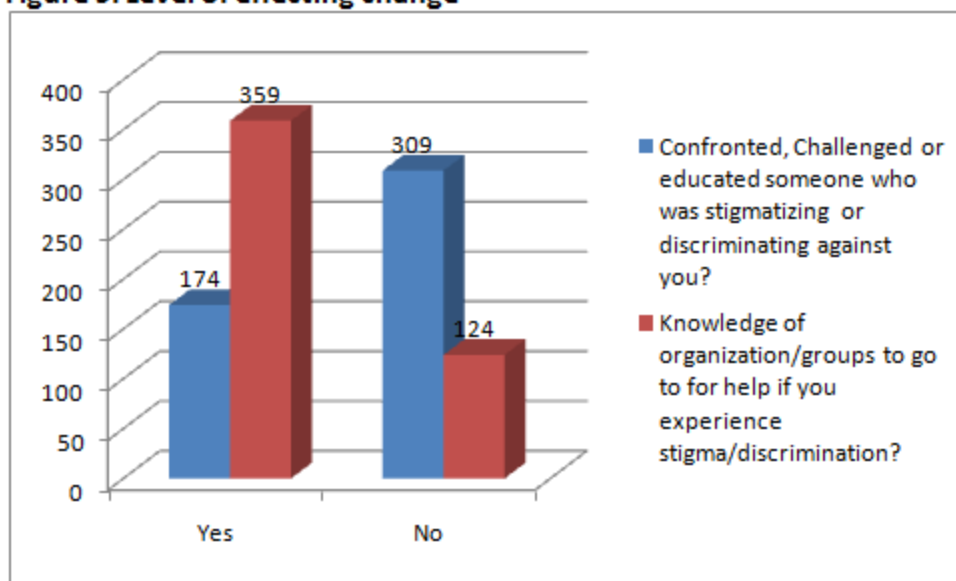


responded to this inquiry (483 persons), only 174 asserted that they have taken steps to change the attitude of people who stigmatize or discriminate against them.

3.13 PLHIV level of awareness of support services

In-country or community support services to PLHIV (non-health) were also investigated in terms of their availability and level of awareness by PLHIV. In the face of stigma and discrimination, PLHIV reserve the right to choice in determining where to seek redress. Organization such as support groups, PLHIV associations and network, legal and human rights platforms, faith-based organizations and the National AIDS Commission have responsibility to support PLHIV when they are stigmatized and discriminated against. The extent to which individual PLHIV uses the services of these organizations was followed during the study. Many of the respondents declared that they have knowledge of organizations from whom to seek help in case of such experience. Three hundred and fifty-eight individuals corresponding to 74% mentioned PLHIV support groups as their source of redress or refugee. Eighty-seven respondents accounting for 18% named PLHIV network (LIBNEP+) as an organization they could seek help from when confronted with issue of stigma and discrimination. Faith-based organizations including churches, mosques and non-governmental organizations are other organizations some claimed to seek help from when needed.

Figure 9: Level of effecting change



Individual involvement with each other in terms of emotional or psychological support was probed. About 73% of respondents said they have supported other PLHIV in the last 12 months. 75% of respondents have said that they are aware of the existence of the network of people living with HIV (LIBNEP+) because their support group is a member of the network. Another 44% has said that they have been involved in rendering voluntary or employment services to programs that provides assistance to people living with HIV. As low as 22% of respondents have said they

were involved in efforts aimed at formulating policies, legislations or guidelines on HIV in Liberia.

Respondents were asked to recommend number ways that PLHIV organizations should address stigma and discrimination. 281 respondents, representing 58%, have called for PLHIV organizations to advocate for the rights of all PLHIV. 18% prefer provision of emotional and referral support, while another 13% believes that the public awareness should be a major task of PLHIV organizations. The table below shows recommendations disaggregated by sex.

Table 11: Number of respondents by recommendations to address stigma and discrimination

Recommendation	Male	%	Female	%	Total	% of total
Advocating for the rights of all PLHIV	74	60.66%	207	57.34%	281	58%
Providing support to PLHIV by providing emotional, physical and referral support	15	12.30%	71	19.67%	86	18%
Advocating for the rights and/or providing support to particularly marginalized group (MSM, injecting drug user, sex worker)	4	3.28%	9	2.49%	13	3%
Educating PLHIV about living with HIV (including treatment literacy)	12	9.84%	26	7.20%	38	8%
Raising the awareness and knowledge of the public about AIDS	17	13.93%	48	13.30%	65	13%
Total	122	100.00%	361	100.00%	483	100%

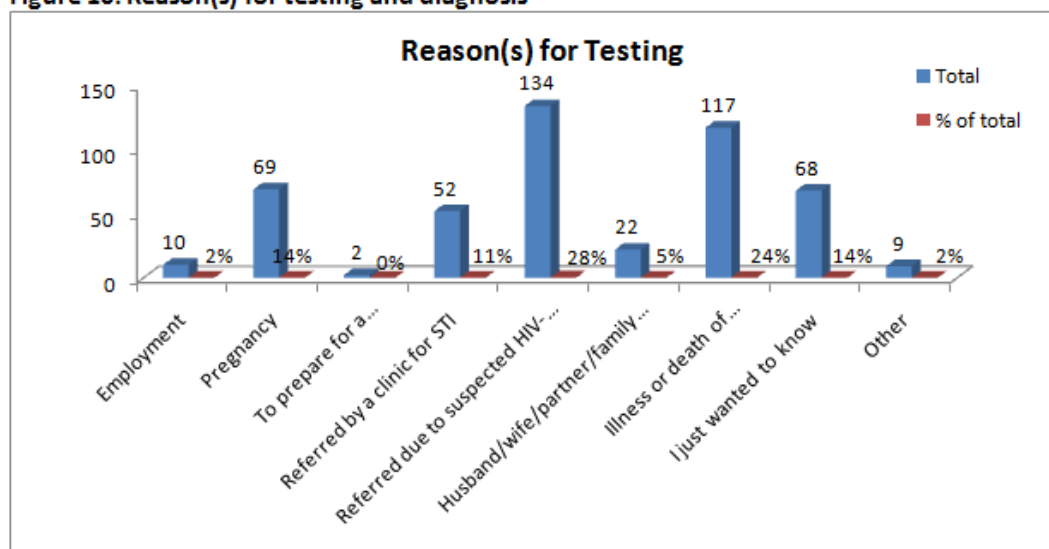
3.14 Testing and Diagnosis

The study also took keen interest in understanding respondents' reasons for testing that led to their diagnosis. This was intended to determine the kind of conditions that triggered testing and diagnosis. It was important to analyze the extent to which universal precautions including a person's decision to be tested, access to pre-test counselling and observance of confidentiality were upheld in the wake of testing and diagnosis.

Approximately 134 respondents, representing 28%, have said that they were tested due to suspected HIV related symptoms. Another 24% has said that test was done upon the illness or death of spouse, while 14% was tested during antenatal care. The graph below indicates various reasons of testing, amount of respondents for each reason and corresponding percentage.



Figure 10: Reason(s) for testing and diagnosis



Respondents were asked as to whether or not the decision to be tested was voluntary or they were coerced to be tested. The decision to be tested for HIV was a choice made by 316 representing 65% of total respondents. The table below shows four categories of decisions under which respondents were tested.

Table 12: Number of respondents by control of decision to be tested

Was the decision to be tested for HIV up to you?	Male	%	Female	%	Total	% of total
Yes, I took the decision myself to be tested	86	70.49%	230	63.71%	316	65%
I took the decision to be tested, but it was under pressure from others	16	13.11%	42	11.63%	58	12%
I was made to take an HIV test(coercion)	12	9.84%	69	19.11%	81	17%
I was tested without my knowledge-I only found out after the test had been done	8	6.56%	20	5.54%	28	6%
Total	122	100.00%	361	100.00%	483	100%

Most respondents have said that they received pre-test and post test and post test counselling during their HIV diagnosis process. Of those who responded to these questions, 79% indicated that they received both pre and post test and post test counselling, while 7% and 10% reported that they only received pre-test and post-test, respectively. About 4% did not receive any counselling at all. The table contains various responses on counselling during HIV test.

Table 13: Number of respondents by receipt of counseling during testing

Did you receive counseling when you were being tested for HIV?	Male	%	Female	%	Total	% of total
I received both pre-and post-HIV test counseling	96	78.69%	287	79.50%	383	79%
I only received pre-test HIV counseling	8	6.56%	26	7.20%	34	7%
I only received post-test HIV counseling	10	8.20%	37	10.25%	47	10%
I did not receive any counseling when I had an HIV test	8	6.56%	11	3.05%	19	4%
Total	122	100.00%	361	100.00%	483	100%

The study also reveals that PLHIV do come under pressure to reveal their status for a number of reasons. Over 130 respondents have said they have experienced pressure from fellow PLHIV to disclose their status. Also 135 respondents have said that they have experienced pressure from non-PLHIV family members and social workers to disclose their HIV status. Table 19 in annex 1 of this report shows experience of pressure to disclose HIV status disaggregated by frequency of time.

3.15 Disclosure and Confidentiality

However, contrary to the principle of confidentiality, PLHIV get disappointed when their status get known to people within their community or place of work. Breach of confidentiality was also assessed in the experiences of respondents. Interestingly, 15% of respondents have said that they were aware their status was revealed by social workers and medical practitioners. The table below describes respondents' level of awareness of status disclosure by service providers.

Table 14: Number of respondents by how much they know medical practitioner have disclosed their status

	Response						Total	
	Yes		No		Not sure			
	#	%	#	%	#	%	#	%
Has a health care professional (e.g. A doctor, nurse, counselor, lab technician) ever told other people about your HIV status without your consent?	76	15.73%	258	53.42%	149	30.85%	483	100.00%



It was also interesting to know whether participants were aware of their medical records being kept confidential. 55% of respondents believed that their medical records are kept confidential. Thirty-five percent (35%) had a contrary view that their records were not confidentially kept while 10% was not sure if their medical records are kept in confidence. Below is a table depicting sexual disaggregated responses on medical record confidentiality.

Table 15: Number of respondents by how much they believe their HIV medical records are Kept confidential

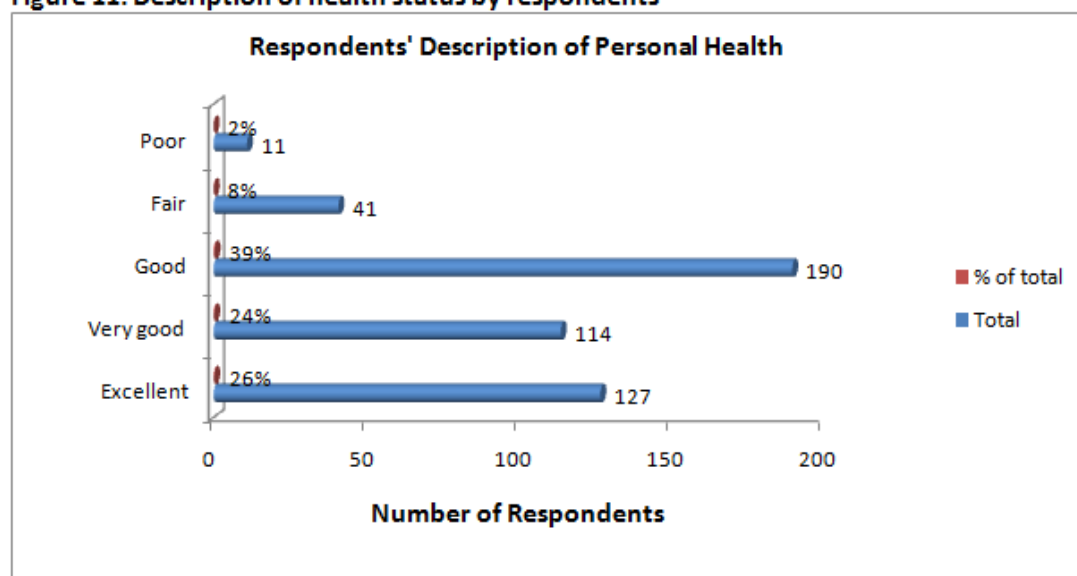
How confidential do you think the medical records relating to your HIV status are?	Male	%	Female	%	Total	% of total
I am sure that my medical records will be kept completely confidential	65	53.28%	201	55.68%	266	55%
I don't know if my medical records are confidential	45	36.89%	125	34.63%	170	35%
It is clear to me that my medical records are not being kept confidential	12	9.84%	35	9.70%	47	10%
Total	122	100.00%	361	100.00%	483	100%

About 61% of respondents said they find the disclosure of their HIV status as an empowering experience. 23% did not think that the disclosure of their status empower them in any way. 14% does not feel that disclosure of HIV status has any bearing on their lives.

3.16 Treatment

Respondents were asked to describe the current status of their health. 26% of respondents have described their health status as excellent. 24% has described their health condition as “very good”, while 39% said they are good. The figure below presents a picture of the description of health status by respondents.

Figure 11: Description of health status by respondents



Respondents were asked if they were currently taking antiretroviral treatment. 89% of respondents have asserted that they are taking antiretroviral treatment. 86% has said that they are taking medication against opportunistic infections. However, the data shows that access to opportunistic infection treatment was a challenge to 15% of respondents. There seems to be a correlation between the health and treatment status of PLHIV respondents. The number of people who are on ARV treatment is almost equivalent to the sum total of PLHIV who described their health as good, very good or excellent.

As serious as the issue of treatment is, the study was equally interested in knowing the extent or frequency at which PLHIV discuss with health care professionals and other relevant persons or organization on the option of their treatment. Out of the 483 PLHIV who responded to this question, 63% said that in the last 12 months they managed to constructively discuss with health care professionals on the subject of their treatment options. Another 57% has been able to discuss with health care professional on the subject of their reproductive health in the last 12 months. Table 24 in annex 1 shows responses disaggregated by sex.

3.17 Having Children

It became interesting to note the number of respondents who have children and at what level their children are aware of their HIV status. The survey shows that 86% have children as opposed to 14% that did not have children. Only 21% has released their HIV status to their children. Below is a sex disaggregated table showing the responses.

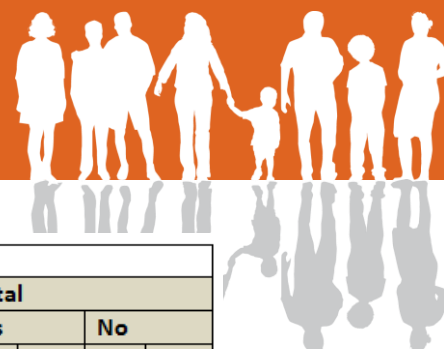


Table 16: Number of respondents who have children												
	Response								Total			
	Yes				No				Yes		No	
	M	%	F	%	M	%	F	%	#	%	#	%
Do you have child/children?	101	82.79%	312	86.43%	21	17.21%	49	13.57%	413	86%	70	14%
If yes, are any of these children known to be HIV positive?	20	16.39%	83	22.99%	102	83.61%	278	77.01%	103	21%	380	79%

Respondents were also followed with regards to possible advice or coercion on their reproductive health options. Post diagnostic reproductive health counselling is an issue of interest in the PLHIV stigma index roll out. 65% of respondents have said they have received reproductive health counselling since they were diagnosed. 19% said they have been advised not to have children; while 14% have admitted of being coerced by health professionals to be sterilized. 17% has declared that they can only obtain antiretroviral treatment when they agree to use certain contraceptive.

Female respondents were asked to state any manner of coercion by health care professional in relation to termination of pregnancy (abortion), method of giving birth and infant feeding practices. They were also asked to provide information relating receipt of antiretroviral treatment intended to prevent mother-to-child transmission of HIV during pregnancy. The table below shows the response.

Table 17: Number of respondents (female) by coercion from HCP to:

In the last 12 months, have you been coerced by a health care professional in relation to any of the following because of your HIV status?	Response						Total	
	Yes		No		Not applicable			
	#	%	#	%	#	%	#	%
Termination of pregnancy (abortion)	15	4.16%	232	64.27%	114	31.58%	165	45.71%
Method of giving birth	78	21.61%	180	49.86%	103	28.53%	150	41.55%
Infant feeding practices	72	19.94%	175	48.48%	114	31.58%	72	19.94%

Approximately 156 women representing 43% of total female respondents have said that they have received PMTCT. 35% said they gave birth to their children before being diagnosed of HIV. Below is a table of the response on receipt, and knowledge of the availability of PMTCT.

Table 18: Number of female respondents by receipt of antiretroviral treatment to prevent mother-to-child transmission of HIV during pregnancy

Have you ever been given antiretroviral treatment to prevent mother-to-child transmission of HIV during pregnancy?	Total	
	#	%
Yes-I have received such treatment	156	43.21%
No-I didn't know that such treatment existed	32	8.86%
No-I was refused such treatment	7	1.94%
No-I did not have access to such treatment	38	10.53%
No-I was not HIV positive when pregnant	128	35.46%
Total	361	100.00%

4.0 PROBLEMS AND CHALLENGES (qualitative assessment and analysis)

One might argue that problems and challenges are a normal part of life; they are inevitable. As true as that might sound, it is always better to understand their nature and extent to be able to seek ways to addressing them. They cannot be allowed to exist perpetually to imperil the success of interventions and cause loss of needed resources. Cognizant of this precept, the study explored some of the problems and challenges surrounding the issues of testing and diagnosis, disclosure and confidentiality, antiretroviral treatment and having child(ren) when HIV+. This exploration took a qualitative approach through open-ended questions within the questionnaire, focus group discussion and key informant interviews to allow respondents fully express themselves based on what they feel and think about them, based on personal experiences, observation and/or perception.

4.1 Testing and diagnosis

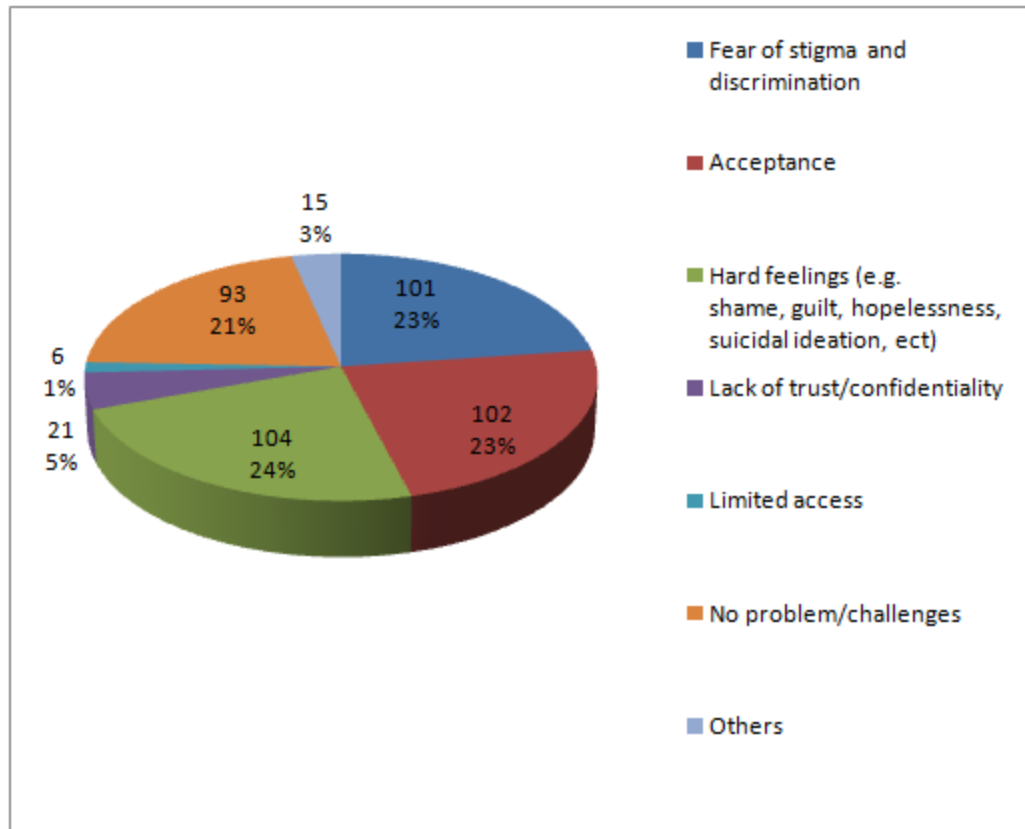
Testing and diagnosis is one of the key instruments that can be used to minimize the spread of the virus and prolong the lives of the carriers by enabling such persons know their status and begin early treatment thereby leading to the aversion of the development of full blown AIDS. The process also helps reduce the proliferation of the virus. This is so because people who know their status are often careful to avoid re-infection through the use of condoms that also provides benefits for minimizing the spread of the disease. However, the process of testing and diagnosis is often challenged by several factors, both internal and external. The study sought to find out from respondents what are some of the problems and challenges facing the process of testing and diagnosis in Liberia. Of the 442 persons (338 females and 104 males) who responded to this question, 101 cited the fear of stigma and discrimination as a key impediment to testing and diagnosis. Respondents pointed out that many people dread



HIV test for fear that if they are tested positive they will be stigmatized and discriminated against by the community. Consequently these people will choose not to take the test and save themselves from the ordeal of stigma and discrimination. Responding to the same question, 102 persons highlighted acceptance as one of the problems and challenges facing HIV testing and diagnosis in the country. Here, they looked at acceptance from two angles: acceptance by the community including family members as HIV positive and the acceptance of the result of being positive. Because of the high level of stigma and discrimination associated with the virus, many people find it very difficult to accept that they are HIV positive. This leaves them subjecting themselves to repeated testing and diagnosis. As a result many of those tested suffer some hard feelings including but not limited to guilt, shame, frustration, hopelessness, worthlessness, too much worries, and worst of all, suicidal ideation. One hundred four persons acceded that they have suffered such situations that tend to interfere with their ability to manage their conditions. In addition, 21 persons cited the lack of trust and confidentiality and 6 indicated limited testing centers, particularly in the rural areas as some of the challenges facing this process. As we shall see later, the issue of confidentiality is another critical point in preventing HIV/AIDS and providing support to the sufferers.

Nonetheless, 93 persons mentioned that they do not find any problem or challenge with the process. In fact these people said that it is very good for one to know one's status, especially through early testing and diagnosis that will help prevent the deterioration of the person's health. The graph below shows a breakdown of the summary analysis of responses to this question.

Figure 12: Distribution of problem/challenges by Testing and Diagnosis



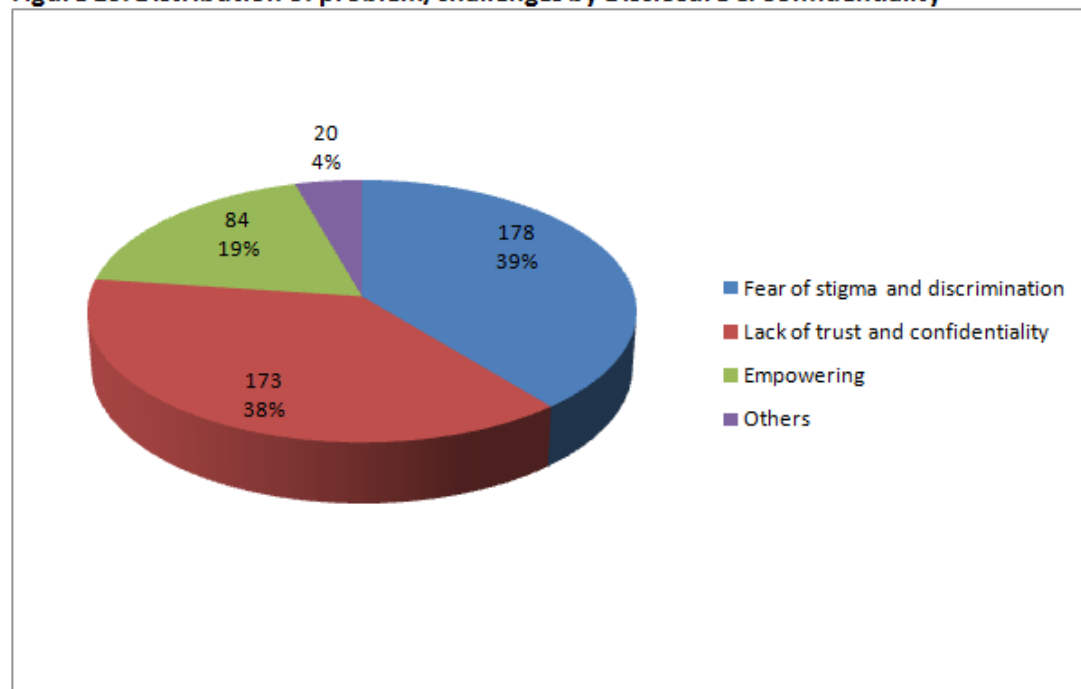
4.2 Disclosure & Confidentiality

Two complementary phenomena which have profound bearing on the state of support, care and treatment for PLHIV are the issues of disclosure and confidentiality. Disclosure could be a source of empowerment and support if done appropriately and received with passion, care and respect. On the other hand, combined with confidentiality, it reduces access to the receipt of treatment, care and support if uncontrolled disclosure occurs, thereby undermining an integral function of the HIV care and prevention programs. Considering the significant roles these issues play, the Stigma Index Roll-out Study attempted to explore factors that might hold back disclosure of HIV status. Of the 455 persons who responded to this question (338 females and 117 males) 178 respondents indicated that fear of stigma and discrimination are holding them back from disclosing their status. They lamented that they are very likely to be gossiped about, pointed at and rejected by the community, friends and even family members. A portion of these people said, that some of them who disclosed their status to their partners were rejected with high level of disdain. They pointed out that these partners did not only reject them but also spread the news of their status around the community in a way that forced them to relocate to different communities to hide and protect their identity. Closely related to the fear of stigma and discrimination is the breach of the principle of confidentiality. One out of every



three respondents cited lack of confidentiality as being responsible for not mustering the courage to disclose their status, even to those who are most concerned and intimate. They claimed that there are limited people to trust to disclose their status to, on grounds that these people, instead of being supportive and caring to them, would embark on exposing them to public glare that bring them lots of embarrassment. Many people in Liberia still see HIV as abominable by which they tend to disassociate themselves with the carriers. Though the majority of the people see the disclosure of their HIV status as difficult and challenging for reasons enumerated above, 84 out of the 455 persons pointed out that disclosure is empowering and the best thing to do. They mentioned that the disclosure of their status was helpful and people to whom they have disclosed their status have been supportive.

Figure 13: Distribution of problem/challenges by Disclosure & Confidentiality



4.3 Antiretroviral Treatment

As much as the prevention of the spread of the epidemic is important, the care, support and treatment of those who are already carrying the virus must be equally given attention to improve their health and prolong their lives. If we must show evidence of our success in the fight against the virus, this must also be indicated by the level of care, support and treatment PLHIV receive. This does not however go without challenges and problems; as such, the stigma index roll out study sought to gain an understanding of the problems and challenges associated with ART⁹. Four hundred thirty-six (436) persons responded to the question which sought to provide

⁹ Antiretroviral treatment

information on this issue. Analysis of their responses shows that 124 persons cited the life-time and twice a day regimen of the ARV¹⁰ treatment as one of the key problems and challenges surrounding the ARV treatment. They feel that it is tiring and boring to be taking drug every day of your life without a rest. Even more, considering the fact that we are human and are therefore subject to the weaknesses of human, particularly forgetting, the ARV treatment becomes very challenging and difficult to follow at times. In like manner, 86 persons pinpointed the side effects of the medication as the major challenges and problems facing the use of the ARV treatment. Many of these people complained of side effects such as swollen feet, low blood, weakness, nausea, just to name a few. They complained that to the extent the side effects of the drugs are debilitating, it threatens to undermine the use and benefits of the drugs.

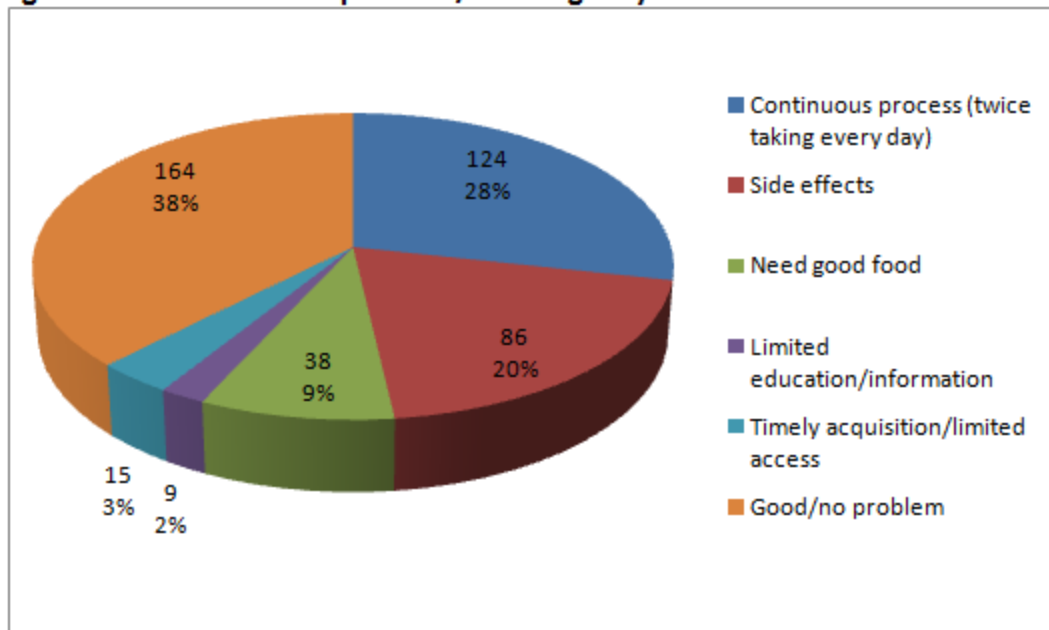
Another issue cited by respondents as challenge and/or problem was the need for food to cope with the strength of the medication. Thirty-eight (38) respondents lamented that the medication is very strong to the extent that if taken without food and/or proper nutrition, it seriously reacts on you. Still 15 of those who responded to this question considered accessibility to the treatment, especially for rural dwellers as one of the problem and/or challenges facing treatment. They said that treatment is not easily accessible to some rural dwellers who have to walk several kilometres before reaching a treatment centre, and on a few occasions are told that the kinds of medications that they need are not available. Additionally, nine persons said that there is limited information provided to them on the use of the medication. In the same respect they said that medications are given them without proper attention, and other said there is a need for a more advanced medication. It is worth making this critical issue a point for further investigation and corresponding improvement in the areas of education/information, care and quality of treatment.

Amidst these lamentations, some PLHIV expressed satisfaction and gratitude for the treatment, pointing that it is good and has saved and prolonged their lives. 164 individuals asserted that they do not see any major problem with the treatment and are doing well on it. It is however interesting to note that the majority of people who claimed that they are doing well on the treatment are people who were very sick with many opportunistic infections before being placed on treatment. They therefore see the treatment as their saviour.

¹⁰ Antiretroviral



Figure 14: Distribution of problem/challenges by ARV Treatment



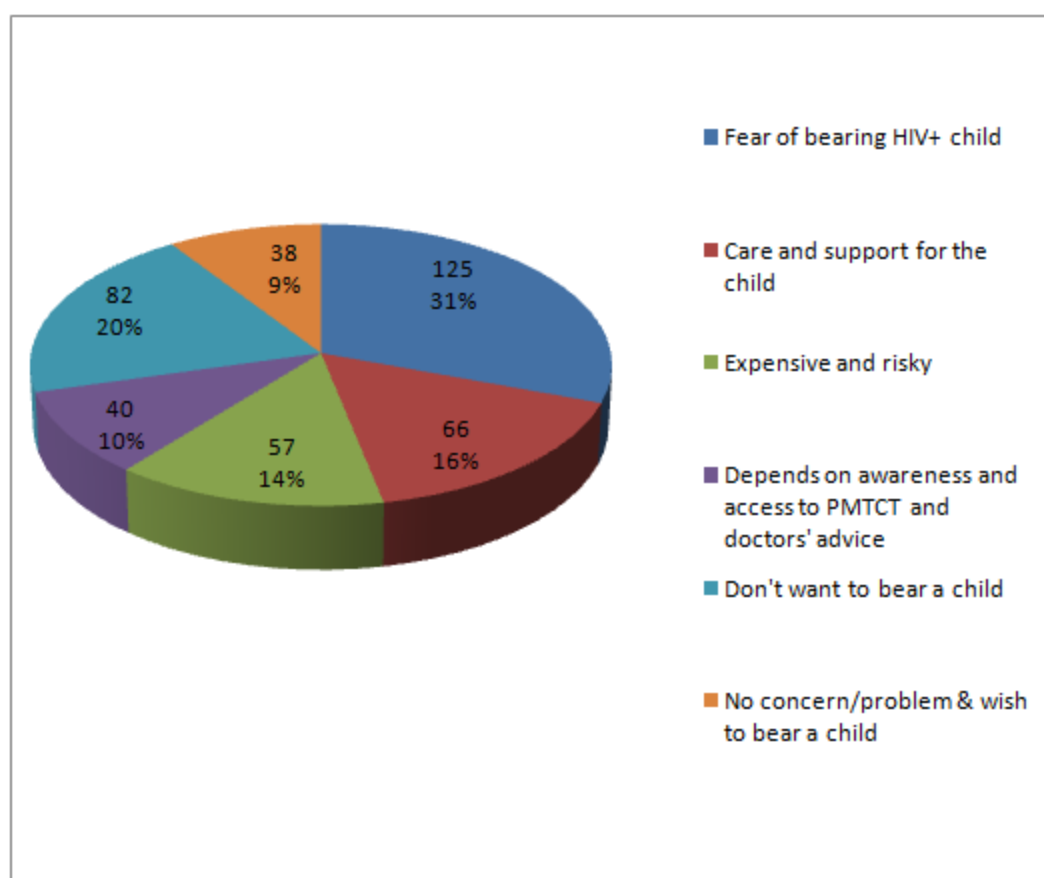
4.4 Having Children when HIV Positive

Looking at the peculiar situation of PLHIV, one of the challenges facing them in general is the possibility of them successfully having children without unusual complication. This is so because PLHIV must take into consideration many factors before even deciding whether to do it or not. The situation is even more challenging for a Third World country like Liberia where access to advanced technology is still limited, either because they are not available or they are not affordable. The majority of the general population lives in poverty and can barely make ends meet daily. Predicated on some of these conditions, the Stigma Index Roll-out Study followed respondents' views and experiences on the issues to get an insight into the crust of the problems and challenges in Liberia. The results revealed that out of 408 PLHIV who responded to this question (310 female, 98 males), 82 persons said that they don't want to bear child(ren) for several reasons ranging from having too many children, reaching menopause, to high risks and cost attached to being positive and having a child. A large proportion of them tend to be faced with a number of challenges and problems. One out of every three person said that they are challenged by the fear of bearing HIV positive babies while one out of every six respondents indicated care and support for the child as their primary challenge. Regarding the economic situation where many Liberians live below the poverty line due to high unemployment rate and high cost of living, particularly special population like the PLHIV who have limited sources of income, it is reasonable to say the cost of caring for a child born to an HIV positive mother is beyond the reach of many of them, especially the purchasing of powder milk. Consistent with this, 57 persons lamented that it is expensive and risky

to bear a child when HIV+. They advanced reasons such as the probability of transferring the virus to the child either during pregnancy, child birth or breastfeeding for those who cannot afford to buy powder milk; the deterioration of the health of the mother, the need for adequate nutritious food, fear of the side effects of the medication on the mother and the unborn baby and lowering CD4 counts. Forty persons indicated that the decision and the ability to bear child depends on awareness on and access to PMTCT and the doctors' advice considering the number of factors that need to be considered before venturing into having a child.

However, 38 persons expressed that they do not see any problem or challenge with bearing child especially with the availability of PMTCT.

Figure 15: Distribution of problem/challenges by having a child (ren) when HIV+





5.0 DISCUSSION

5.1 General information about respondents and his/her household

The majority of PLHIV respondents were females (74%). The survey also reveals that 86.31% of respondents live in large towns or cities followed by those who live in small town or village (9.75%). These findings relate to similar study in most of the countries that have rolled out the index and shows that women seem to bear more burden of the epidemic than their male counterpart. This is also consistent with the 2007 Liberia Demographic Health Survey findings which reveal that HIV is more prevalent among adult women age 15-49 (1.8%) than adult men of the same age category (1.2%). It points to the need for more female directed intervention that will reduce their vulnerability to HIV.

Most PLHIV have got to know their status in the last four years (two-thirds of them), with progressive increase in getting to know about one's status over the last 9 years but a sharp decline in the last 1 year. This suggests that though the first case of HIV was diagnosed in Liberia in 1986¹¹ testing and diagnosis has not been very effective as evident by the number of persons who came to know their status just approximately four years ago. Many factors could be responsible for this sluggishness in the procedure such as the war and the low incidents of infection by the virus; however, the forces of stigma and discrimination are key drivers that have been holding many people back from performing their test, particularly in its early discovery when these sentiments were extremely high thus making many people to prefer dying than to be tested for and diagnosed of HIV.

Social protection and mitigation factors outside of the support groups are limited for PLHIV respondents. Many variables could possibly be responsible for this. However, evidence from the study instigates the limited intimate relationship, the negative attitude of society towards them particularly those of their friends and family members and the self-castigating perception they harbor of themselves as fundamental underlying factors. More than 60% of the respondents are either in unsecured relationship or not in any relationship at all. Some PLHIV have even been rejected by their partners and family members who came to know their status either by personal disclosure or through other means. It is therefore important that social protection and inclusion programs are designed and implemented that will not only empower PLHIV but will also involve key individuals in their lives understanding their conditions and being supportive of them.

Most of the PLHIV respondents (76.57%) reported that they are sexually active. Judging on the basis that the main mode of HIV transmission in Liberia is through sexual intercourse, particularly heterosexual intercourse, this raises concerns and shows the need for sustained awareness raising and education on the issues of prevention to curb the spread of the disease and minimize the chances of re-infection.

¹¹ The first HIV case was detected at the Currant Lutheran Hospital in Zorzor, Lofa County in 1986.

Consistent with the overall educational level of the country, the level of education among PLHIV respondents is generally low, particularly technical and higher education (11%). This also shows up in the employment arena where only 8% of the respondents are in full time employment, while another 6.4% are part time employees. While HIV status could be a reason for the low level of employment as indicated in the responses, educational level and the country's economic condition remain another set of unimpeachable reasons for the low level of employment.

5.2 Experience of External and Internal Stigma by PLHIV Respondents

Stigma and discrimination remain pervasive in the Liberian society and linger as key impediments to the prevention of HIV, and the care and support of PLHIV. Compared with external stigma, PLHIV respondents are nearly 3 times more likely to experience internal stigma than stigma from other people. Basically, the most common type of external stigma experienced by PLHIV is gossip as evidenced by their knowledge of awareness of people gossiping about them (48%) followed by verbal insults (32%). On the other hand, internal stigma involving shame (67%) and guilt (55%) ranked at the upper extreme of the types of internal stigma experienced by PLHIV. Most respondents believe that people stigmatize and discriminate against them because they fear getting infected by them through casual contact and because they have limited knowledge as to how the virus is transmitted. This finding is consistent with findings from most countries including Nigeria and Swaziland where internal stigma is more common among PLHIV respondents.

The experience of stigma and discrimination is one of the greatest impediments to the fight against HIV/AIDS. These social menaces have the propensity to deter people from knowing their status and practicing safe and healthy behaviours to counter the spread of the disease. On that account for an HIV prevention and response program to maximize results it must understand the extent of this problem to enable them develop strategies that will make the program more effective and efficient. It speaks of the need for continuous efforts in to address the issues of stigma and discrimination for an effective and efficient programming/intervention.

Most of the PLHIV respondents harbour some sorts of fear. In the light of this, 294 persons representing 61% of the total respondents of 483 reported that they have fear of being gossiped about. Another 239 representing 49% indicated that they are afraid that someone would not want to be sexually intimate with them because of their status. Fear is another cardinal issue for PLHIV and one of the drivers that have the propensity to deter this population from testing, disclosure and seeking support. While it is true that the fear level varies across the parameters, it however shows that many PLHIV have fear of one form or the other. This therefore points to an issue closely related to internal stigma that needs to be addressed concomitantly if the fight against the pandemic must emerge victorious. There is a need to increase efforts to neutralize the minds of PLHIV in terms of their fear and to work to reduce and/or remove those factors that give rise to the fears.



Though many PLHIV respondents have heard of key documents that promote and protect their rights (61%), only a few of them have read these key documents (28-29%). What this means is that many PLHIV may not be able to take effective actions in defence of their rights when abused since many do not know what their rights are, and what measures to take to seek redress. This leaves the need for more efforts to enable PLHIV have a reasonable understanding of these documents to be able to take actions as required. It is worth noting here that the low level of knowledge of PLHIV respondents on their rights run across most country that have rolled out the study, for instance, Swaziland.

Similarly, most PLHIV respondents (63.98%) have not mustered the courage to effect positive change by either educating people about the wrong inherent in the act of stigma and discrimination, or taking action against these people to stop such behaviour and warn would-be doers to desist from the practice. In as much as there is a need for external support to reduce the scorching effects of these nightmares, there is equally the need for PLHIV to take initiatives directed towards finding solution to their problems. It is interesting to note that changes that emanate from one-self are often more effective and sustainable than those provided by others.

5.3 Testing and Diagnosis

Many PLHIV respondents were tested for reasons other than just their desire to know their status. Twenty-eight percent (28%) were tested due to suspected HIV related symptoms; 24% tested due to illness or death of spouse; while 14% were tested during antenatal care. While it is true that the HIV test could be done at any time, it medically advisable to get to know your status early so as to avoid the deterioration of one's health by taking measures that will maintain and/or increase the CD4 count level. It is therefore important that people be encouraged to do their HIV test when they are healthy. Encouragingly, the decision to be tested for HIV was a choice made by 316 representing 65% of total respondents. Most respondents (79%) have said that they received pre-test and post-test counselling during their HIV diagnosis process. However, about 4% did not receive any counselling at all.

5.4 Disclosure and Confidentiality

Interestingly, 15% of respondents hinted that they were aware their status was revealed by social workers and medical practitioners. Similarly, 35% of PLHIV respondents feel that their medical records were not confidentially kept while 10% were not sure if their medical records are kept in confidence. These might be relatively smaller percentages; however, a breach of confidentiality gets PLHIV disappointed and affects their willingness to trust others in terms of disclosing their status. Hopefully, 61% of respondents said they find the disclosure of their HIV status

as an empowering experience. This shows that with all the challenges faced by PLHIV respondents, a good number still feel that the disclosure of status is empowering. This signals hope that with increase awareness and support for PLHIV they will be able to disclose their status.

5.5 Treatment

More than two-thirds of the PLHIV respondents (89%) described their health status between good and excellent. Similar number of PLHIV respondents (89%) expressed that they are currently taking ARV treatment. This is encouraging, and could help greatly in the achievement of the HIV/AIDS Millennium Development Goals that speaks of zero HIV related death by 2015 provided the progress made in this arena is sustained through relevant interventions such as reducing stigma and discrimination, encouraging disclosure and improving the regimen.



6.0 CONCLUSION

The HIV-related stigma and discrimination study is a global study being rolled out by countries around the globe. The main objective of the study is to document the various experiences of PLHIV within their communities regarding HIV-related stigma and discrimination at the levels of the individual, family, community and the nation. It also seeks to increase the evidence base for policies and programs to reduce HIV related stigma and discrimination as we strive to meet the goals of the MDG. The Liberian study was conducted by PLHIV with 530 respondents around the country using questionnaire, focus group discussion and key informant interviews.

Stigma and discrimination remain pervasive in the Liberian society and linger as key impediments to the prevention of HIV, and the care and support of PLHIV. Compared with external stigma, PLHIV respondents are nearly 3 times more likely to experience internal stigma than stigma from other people. Basically, the most common types of external stigma experienced by PLHIV are gossip and verbal insults, while shame, guilt and low self-esteem are the most common type of internal stigma experienced by them.

University/technical education among PLHIV respondents is low as well as the employment level, as it is just a relatively small proportion of PLHIV respondents are in full time employment. There is a critical gap in the knowledge of PLHIV respondents on their rights and responsibilities. Similar gaps seem to exist among people on the mode of transmission of HIV as suggested by the perception of PLHIV respondents on the perceived reasons for people stigmatizing or discriminating against them.

Encouragingly, most PLHIV respondents are on ART and have described their health as good. This is a positive sign for the realization of the MDG that calls for zero HIV related death by 2015.

Nonetheless, more carefully strategized interventions are required to combat the menace of stigma and discrimination, increase the knowledge of people on the mode of transmission of HIV that might be contributing to their negative attitude towards PLHIV, discuss the contents of policies and laws that protect the rights of PLHIV so that they can be aware of their rights and responsibilities and be able to take action as necessary.

7.0 Recommendations

The findings of the survey points to a number of things that need to be done in order not just to minimize and/or eradicate the menace of stigma and discrimination but to create the necessary conditions under which PLHIV can thrive. Arising from the findings, these recommendations also correspond to the views and suggestions of PLHIV and some stakeholders in the fight for the overall prevention of HIV/AIDS in Liberia. They were born out of the three processes used to collect data for the survey that include the questionnaire, focus group discussion and key informant interviews. They are:

1. Seek the establishment of an empowerment scheme for PLHIV. This could include academic program and vocational training, business, etc. depending on individual need and context;
2. Re-strategize awareness raising methodologies to enhance knowledge of the general population on the nature of HIV, particularly on the mode of transmission and the need to support and care for people living with and affected by HIV/AIDS. Many people still seem jittery about HIV and do not understand the mode of transmission, for which they fear getting infected through casual contact. This could involve specifically including HIV in school curriculum, working with religious leaders, working with families, etc.;
3. Build the capacity of PLHIV over time, to enable them take initiatives on their own and breach the capacity gaps prevalent among PLHIV. This should be done through a diversified approach that will recognize all sectors of the PLHIV population. It could be through mentorship, apprenticeship, skills training, professional placement, etc.;
4. Provide supplementary feeding to PLHIV on treatment to enable them resist the strength of the medication and encourage them follow the treatment procedure;
5. Provide supplementary feeding, incentive and support to HIV+ mothers and their babies during pregnancy and continue support for the child until completion of primary education;
6. Encourage and support PLHIV into the medical field so that they can be actively involved in the provision of care and support to colleagues;



7. Actively involve PLHIV to the extent possible and necessary in all activities affecting them for ownership and sustainability;
8. Expand testing and treatment centres to more locations across the country to increase access to as many PLHIV as possible, particularly in the rural areas;
9. Seek means to improve the current types of ART to reduce the side effects of the medication which may be a contributing factor for loss to follow-up and the failure to follow treatment procedure;
10. Increase the number of CD4 count machines around the country to enable people know their status level and make some key decisions in their lives such as bearing child;
11. Reduce the HIV Law into simple English and disseminate it. Put in place a program to educate PLHIV on key documents that protect their rights.
12. Provide continuous training for health care providers and social workers on how to care for and support PLHIV, including respecting the principle of confidentiality;
13. Advocate for the rights of PLHIV through their network, civil society organizations and government institutions such as NAC and NACP. This should also be a part of the empowerment process for PLHIV to enable them advocate for themselves rather than people continuously advocating for them;
14. Establish a complaint and response mechanism to get information from and provide feedback to PLHIV on services provided to them. This will help improve the way people work with them through their involvement and participation in issues that affect them.

ANNEXES

Annex 1: Source Data Tables

Table 1: Number of respondents by sex and age group

age group	male	% of male	Female	% of female	Transgender	% of transgender	Total	% total
Youth aged 18-19	1	0.82%	12	3.32%	0	0%	13	3%
Adult aged 20-24 years	8	6.56%	49	13.57%	0	0%	57	12%
Adult aged 25-29 years	18	14.75%	85	23.55%	0	0%	103	21%
Adult aged 30-39 years	40	32.79%	128	35.46%	0	0%	168	35%
Adult aged 40-49 years	47	38.52%	77	21.33%	0	0%	124	26%
Adult 50+ years	8	6.56%	10	2.77%	0	0%	18	4%
Total	122	100.00%	361	100.00%	0	0%	483	100%

Table 2: Number of respondents by Relationship Status

Relationship status	Female	% of female	Male	% of male	Total	% total
Married/cohabiting with partner home	96	26.59%	53	43.44%	149	31%
Married/cohabiting but partner away	25	6.93%	4	3.28%	29	6%
In a relationship but not living together	75	20.78%	23	18.85%	98	20%
Single	129	35.73%	35	28.69%	164	34%
Divorced/separated	14	3.88%	6	4.92%	20	4%
Widow/Widower	22	6.09%	1	0.82%	23	5%
Total	361	100.00%	122	100.00%	483	100%

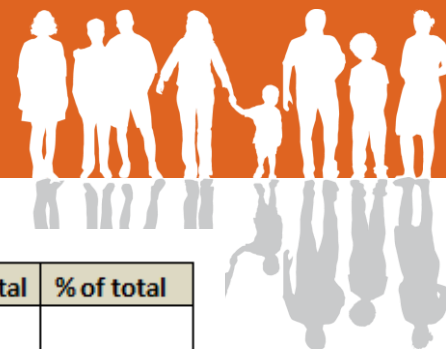


Table 3: Number of respondents by categories/associations

Categories	Male	%	Female	%	Total	% of total
Men who have sex with men	11	9.02%	1	0.28%	12	2%
Gay or lesbian	1	0.82%			1	0%
Transgender			3	0.83%	3	1%
Sex worker	2	1.64%	10	2.77%	12	2%
Injecting drug user	3	2.46%			3	1%
Refugee or asylum seeker	9	7.38%	32	8.86%	41	8%
Internally displaced person	17	13.93%	47	13.02%	64	13%
Member of an indigenous group	9	7.38%	44	12.19%	53	11%
Migrant worker	1	0.82%	1	0.28%	2	0%
Prisoner					0	0%
None	69	56.56%	223	61.77%	292	60%
Total	122	100.00%	361	100.00%	483	100%

Table 4: Number of respondents by level of education

Level of education	Male	% of male	Female	% of female	Total	% of total
No formal education	10	8.20%	105	29.09%	115	24%
Primary school	33	27.05%	118	32.69%	151	31%
Secondary school	45	36.89%	120	33.24%	165	34%
Technical college/university	34	27.87%	18	4.99%	52	11%
Total	122	100.00%	361	100.00%	483	100%

Table 5: Number of respondents by employment status

Employment status	Male	% of male	Female	% of female	Total	% of total
In full-time employment/employee	15	12.30%	24	6.65%	39	8.07%
In part-time employment/employee	12	9.84%	19	5.26%	31	6.42%
Working full-time not as employee/self employed	18	14.75%	34	9.42%	52	10.77%
Casual worker/self employed	36	29.51%	66	18.28%	102	21.12%
Unemployed and not working at all	41	33.61%	218	60.39%	259	53.62%
Total	122	100.00%	361	100.00%	483	100.00%

Table 6: Number of respondents by experience of external stigma and discrimination

Type of stigma and discrimination	Never	Once	A few times	Often	Total
Excluded from social gathering	416	22	27	18	483
Excluded from religious activities/place of worship	448	14	14	7	483
Excluded from families activities	405	30	25	23	483
Aware of being gossiped about	252	52	89	90	483
Verbally insulted	329	72	48	34	483
Physically harassed/threatened	402	42	21	18	483
Physically assaulted	381	56	28	18	483
Subjected to psychological pressure of manipulation by partner	386	52	23	22	483
Experienced sexual rejection	398	35	26	24	483
Discriminated against by PLHIV	455	13	12	3	483
Other in household experience stigma/discrimination	390	42	34	17	483

Table 7: Number of responses by reason of stigma & discrimination

	Male	% of male	Female	% of female	Total	% of total
People are afraid of getting infected with HIV from me	28	26.21%	98	32.21%	126	26%
People don't understand how HIV is transmitted and are afraid I will infect them with HIV through casual contact	24	14.56%	106	21.48%	130	27%
People think that having HIV is shameful and they show not be associated with me	12	10.68%	40	9.06%	52	11%
Religious beliefs or moral judgment	4	1.94%	4	0.67%	8	2%
People disapprove of my lifestyle or judgment	7	3.88%	7	2.35%	14	3%
I look sick with symptoms associated HIV	6	3.88%	17	4.36%	23	5%
I don't know/I am not sure of the reason	41	38.83%	89	29.87%	130	27%
Total	122	100.00%	361	100.00%	483	100%



Table 8a: Number of respondents by access to work, health and education

Level of access	Never	Once	A few times	Often	Total
Forced to change resident/unable to rent accommodation because of HIV status	377	85	14	7	483
Lost a job or another source of income because of HIV status	426	46	10	1	483
Change of job description or nature of work, or refused promotion because of your HIV status	456	22	2	3	483

Table 8b: Number of respondents by access to work, health and education

Level of access	Never	Once	A few times	Often	Not applicable	Total
Dismissed, suspended prevented from attending educational institution because of HIV status	451	6	0	0	26	483
Child (ren) Dismissed, suspended prevented from attending educational institution because of your HIV status	451	6	2	2	22	483
Denied health/dental services because of HIV status	455	9	3	0	16	483

Table 9: Number of respondents by refusal of employment/work opportunity, denial of family planning and reproductive health services

Level of access	Yes	% of yes	No	% of no	Total	% of total
Refused employment or a work opportunity because of HIV status	33	6.83%	450	93.17%	483	100.00%
Denied family planning services because of HIV status	24	4.97%	459	95.03%	483	100.00%
Denied sexual and reproductive health services because of HIV status	16	3.31%	467	96.69%	483	100.00%

Type of experience	Response								Total			
	Yes				No				Yes		No	
	M	%	F	%	M	%	F	%	#	%	#	%
I feel ashamed	81	66.39%	244	67.59%	41	33.61%	117	32.41%	325	67%	158	33%
I feel guilty	65	53.28%	199	55.12%	57	46.72%	162	44.88%	264	55%	219	45%
I blame myself	68	55.74%	190	52.63%	54	44.26%	171	47.37%	258	53%	225	47%
I blame others	20	16.39%	66	18.28%	102	83.61%	295	81.72%	86	18%	397	82%
I have low self esteem	47	38.52%	152	42.11%	75	61.48%	209	57.89%	199	41%	284	59%
I feel I should be punished	7	5.74%	30	8.31%	105	94.26%	331	91.69%	37	8%	436	90%
I feel suicidal	14	11.48%	42	11.63%	108	88.52%	319	88.37%	56	12%	427	88%
I have chosen not to attend social gatherings	24	19.67%	70	19.39%	98	80.33%	291	80.61%	94	19%	389	81%
I have isolated myself from my family and/or friends	19	15.57%	70	19.39%	103	84.43%	291	80.61%	89	18%	394	82%
I took the decision to stop working	14	11.48%	55	15.24%	108	88.52%	310	84.76%	69	14%	418	87%
I decided not to apply for a job/work or for a promotion	9	7.38%	43	11.91%	113	92.62%	318	88.09%	52	11%	431	89%
I withdrew from education/training or did not take up an opportunity for education/training	17	13.93%	41	11.36%	105	86.07%	320	88.64%	58	12%	425	88%
I decided not to get married	22	18.03%	66	18.28%	100	81.97%	295	81.72%	88	18%	395	82%
I decided not to have sex	12	9.84%	82	22.71%	110	90.16%	279	77.26%	94	19%	389	81%
I decided not to have (more) children	58	47.54%	192	53.19%	64	52.46%	169	46.81%	250	52%	233	48%
I avoided going to a local clinic when I needed to	29	23.77%	96	26.59%	93	76.23%	265	73.41%	125	26%	358	74%
I avoided going to a hospital when I needed to	17	13.93%	30	8.31%	105	86.07%	331	91.69%	47	10%	436	90%



Table 11: Number of respondents by level of fears

Type of experience	Response								Total			
	Yes				No				Yes		No	
	M	%	F	%	M	%	F	%	#	%	#	%
Being gossiped about	75	61.48%	219	60.66%	47	38.52%	142	39.34%	294	61%	189	39%
Being verbally insulted, harassed and/or threatened	50	40.98%	124	34.35%	72	59.02%	237	65.65%	174	36%	309	64%
Being physically harassed and/or threatened	34	27.87%	97	26.87%	88	72.13%	264	73.13%	131	27%	352	73%
Being physically assaulted	37	30.33%	96	26.59%	85	69.67%	265	73.41%	133	28%	350	72%
Afraid that someone would not want to be sexually intimate with you because of your HIV-positive status	65	53.28%	174	48.20%	57	46.72%	187	51.80%	239	49%	244	51%

Table 12: Number of respondents by Knowledge of their rights, laws and policies

Knowledge	Response								Total			
	Yes				No				Yes		No	
	M	%	F	%	M	%	F	%	#	%	#	%
Have you heard of the Declaration of Commitment on HIV/AIDS	81	66.39%	216	59.83%	41	33.61%	145	40.17%	297	61%	186	39%
If yes have you ever read or discussed the content of this Declaration	34	27.87%	103	28.53%	88	72.13%	258	71.47%	137	28%	346	72%
Have you heard of the HIV/AIDS law	64	52.46%	226	62.60%	58	47.54%	135	37.40%	290	60%	193	40%
If yes, have you read or discussed the content of the HIV/AIDS law?	32	26.23%	109	30.19%	90	73.77%	252	69.81%	141	29%	342	71%

Table 13: Number of respondents by level of effecting change

Level of change	Response								Total			
	Yes				No				Yes		No	
	M	%	F	%	M	%	F	%	#	%	#	%
Confronted, Challenged or educated someone who was stigmatizing or discriminating against you?	46	37.70%	128	35.46%	76	62.30%	233	64.54%	174	36%	309	64%
Knowledge of organization/groups to go to for help if you experience stigma/discrimination?	93	76.23%	266	73.68%	29	23.77%	95	26.32%	359	74%	124	26%

Table 14: Number of respondents by involvement with, and/or support to each other

Level of change	Response								Total			
	Yes				No				Yes		No	
	M	%	F	%	M	%	F	%	#	%	#	%
In the last 12 months have you supported other people living with HIV?	90	73.77%	262	72.58%	32	26.23%	99	27.42%	352	73%	131	27%
Are you currently a member of a people living with HIV support group and/or network?	79	64.75%	282	78.12%	43	35.25%	79	21.88%	361	75%	122	25%
In the last 12 months have you been involved, either as a volunteer or an employee, in any program that provides assistance to people living with HIV?	54	44.26	157	43.49%	68	55.74	204	56.51%	211	44%	272	56%
In the last 12 months, have you been involved in any efforts to develop legislation, policies or guidelines related to HIV?	29	23.77	76	21.05%	93	76.23	285	78.95%	105	22%	378	78%

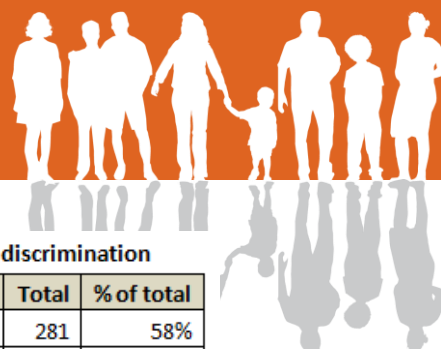


Table 15: Number of respondents by recommendations to address stigma and discrimination

Recommendation	Male	%	Female	%	Total	% of total
Advocating for the rights of all PLHIV	74	60.66%	207	57.34%	281	58%
Providing support to PLHIV by providing emotional, physical and referral support	15	12.30%	71	19.67%	86	18%
Advocating for the rights and/or providing support to particularly marginalized group (MSM, injecting drug user, sex worker)	4	3.28%	9	2.49%	13	3%
Educating PLHIV about living with HIV (including treatment literacy)	12	9.84%	26	7.20%	38	8%
Raising the awareness and knowledge of the public about AIDS	17	13.93%	48	13.30%	65	13%
Total	122	100.00%	361	100.00%	483	100%

Table 16: Number of respondents by reason(s) for testing

Why were you tested for HIV?	Male	%	Female	%	Total	% of total
Employment	4	3.28%	6	1.66%	10	2%
Pregnancy	1	0.82%	68	18.84%	69	14%
To prepare for a marriage/sexual relationship	1	0.82%	1	0.28%	2	0%
Referred by a clinic for STI	12	9.84%	40	11.08%	52	11%
Referred due to suspected HIV-related symptoms	35	28.69%	99	27.42%	134	28%
Husband/wife/partner/family member tested positive	8	6.56%	14	3.88%	22	5%
Illness or death of husband/wife/partner/family member	31	25.41%	86	23.82%	117	24%
I just wanted to know	26	21.31%	42	11.63%	68	14%
Other	4	3.28%	5	1.39%	9	2%
Total	122	100.00%	361	100.00%	483	100%

Table 17: Number of respondents by control of decision to be tested

Was the decision to be tested for HIV up to you?	Male	%	Female	%	Total	% of total
Yes, I took the decision myself to be tested	86	70.49%	230	63.71%	316	65%
I took the decision to be tested, but it was under pressure from others	16	13.11%	42	11.63%	58	12%
I was made to take an HIV test (coercion)	12	9.84%	69	19.11%	81	17%
I was tested without my knowledge-I only found out after the test had been done	8	6.56%	20	5.54%	28	6%
Total	122	100.00%	361	100.00%	483	100%

Table 18: Number of respondents by receipt of counseling during testing

Did you receive counseling when you were being tested for HIV?	Male	%	Female	%	Total	% of total
I received both pre- and post-HIV test counseling	96	78.69%	287	79.50%	383	79%
I only received pre-test HIV counseling	8	6.56%	26	7.20%	34	7%
I only received post-test HIV counseling	10	8.20%	37	10.25%	47	10%
I did not receive any counseling when I had an HIV test	8	6.56%	11	3.05%	19	4%
Total	122	100.00%	361	100.00%	483	100%

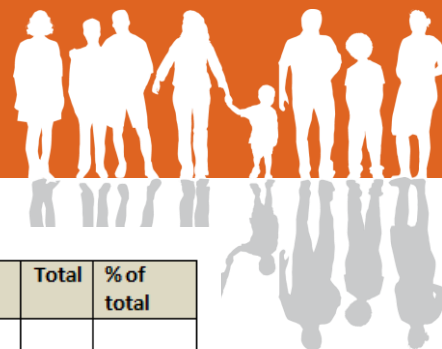


Table 19: Number of respondents by pressure to disclose status

Experience of pressure	Never	%	Once	%	A few times	%	Often	%	Total	% of total
How often do you feel pressure from other PLHIV or from groups or networks of PLHIV to disclose your HIV status?	346	71.64%	32	6.63%	32	6.63%	73	15.11%	483	100.00%
How often do you feel pressure from non PLHIV (eg. family members, social workers, etc.) to disclose your HIV status?	348	72.05%	43	8.90%	40	8.28%	52	10.77%	483	100.00%

Table 20: Number of respondents by how much they know medical practitioner have disclosed their status

	Response						Total	
	Yes		No		Not sure			
	#	%	#	%	#	%	#	%
Has a health care professional (eg. A doctor, nurse, counsellor, lab technician) ever told other people about your HIV status without your consent?	76	15.73%	258	53.42%	149	30.85%	483	100.00%

Table 21: Number of respondents by how much they believe their HIV medical records are kept confidential

How confidential do you think the medical records relating to your HIV status are?	Male	%	Female	%	Total	% of total
I am sure that my medical records will be kept completely confidential	65	53.28%	201	55.68%	266	55%
I don't know if my medical records are confidential	45	36.89%	125	34.63%	170	35%
It is clear to me that my medical records are not being kept confidential	12	9.84%	35	9.70%	47	10%
Total	122	100.00%	361	100.00%	483	100%

Table 22: Number of respondents by how they find the disclosure of their status?

	Response						Total	
	Yes		No		Not applicable			
	#	%	#	%	#	%	#	%
Did you find the disclosure of your HIV status an empowering experience?	298	61.70%	113	23.40%	72	14.91%	483	100.00%

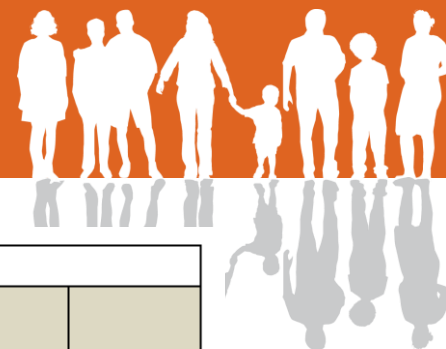


Table 23: Number of respondents by current status of health						
In general, how would you describe the status of your health at the moment?	Male	%	Female	%	Total	% of total
Excellent	26	21.31%	101	27.98%	127	26%
Very good	37	30.33%	77	21.33%	114	24%
Good	49	40.16%	141	39.06%	190	39%
Fair	6	4.92%	35	9.70%	41	8%
Poor	4	3.28%	7	1.94%	11	2%
Total	122	100.00%	361	100.00%	483	100%

Table 24: Number of respondent by status of treatment												
Treatment status	Response								Total			
	Yes				No				Yes		No	
	M	%	F	%	M	%	F	%	#	%	#	%
Are you currently taking antiretroviral treatment?	103	84.43%	326	90.30%	19	15.57%	35	9.70%	429	89%	54	11%
Do you have access to antiretroviral treatment, even if you are not currently taking it?	110	90.16%	330	91.41%	12	9.84%	31	8.59%	440	91%	43	9%
Are you currently taking any medication to prevent or treat opportunistic infections?	99	81.15%	318	88.09%	23	18.85%	43	11.91%	417	86%	66	14%
Do you have access to medication for opportunistic infections, even if you are not currently taking it?	93	76.23%	319	88.37%	29	23.77%	42	11.63%	412	85%	71	15%
In the last 12 months, have you had a constructive discussion with a health care professional on the subject of your HIV-related treatment options?	90	75.63%	215	59.56%	32	24.37%	146	40.44%	305	63%	178	37%
In the last 12 months, have you had a constructive discussion with a health care professional on the other subjects such as your sexual and reproductive health, sexual relationship, etc.?	69	56.56%	204	56.51%	53	43.44%	157	43.49%	273	57%	210	43%

Table 25: Number of respondents who have children												
	Response								Total			
	Yes				No				Yes		No	
	M	%	F	%	M	%	F	%	#	%	#	%
Do you have child/children?	101	82.79%	312	86.43%	21	17.21%	49	13.57%	413	86%	70	14%
If yes, are any of these children known to be HIV positive?	20	16.39%	83	22.99%	102	83.61%	278	77.01%	103	21%	380	79%

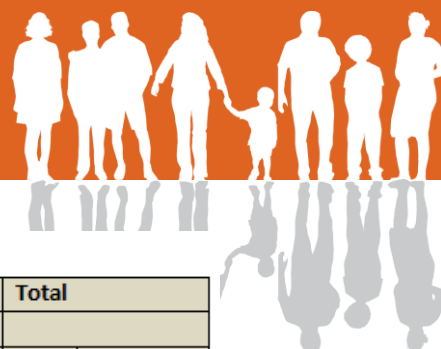


Table 26: Number of respondents by advice/decision having children

	Response						Total	
	Yes		No		Not applicable			
	#	%	#	%	#	%	#	%
Since being diagnosed as HIV positive, have you ever received counselling about your reproductive options?	318	65.84%	135	27.95%	30	6.21%	483	100.00%
Has a health care professional ever advised you not to have a child since you were diagnosed as HIV positive?	96	19.88%	353	73.08%	34	7.04%	483	100.00%
Has a health care professional ever coerced you into being sterilized since you were diagnosed as HIV positive?	72	14.91%	369	76.40%	42	8.70%	483	100.00%
Is your ability to obtain antiretroviral treatment conditional on the use of certain forms of contraception?	84	17.39%	282	58.39%	117	24.22%	483	100.00%

Table 27: Number of respondents (female) by coercion from HCP to:

In the last 12 months, have you been coerced by a health care professional in relation to any of the following because of your HIV status?	Response						Total	
	Yes		No		Not applicable			
	#	%	#	%	#	%	#	%
Termination of pregnancy (abortion)	15	4.16%	232	64.27%	114	31.58%	165	45.71%
Method of giving birth	78	21.61%	180	49.86%	103	28.53%	150	41.55%
Infant feeding practices	72	19.94%	175	48.48%	114	31.58%	72	19.94%

Table 28: Number of female respondents by receipt of antiretroviral treatment to prevent mother-to-child transmission of HIV during pregnancy

Have you ever been given antiretroviral treatment to prevent mother-to-child transmission of HIV during pregnancy?	Total	
	#	%
Yes -I have received such treatment	156	43.21%
No-I didn't know that such treatment existed	32	8.86%
No-I was refused such treatment	7	1.94%
No-I did not have access to such treatment	38	10.53%
No-I was not HIV positive when pregnant	128	35.46%
Total	361	100.00%

Table 29: Years of knowledge of HIV status

Years					Total	
	M	%	F	%	#	%
0-1 yr	17	13.93%	57	15.79%	74	15.32%
1-4 yrs	61	50.00%	185	51.25%	246	50.93%
5-9 yrs	37	30.33%	103	28.53%	140	28.99%
10-14 yrs	5	4.10%	16	4.43%	21	4.35%
15+ yrs	2	1.64%	0	0.00%	2	0.41%
Total	122	100.00%	361	100.00%	483	100.00%



Annex 2: Procedure/Guide for FGD & Key Informant Interview Guide/Procedure for the conduct of Focus Group Discussion & Key Informant Interview for the HIV Stigma Index Study Roll-out in Liberia

A. Procedure

Warmly greet the interviewee (greet with smile and extend hand shake)

Introduce yourself and the institution you are from

Explain the purpose for which you are there and how the information he/she will provide could make a difference in the lives of PLHIV

Explain the principle of confidentiality and how it will be respected

Get his/her consent by asking if he/she will like to share before proceeding

Begin the discussion with some current events or with some personal but open issues such as asking about his work or family

Proceed with the discussion when you see he/she is in a better mood to engage with you

Be observant and tune to his/her nonverbal messages

B. Questions for FGD & KII

1. What do you see as the main problems and challenges about HIV testing and diagnosis?
2. What do you see as the main problems and challenges about disclosure and confidentiality as HIV positive?
3. What do you see as the main problems and challenges about ARV treatment and care?
4. What do you see as the main problems and challenges about having children when HIV positive?
5. What do you see as the common types of stigma and discrimination experienced by PLHIV in your community or Liberia as a whole?
6. What do you think is the level of stigma and discrimination in Liberia? Is it taking an increasing, a decreasing or a static trend in the country? What do you think is responsible for this?

7. What will be your recommendations to reduce or stop stigma and discrimination against PLHIV in Liberia? Or, what five or ten things can you suggest to do so as to reduce or stop stigma and discrimination in Liberia?



Annex 3: Informed Consent Form



PEOPLE LIVING WITH HIV STIGMA INDEX Conducted by LIBNEP+ in collaboration with NAC & Partners' Initiative

INFORMED CONSENT FORM

(To be completed by the interviewee and the interviewer.)

My name is _____. I am administering a questionnaire about the experiences of people living with HIV, particularly the experiences of stigma and discrimination they may have had. I have provided you with an information sheet that describes the purpose of this survey and how the information collected from this interview will form part of a larger survey that is being conducted in this country to document some of the experiences of people living with HIV. The information sheet also outlined what types of information you will be asked, how we will keep this information confidential and the potential risks involved in your participating in this survey. Before we begin the questionnaire, I would like to make sure that you are voluntarily willing to participate in this survey and that you have obtained all the information that you need in order to make an informed choice about your participation.

This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. You do not have to decide today whether or not you will respond to this questionnaire. Before you make a decision, you can talk to anyone you feel comfortable with about the questionnaire and/or the survey. Please feel free to also contact the project team leader if you have any questions or concerns about this questionnaire or the survey. These are the contact details for the team leader:

Name _____

Contact(s): _____

If, however, you choose to respond to this questionnaire and thus participate in the survey, I will ask you some questions about some of your experiences as a person living with HIV, in particular those related to the experiences of stigma or discrimination you may have had. I expect that the interview will take between two

and three hours. Before asking you whether or not you would like to be a participant, I would like you to know that:

1. Your participation in this survey is entirely voluntary. It is your choice whether to participate or not.
2. You are free to not answer any of the questions in the questionnaire.
3. You may stop participating in the interview at any time that you wish.
4. You will be given an amount of US\$ 5.00 to help settle any expenses you may have incurred for your participation.

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

Do you consent to participating in the interview?

Yes (1)

No (2)

If **NO**: Thank you for your time.

If **YES**: Thank you for agreeing to take part in this project.

By saying yes, that means that you have read the information on the information sheet, or it has been read to you. You have had the opportunity to ask questions related to the questionnaire and the People Living with HIV Stigma Index survey and any questions you have asked have been answered to your satisfaction. You consent voluntarily to be a participant in this project and you understand that you have the right to end the interview at any time. If you agree, I will now sign this form to confirm that your consent has been obtained.

Signature/initials of interviewer: _____

Date of interview: _____

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

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



Signature/initials of interviewee: _____

Date of interview: _____

In case of any concerns related to issues of ethical violation(s), you may please contact the following individuals from the Institutional Review Board (Ethics Committee):

1. Ms. Cecelia Morris-0886-522 833
2. Jemee Tegli-0886-583 774

Annex 4: Confidentiality Agreement



PEOPLE LIVING WITH HIV STIGMA INDEX Conducted by LIBNEP+ in collaboration with NAC & Partners' Initiative

CONFIDENTIALITY AGREEMENT: INTERVIEWER

I, _____, an interviewer administering the People Living with HIV Stigma Index survey in Liberia, agree to the following:

(a) I will take all possible steps to protect the confidentiality of the information I receive during the interviews I conduct. This means that I will not disclose any personally identifying information to anyone, unless:

- i. explicitly instructed to do so by the participant in the pilot/study; or
- ii. compelled to disclose specific information under a court order of a competent court.

(b) I will not record any personally identifying information on the questionnaire.

(c) I will keep the “key” (contact list and questionnaire code) in a secure location (e.g. under lock and key), and stored separately from the questionnaires.

(d) Any information stored electronically will be on a password-protected system where I have sole access or in a password-protected file.

(e) Following the data entry and verification process, and upon instruction from the project leader with Partners' Initiative, I will destroy all completed questionnaires and the “key”. I will retain a contact list for the purpose of sharing results of the study with participants expressing interest in receiving such information.

INTERVIEWER:

Signature:

Name (printed):

Date:



Place (city, country):
PROJECT LEADER OR WITNESS:
Signature:
Name (printed):
Date:
Place (city, country):



PEOPLE LIVING WITH HIV STIGMA INDEX
Conducted by LIBNEP+ in collaboration with NAC & Partners' Initiative

CONFIDENTIALITY AGREEMENT: TEAM LEADER

I, _____, a team leader responsible for overseeing and supporting the delivery of the People Living with HIV Stigma Index survey in Liberia agree to the following:

(a) I will take all possible steps to protect the confidentiality of the information that is under my care. This means

that I will not disclose any personally identifying information to anyone, either verbally or in writing, unless:

- i. explicitly instructed to do so by a participant in the pilot/study; or
- ii. Compelled to disclose specific information under a court order of a competent court.

(b) I will take all possible steps to protect the confidentiality of employee/volunteer information in accordance with local laws and regulations.

(c) Any information stored electronically will be on a password-protected system or in a password-protected file, and I will ensure that only project employees/volunteers who need access to this information have the necessary password.

(d) I will instruct interviewers administering the People Living with HIV Stigma Index survey to keep the “key” (contact list and questionnaire code) in a secure location (e.g. under lock and key), and stored separately from the questionnaires.

(e) Following the data entry and verification process, I will destroy all completed questionnaires and the “key”. I will instruct interviewers to do the same. I will retain a contact list for the purpose of sharing results of the study with participants expressing interest in receiving such information.

(f) I will protect the identity of all people participating in the People Living with HIV Stigma Index survey. I will do nothing that discloses the identity of someone who is or has been associated with the project.

(g) I am responsible for ensuring that appropriate ethical standards are maintained in this project. As part of the training that is provided to interviewers administering the People Living with HIV Stigma Index survey, I will instruct them not to record any personally identifying information on the questionnaire. I will remove (or make illegible) any personally identifying information that I observe when reviewing completed questionnaires (e.g. while doing quality checks).

TEAM LEADER:

Signature:

Name (printed):

Date:

Place (city, country):

WITNESS:

Signature:

Name (printed):

Place (city, country):



PEOPLE LIVING WITH HIV STIGMA INDEX
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CONFIDENTIALITY AGREEMENT: DATA CLERK

I, _____, a data clerk assisting with the People Living with HIV Stigma Index survey project in Liberia, agree to the following:



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

(b) I will not enter any information into the electronic storage system that could be personally identifying. If I have doubts about whether or not information recorded on the questionnaire could be personally identifying, I will consult with the team leader. I understand that personally identifying information is to be removed from the paper questionnaire or made illegible (e.g. blacked out with a pen or marker).

(c) I will use computer equipment in accordance with the instructions provided to me by the team leader. I will keep the password or access code for computer equipment and files in a safe place, and I will not disclose this information to anyone unless explicitly instructed by the team leader.

(d) Back up copies of the data – whether on disk, electronic storage devices (e.g. “flash drives” or memory sticks) or in hard copy – will be stored in a secure location, in accordance with the instructions of the team leader.

DATA CLERK:

Signature:

Name (printed):

Date:

Place (city, country):

PROJECT LEADER OR ANOTHER WITNESS:

Signature:

Name (printed):

Date:

Place (city, country):



PEOPLE LIVING WITH HIV STIGMA INDEX
Conducted by LIBNEP+ in collaboration with NAC & Partners' Initiative

CONFIDENTIALITY AGREEMENT: DATA ANALYST

I, _____, a data analyst assisting with the People Living with HIV Stigma Index survey project in Liberia, agree to the following:

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

(b) I will use computer equipment and data in accordance with the instructions provided to me by the team leader. I will keep the password or access code for computer equipment and files in a safe place, and I will not disclose this information to anyone unless explicitly instructed by the team leader.

DATA CLERK:

Signature:

Name (printed):

Date:

Place (city, country):

PROJECT LEADER OR ANOTHER WITNESS:

Signature:

Name (printed):

Date:

Place (city, country):

