Lesotho Network of People Living with HIV and AIDS

THE PEOPLE LIVING WITH HIV STIGMA INDEX

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Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Treatment
ARV	Antiretroviral
BOS	Bureau of Statistics
CSO	Civil Society Organisations
FP	Family Planning
FNCO	Food and Nutrition Coordinating Office
GNP+	Global Network of PLHIV
GOL	Government of Lesotho
HCT	HIV Counselling and Testing
HIV	Human Immunodeficiency Virus
ICW	International Community of Women living with HIV
IDU	Injecting Drug User
LDHS	Lesotho Demographic and Health Survey
LENEPWHA	Lesotho Network of People Living with HIV&AIDS
LGBTI	Lesbians, Gay, Bisexual, Transgender and Intersex
LNFOD	Lesotho National Federation of Organisations of the Disabled
MOH	Ministry of Health
MSM	Men having sex with men
NGO	Non-Governmental Organizations
PEPFAR	The United States President's Emergency Plan for AIDS Relief
PHDP	Positive Health Dignity and Prevention
PLHIV	People Living with HIV
PMTCT	Prevention of Mother to Child Transmission
STIs	Sexually Transmitted Infections
SW	Sex Worker
TB	Tuberculosis
TWG	Technical Working Group
UNAIDS	Joined United Nations Programme on AIDS
WHO	World Health Organization
WFP	World Food Programme
WILSA	Women in Law for Southern Africa – Lesotho Chapter

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Foreword

The establishment of Lesotho Network of People living with HIV and AIDS in 2005 was a major step in the response to HIV and AIDS, and the fight against HIV&AIDS related stigma and discrimination in Lesotho.

In the history of the HIV&AIDS epidemic and since the first HIV National Strategic Plan in 2006, Lesotho has prioritised the prevention of new HIV infections and access to treatment, care and support. These can be achievable through the elimination of stigma and discrimination as an entry point for effective HIV & AIDS programmes. Truly, human rights violations such as stigma and discrimination faced by People living with HIV and AIDS and those affected have proven to threaten universal access to treatment and improved health conditions.

As LENEPWHA envisages supporting the Lesotho government in the response to HIV and AIDS, it commissioned the national HIV stigma index with the purpose to unravel to the surface, the element of impeding human rights violations as a threat to the to HIV response. Stigma and discrimination against people living with HIV and AIDS is still a challenge in Lesotho as the findings of this unique report highlight.

The hard individual experiences which build up this report cannot be taken for granted if Lesotho is to redress the situation; as it results in it being one of the poorly performing countries in harnessing the levels of new infections, and access to life saving Anti- retroviral treatment (ART).

The findings of this report will therefore be used to advocate against existent elements of stigma as they present within various settings in communities and service delivery points. It gives me great pleasure to present to the nation the stigma situation and findings and call upon all role players to support initiatives that are aimed at eliminating stigma and discrimination.

B.P.Ranthithi

EXECUTIVE DIRECTOR

Executive Summary

HIV stigma and discrimination is still one of the major barriers to accessing treatment, prevention, and care and support services. With findings from this study, LENEPHWA seeks to develop an evidence-based advocacy and resource mobilisation strategy targeting all players in the HIV multi-sectoral response. Stakeholders include PLHIVs, policy makers, planers, programme staff and financiers of the AIDS response.

Methodology

The study used a standard GNP+ Stigma Index questionnaire, whose interviews were conducted by PLHIV. The study was conducted from October to December 2013. About 1085 interviews were conducted, which included 50 people from most at risk groups (sex workers, MSM, IDUs, inmates), 737 females, 345 males and 3 transgender.

Major Findings

Background Characteristics: From a total surveyed population, about 70% were females. Over two-thirds of the population was aged 40 years and above. Majority (60%) of the respondents were urban residents and the rest were rural based. Among the key populations and vulnerable groups interviewed (243), most were migrant workers, inmates and key populations SW, IDU & transgender. 314 persons reported having had children orphaned by AIDS in their household. The average daily income was found to be M18.00 (USD1.75[1]). Also, more than 50% of the respondents reported having spent a day or more without enough food. Regarding education background, 62% of the PLHIV have primary education and 11% have no formal education. Furthermore, 63% PLHIV were unemployed.

Among the respondents, it was also reported that 72% of men and 54% of women were sexually active. 55% were currently married or cohabiting and 22% were widowed. Over half (52%) of PLHIV were living with HIV for about 5-9 years after diagnosis.

Social Exclusions: Gossip, verbal & physical abuse and exclusion from social, religious and family gatherings or activities, were the main forms of HIV related stigma and discrimination which were experienced by PLHIV with percentages ranging from 6.7% to 41.1%.

Access to Socio-Economic Services: Among those who experienced stigma and discrimination because of their HIV status, 43% experienced job loss or other sources of income, 15% were refused employment, 5% changed residence or were not allowed to rent private residences. Less than 4% were denied education services or dismissed from educational institutions. Less than 1% of children we denied or dismissed from educational institutions. In 12 months preceding the survey, less than 6% reported to have been denied access to health care services.

[1] 14th May 2014 exchange rate

Internalised Stigma and Fears: Feelings of internalised stigma and fears were prevalent; 31% blame others, 25% are ashamed to be living with HIV, 20% feel guilty.

As a result of self-stigma and fears, PLHIV tend to make personal decisions of exclusion or avoidance

The most common decisions were to avoid

- Having (more) children (33.5%)
- Sex (19.8%)
- Getting married (14.7%)

Rights, Laws and Policies: Overall, about one in ten of PLHIV reported to have had their rights violated in one form or another

- About 1 in 12 (8%) of PLHIV were forced to submit to a medical or health procedure which included HIV testing.
- About 1% have been denied health insurance because of HIV+ status in the last 12 month
- Less than 1% have been arrested or taken to court on a charge related to HIV status,
- Less than 1% had to disclose the HIV status to apply for residence or nationality

Of the PLHIV that had their rights violated, only about a quarter (25%) sought legal redress. Those that did not seek redress was as a result of bureaucratic and lengthy processes

Effecting Change: In the 12 months preceding the survey,

- Nearly 40% of the population reported to having confronted, challenged or educated someone who was stigmatising and/or discriminating
- 72.4% had knowledge of organisations or groups that support people living with HIV
- 81% have knowledge about PLHIV support groups and 43.5% know about Network of people living with HIV that they can help them address stigma and discrimination
- Just about 18.5% of the respondents reported to have been involved in efforts to develop legislation, policies or guidelines related to HIV
- 67.3% believe they had ability to influence legal/rights matters affecting people living with HIV.
- Over 50% believed advocating for the rights of all people living with HIV as a way of change in addressing stigma and discrimination

HIV Testing and Diagnosis: The study found that 4% of those that tested for HIV were pressured, 6% reported to have been forced to take HIV test. About 88.4% received pre and post HIV counselling.

Disclosure and Confidentiality: About 3.7% of respondents reported that their HIV status was disclosed by a health care worker without their consent and 23.4% believed their records were not kept confidential

Treatment: At the time of the survey,

- About 3 out of 4 PLHIV were in good to excellent health status
- Less than 5% were in poor health status
- Nearly all (96%) PLHIV were on treatment
- 38% were of those not accessing treatment were using alternative remedies
- 38% did not have access to OI treatment

Having children

- 59.3% of the respondents reported to have received counselling on reproductive health after being diagnosed with HIV while remaining 40.7% did not
- 22.3% were advised not to have children
- 17 (3.1%) persons reported to have accessed ARV treatment on condition they used some form of contraception
- 23.7% of the female respondents reported to have received ARV treatment to prevent mother to child transmission
- Total of 131 (97%) female respondents reported to have received information about healthy pregnancy and motherhood as part of the programme to prevent mother-to child transmission of HIV

Recommendations

a. All stakeholders must use evidence-based strategic information results of the Stigma Index study to inform legal reforms of policies and laws that protect and promote rights of PLHIV.
b. Inform targeted programming to address specific issues of stigma and discrimination, and PHDP
c. Increase awareness, engagement and advocacy with CSOs, Government & Development Partners on issues emanating from the Stigma Index study.
d. Develop an action plan based on common issues affecting PLHIV to be used in legal reforms and programming

Acknowledgements

Lesotho network of people living with HIV and AIDS (LENEPWHA) would like to thank Global Network of People Living with HIV (GNP+) for providing the standard Stigma Index questionnaire and technical guidance for the study, in particular through Liz Tremlett (the International Coordinator of the PLHIV Stigma Index). We thank the Lesotho Ministry of Health for approval and guidance during the process of undertaking this study. We also convey our gratitude to our development partners UNAIDS and Irish Aid for their valuable financial and Technical Support without them this study would not have been possible.

We would like to acknowledge the invaluable role of the members of LENWAPHA members who participated in this study, whether as interviewers or interviewees. We thank them for their time and for sharing their experiences. We trust that these findings will contribute to improving the health and quality of their lives and that of people living with HIV in general. The LENEPWHA secretariat members with the technical support of Mr. John Taineomwangire- Programs Manager and leadership of Mr. Boshepha Ranthithi- Executive Director are applauded for this vital piece of work the first of its kind in Lesotho.

The implementation of this study would not have been possible without the support of a large team of very dedicated technical working group (TWG) comprised of representatives from Lesotho Network of People Living with HIV&AIDS (LENEPWHA); Lesotho Network of AIDS service Organisations (LENASO), UNAIDS, WHO, WILSA, WFP, FNCO, Lesotho Council of NGOs, Ministry of Health (Directorate of Disease Control), MATRIX support group and Community of Women living with HIV.

The drafting of the report was facilitated and led by Thabo Rakhetsi. Data input and analysis was led and facilitated by Seeiso Lehlehla. Additional technical assistance was provided by Puleng Phatela of Ministry of Health, Chibwe Lwamba and Puleng Letsie of UNAIDS Lesotho.

Study Background

1.1 Lesotho Population

In 2011, Lesotho population was estimated to be 1,894,194; with 959,837(50.7%) being females while 934,357 (49.3%) being males. In Lesotho, 23.7 percent of the population is estimated to leave in the urban areas. Lesotho is considered to be young because 33.7 percent of the population is aged below 15 years[2].

1.2 HIV and AIDS in Lesotho

The HIV and AIDS epidemic dates back to 1986 when the first HIV case was documented in Lesotho. Lesotho's hyper endemic HIV situation is driven by heterosexual practices such as multiple and concurrent sexual partnerships, transactional and intergenerational sex. These practices, together with low levels of full male circumcision and low consistent condom use, result in a high number of preventable infections[3] (GOL, 2009).

According to Ministry of Health Annual Joint Review 2013 over 365,000 are estimated to be living with HIV. The adult prevalence rate of HIV is 23 percent and TB/HIV co-infection is 74 per cent. HIV prevalence among SW, MSM & IDUs is unknown. Prisoner and factory worker prevalence is 31 and 42.7 percent, respectively. Annually there are over 25, 000 new infections. Of the new HIV infections that occur, more than two are within stable relationships[4].

Access to ART for eligible children, adults and pregnant women is less than 60 per cent and 72 percent of those enrolled in treatment are retained after the 1st year of initiation. Higher percentages (42%) of females know their HIV status compared to while only 24 percent of their male counterparts. Accepting attitude towards PLHIVs is 42 percent among women and 33 percent among males[5].

There has not been a study on stigma in Lesotho. This is the first stigma Index study for The People Living with HIV for Lesotho and among the few countries in the Eastern and Southern Africa Region. The study is aimed to determine forms, factors and consequences of stigma and discrimination among PLHIV

[2] Bureau of Statistics (2013): 2011 Lesotho Demographic Survey, Analytical Report Vol. 1. Maseru, Lesotho
[3]GOL. 2009. Lesotho HIV Prevention and Modes of Transmission Analysis. Maseru, Lesotho:UNAIDS/NAC/MOHSW
[4]Ministry of Health (2013): Annual Joint Review Report 2012/13. Maseru, Lesotho

[5] Ministry of Health (2013): Annual Joint Review Report 2012/13. Maseru, Lesotho

1.3 Stigma and Discrimination

HIV-related stigma is increasingly recognised as the single greatest challenge to slowing the spread of the disease at the global, national, and community/provider level. Stigma refers to unfavourable attitudes and beliefs directed toward someone while HIV-related stigma refers to all unfavourable attitudes and beliefs directed toward people living with HIV (PLHIV) or those perceived to be infected, and toward their significant others and loved ones, close associates, social groups, and communities[6]. People who often are already socially marginalised are the poor people, men who have sex with men, injecting drug users, and sex workers as they frequently bear the heaviest burden of HIV-related stigmatisation. Also people who are perceived to be living with HIV or are HIV positive are associated to these groups and stigmatised[7].

Discrimination is defined as treatment given to individual or group with partiality or prejudice. This is often defined under fundamental human rights and entitlement to various things; including things like healthcare, employment, the legal system, social welfare, and reproductive and family life as well as education.

Stigma and discrimination are linked. Stigmatised individuals may suffer discrimination and human rights violations. It should however be noted that, HIV-related stigma appears to be more severe than the stigma associated with other life-threatening infectious diseases. Given these conditions it is hard or even impossible for people to test for HIV, disclose their status or even seek treatment. Thus making it nearly impossible to make provisions by government, NGOs and civil society in addressing the HIV and AIDS pandemic.

1.4 Lesotho Network of People Living with HIV and AIDS (LENEPWHA)

Formed in May 2005, Lesotho network of people living with HIV and AIDS is mandated to represent, protect and promote the interests and needs of PLHIV in Lesotho. With a national membership of over 300 support groups, LENEPWHA has been at the forefront of mobilizing people living with HIV in the country and ensuring there is access to care, treatment and support services. Guided by the principle of greater and meaningful involvement of PLHIV, LENEPWHA is at the fore front of amplifying the voices of PLHIV in Lesotho with a united front. And all these efforts are geared towards ensuring that a person living with HIV enjoys full human rights without any form of stigma and discrimination.

[6] Module 5 Stigma and Discrimination Related to MTCT
http://www.cdc.gov/globalaids/Resources/pmtct-care/docs/PM/Module_5PM.pdf
[7] Module 1.4 HIV/AIDS-related stigma and discrimination R. Smart
http://www.iiep.unesco.org/fileadmin/user_upload/Cap_Dev_Training/pdf/1_4.pdf

1.5 Rationale for conducting the research

The rationale for undertaking this research is to develop strong evidence and data that will make the case to policy makers and planners to allocate appropriate resources to combat discrimination, stigmatization, malnutrition and food security programmes, targeting PLHIV and TB.

National HIV & AIDS Strategic Plan (2006-2011) advocate to create a legal, policy environment that reduces vulnerability, stigma and discrimination to HIV infection. Various laws including the Legal Capacity of Married Person's Act (2006), the Sexual Offences Act (2003), and the amended Labour Code No. 5 of 2006, have been developed despite implementation challenges, and freedom from all sorts of stigma and discrimination are central to these legal instruments. LENEPHWA stand is that Lesotho HIV & AIDS Bill Draft 2008 must be retrieved and be revised so it can be implemented as currently it has some limitations.

Despite the government's will and commitment to end stigma and discrimination, it has continued to manifest. It is against this backdrop that LENEPWHA, a national network of people living with HIV and AIDS with the majority of its members bearing the brunt of stigma and discrimination proposes to unfold the stigma trends in Lesotho as a move towards achieving zero HIV related stigma and discrimination.

1.6 Objectives of the Study

The following are the objectives for this assessment:

i. To understand the underlying factors that cause and allow stigma, denial and discrimination among people living with HIV and AIDS in Lesotho;
ii. To analyse the policy and legal framework as it relates to stigma, denial and discrimination as experienced by PLHIV;
iii. To document how stigma, denial and discrimination are manifested in various communities and institutional settings;
iv. To map out consequences of denial, stigma and discrimination for people living with HIV and Aids and the national response.
v. To describe the effective strategies that needs to be put in place to fight stigma and discrimination.
vi. To make policy and legislative recommendations for future interventions to reduce HIV-related stigma, denial and subsequent discrimination.

1.7 Scope of the Study

A sample of 1085 people living with HIV was taken. The sample frame (3275) consisted of all LENEPWHA members in 10 districts.The sample were further disaggregated as follows: 737 females, 345 males and 3 transgender. These included 50 LGBTI, 20 inmates and 30 sex workers. Nearly 70 percent of the sample constituted female because they constitute the most within the LENEPHWA membership. A standard

Global Stigma Index questionnaire was administered by PLHIV members. In August 2013, 50 PLHIV enumerators we trained in interviewing techniques to ensure quality data collection. Data collection took about 12 weeks and was undertaken between October to December 2013.

After data collection was completed, data entry, processing, cleaning, validation and tabulation took place between December 2013 and February 2014. Narrative report writing, dissemination and finalization was undertaken between February and published in April 2014.

1.8 Ethical clearance and confidentiality

This study required confidentiality, especially as the topic under investigation was sensitive and highly stigmatised. The People Living with HIV Stigma Index is not intended to be an abstract academic exercise that is done "to" our community, but to embrace a participatory spirit for all those involved. People living with HIV were at the centre of the process as interviewers, interviewees and as drivers of how the information was collected, analysed and used. Given the potentially dire consequences of breach of confidentiality, an ethical clearance was sought for the study from the Ministry of Health Research Ethics Committee.

1.9 Study Limitations

Responses are based on one-third sample of LENEPHWA membership and not the entire population of PLHIV. In addition, only people openly living with HIV and were members of the LENEPHWA support groups across the country were randomly and purposively considered. Also data collection was done in combination with Nutritional and Vulnerability Assessment. Some of the variables had low response rate

Results: Background Characteristics and Household Composition

This section presents demographic characteristics of the PLHIV population under study. This section is vital in understanding the PLHIV population and the challenges that they face. The demographics include among others age, sex, residence, education, marital status (relationship status), sexual activity, and household composition as well as duration of time known to be living with HIV.

2.1 Age and Sex Distribution

A total of 1085 people took part in this survey, 345(31.8%) were males 737(67.9%) were females and transgender were 3(0.002%). Of the total population 52.3 percent were aged 50 years and above, 26.9 percent were aged 40 to 49 and 0. 4percentwe aged 15 to 19.

Table 1: Age and Sex distribution

Age	Sex						Total	
	Male		Female		Transgender			
	Number	%	Number	%	Number	%	Number	%
15-19 years	3	0.9	1	0.1	0	0.0	4	0.4
20-24 years	11	3.2	22	3.0	1	33.3	34	3.1
25-29 years	17	4.9	54	7.3	2	66.7	73	6.7
30-39 years	69	20.0	154	20.9	0	0.0	223	20.6
40-49 years	97	28.1	195	26.5	0	0.0	292	26.9
50 years and above	148	42.9	311	42.2	0	0.0	459	42.3
%		**100.0**		**100.0**		**100.0**		**100.0**
Number	**345**		**737**		**3**		**1085**	

Of a total of 1065 who indicated their place of residence 39.2 percent (417) were from rural areas while 60.7 percent were from Urban. From table 2 we can observe that there were more females than male respondents in both rural areas and urban areas. It can also be noted that only in small town or village transgender were present.

Table 2: Age and Sex distribution, by place of residence

Age	Rural area		Urban			No response	
	Male	Female	Male	Female	Transgender	Male	Female
15-19 years	0.0	0.3	0.9	0.0	0.0	11.1	0.0
20-24 years	2.5	2.3	3.2	3.5	33.3	11.1	0.0
25-29 years	2.5	5.7	6.5	8.4	66.7	0.0	9.1
30-39 years	24.4	21.1	17.5	20.6	0.0	22.2	27.3
40-49 years	29.4	29.9	27.2	24.1	0.0	33.3	27.3
50 years and above	41.2	40.6	44.7	43.5	0.0	22.2	36.4
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**
Number	**119**	**298**	**217**	**428**	**3**	**9**	**11**

2.2 Household Structure

From Table 3 below, it can be observed that there are more household members in age group 0-14 (23.9%) followed by those in age group 50 years and above. While the least proportions are in age groups 25-29 years. It can also be noted that the average household size for selected population is 3.

Table 3: Respondents' household members by age group

Respondents household which has member in specific age group	Responses	
	Number	Percept
0-14 years	782	23.9%
15-19 years	479	14.7%
20-24 years	401	12.3%
25-29 years	320	9.8%
30-39 years	387	11.8%
40-49 years	344	10.5%
50 years and above	553	16.9%
Total	**3266**	**100%**

2.3 Children Orphaned by AIDS

Table 4 shows the number of orphans or those who reported to have orphans in their household. Results show that there were 314 persons who reported to have children orphaned by AIDS in their household. 152(48.4%) reported that there was one orphan in their household and 153 (49%) had between 2-4 orphans. Only 9 respondents (2.9%) reported to have five or more orphans in the households.

Table 4: Children orphaned by AIDS disaggregated by number in each household

Number of children and youths who are AIDS orphans	Number	Percentage
1	152	48.4
2	97	30.9
3-4	56	17.8
5+	9	2.9
Total	**314**	**100.0**

2.4 Average Daily Income

The average daily income for male and females is nearly equal M18.00 (USD 1.75)[8] while the variations in males (40.293=3.91 USD) average daily income is higher that of females (30.629= 2.97USD).

Table 5: Average income

Average income per day	Male	Female	Transgender	Total
Mean	18.21	18.03	46.67	18.17
Standard Deviation	40.293	30.629	80.829	34.154
Number	**345**	**737**	**3**	**1085**

2.5 Access to Food

A total of 593 respondents reported to have gone a day or more without enough food. A high proportion 47.2 percent (280) had gone without food for over 3 days

Table 6: Number of days without enough food

Number of days without enough food	Male	Female	Transgender	Number	%
One day	9.6	11.1	0.0	63	10.6
Two days	20.4	21.2	0.0	124	20.9
Three days	18.6	22.4	0.0	126	21.2
More than three days	51.5	45.3	100.0	280	47.2

2.6 Sexual activity and relationship status

A total of 59.4 percent (n=644) reported to be sexually active. When disaggregating by sex, a high proportion of males 71.6% (n=247) were sexually active as compared to 53.7 percent (n=396) of females.

2.7 Key Populations

Of the selected population, it can be seen from Table 7 that 12percent were migrants, 5.2 percent were inmates and 1.8 percent MSM. 76.8 percent of the population did not report belonging to any of the key population groups.

[8] 14th May 2014 exchange rate

Table 7: Respondents belonging to key populations

Categories	Sex				
	Male	Female	Transgender	Number	%
Men who have sex with men	3.0	0.3	0.0	13	1.2
Gay or lesbian	3.0	0.8	60.0	20	1.8
Transgender	0.6	0.3	0.0	4	0.4
Sex worker	0.0	1.4	20.0	11	1.0
Injecting drug user	0.3	0.7	0.0	6	0.5
Refugee or asylum seeker	0.3	0.1	0.0	2	0.2
Internally displaced person	0.3	0.1	0.0	2	0.2
Member of an indigenous group	1.4	0.4	20.0	9	0.8
Migrant worker	18.0	8.9	0.0	131	12.0
Inmate	12.7	1.6	0.0	58	5.2
I don't belong to, and have not in the past belonged to, any of these categories	60.5	85.4	0.0	849	76.8

Nearly 40 percent of the sampled population are married or cohabiting and husband/wife/partner is currently living in household while about 15 percent are married or cohabiting but husband/wife/partner is temporarily living/working away from the household. It can also be noted that 238 (21.9%) are currently widowed. More than 50 percent of the sampled population is currently in a relationship.

Table 8: Current relationship status

Characteristics	Sex				
	Male	Female	Transgender	Number	%
Current relationship status (N=1085)					
Married or cohabiting and husband/wife/partner is currently living in household	52.2	34.2	0.0	432	39.8
Married or cohabiting but husband/wife/partner is temporarily living/working away from the household	16.8	14.7	33.3	167	15.4
In a relationship but not living together	10.7	6.8	66.7	89	8.2
Single	6.1	10.4	0.0	98	9.0
Divorced/separated	3.8	6.1	0.0	58	5.3
Widow/widower	10.1	27.5	0.0	238	21.9
No response	0.3	0.3	0.0	3	0.3

Table 9 shows duration of relationship by sex. In the survey population, high proportions (24.1%) of males and females have been in relationships for more than 15 years, and these are followed by those who have been in a relationship for 1-4 years. It can also be observed that the least proportion is observed for those in relationships for 10 to 14 years.

Table 9: Duration of relationship by sex

Duration involved with partner (N=688)	Sex				
	Male	Female	Transgender	Number	%
0-1 year	12.4	13.4	33.3	90	13.1
1-4 years	20.7	22.9	66.7	153	22.2
5-9 years	18.9	14.6	.0	112	16.3
10-14 years	5.8	9.5	.0	55	8.0
15+ years	23.3	24.9	.0	166	24.1
No response	18.9	14.6	.0	112	16.3

2.8 Education and Economic status

A total of 1052 people responded to the question on employment status. Table 10 shows that 63.2 percent of the respondents reported being unemployed and not working at all. This could explain why most people reported not to have had enough food daily (Table 6). Higher proportions of females (7.1%) are self-employed as compared to males (4.2%). It should also be noted that 14.0 percent of females are on part time employment while 12.4 percent of males have the same employment status.

Table 10: Current employment status

Current Employment Status (N=1052)	Sex				
	Male	Female	Transgender	Number	%
In full-time employment (as an employee)	12.4	5.6	0	81	7.7
In part-time employment (as an employee)	12.4	14	0	142	13.5
Working full-time but not as an employee (self-employed)	4.2	7.1	0	65	6.2
Doing casual or part-time work (self-employed)	9.4	9.5	0	99	9.4
Unemployed and not working at all	61.5	63.8	100	665	63.2

Table 11 shows that 10.8 percent of the population has no formal education while about 62.5 percent has primary education. Less than 3 percent of the population had technical /university education. The table further shows education disaggregated by sex. High proportions of females (67.3%) had primary education and males 52.5%). It can also be observed that proportions of males with no formal education (23.8%) and technical, college/university (5.5%) are higher than females.

Table 11: Highest level of Education

Highest level of formal education (N=1085)	Sex				
	Male	Female	Transgender	Number	%
No formal education	23.8	4.7	0.0	117	10.8
Primary school	52.5	67.3	33.3	678	62.5
Secondary school	15.9	25.6	33.3	245	22.6
Technical college/university	5.5	1.4	33.3	30	2.8
No response	2.3	.9	0.0	15	1.4

Table 12: Number of years living with HIV

Duration living with HIV (N=1085)	Sex				
	Male	Female	Transgender	Number	Total
0-1 year	9.6	6.5	33.3	82	7.6
1-4 years	28.4	26.9	66.7	298	27.5
5-9 years	49.3	53.9	0.0	567	52.3
10-14 years	11.3	10.3	0.0	115	10.6
15+ years	1.2	2.3	0.0	21	1.9
No response	0.3	0.1	0.0	2	0.2

Table 12 shows the number of years of the surveyed population living with HIV since diagnosis. It can be observed that more than half (52.3%) have been living with HIV for 5-9 years after diagnosis. Only 1.9 percent of the population reported to be living with HIV for over 15 years after diagnosis. Less than 10 per cent of the PLHIVs were newly diagnosed

Results: Experience of Stigma and Discrimination

This section presents results on HIV-related stigma and discrimination with regards to access to work and health and education services; internalised stigma; the protection of the rights of people living with HIV through the law, policy or practice; and effecting change.

3.1 Experience of HIV Related Stigma and Discrimination

Table 13shows the proportion as well as the number of people who have experienced stigma and discrimination related to HIV. The percentage of people that have experienced some form of stigma and discrimination range from 2.8 to 41.1 percent. These experiences range from household to either religious or social communities. The experiences are verbal, psychological or even physical in some instances.

It should be noted that over 6.7 percent of PLHIV have experienced exclusion from family activities, 6.1 percent experienced sexual rejection and 6.6 percent experienced family discrimination. The experiences of exclusion from religious activities, discriminated against by other people living with HIV, and subjection to psychological pressure or manipulation by partner because of HIV status were experienced by 2.8 (n=29) to 4.3 percent (n=45) of the surveyed population.

Table 13: Responded Experiences of HIV related Stigma and Discrimination in the last 12 Months

Stigma and Discrimination	Frequency	Percentage	Total
Exclusion from social gatherings or activities	171	16.1	1063
Exclusion from religious activities or places of worship	45	4.3	1046
Exclusion from family activities	72	6.7	1072
Frequency of being gossiped about	440	41.1	1071
Frequency of being verbally insulted, harassed and/or threatened	289	26.8	1077
Frequency of being physically harassed and/or threatened	161	15.0	1075
Frequency of being physically assaulted	113	10.5	1074
Frequency of subjection to psychological pressure or manipulation by partner in which HIV+ status was used	31	3.1	988
Frequency of sexual rejection experienced in the last 12 months	60	6.1	988
Frequency of being discriminated against by other people living with HIV	29	2.8	1046
Frequency of family discrimination as a result of your HIV+ status	69	6.6	1038

3.1.1Being gossiped about

Table 12 shows that over 41.1percent reported to have experienced being gossiped about. This is about 440 of the total of 1071 of the surveyed population. About 25 percent reported to have been gossiped about often. Though this is the case it should

also be noted that about over 50 per cent reported that they have never been gossiped about.

3.1.2 Verbally insulted, harassed and/ or threatened

Table 12 also shows that about 27 per cent (289) of PLHIVs were verbally insulted, harassed and/or threatened. This is also the second most prevalent form of stigma and discrimination.

3.1.3 Exclusion from Social Gathering

A total of 171 persons that is 16.1 percent reported to have been excluded from social gatherings.

3.1.4 Physical Harassment

Results from table 12 indicate that 15 percent of PLHIVs reported to have experienced physical harassment and/ or threats. Close to 5 percent reported that these experiences occurred often within 12 months preceding the survey, indicating that the acts were quite recent.

3.1.5 Physical assault

Table 12 further shows that just over 10 percent (113 persons) of PLHIVs experienced physical assault because of their HIV status. Nearly 3 percent (2.9%) reported to have often experienced physical assault within 12 months preceding the survey.

3.2 Perceived reasons for experiencing Stigmatisation and Discrimination

PLHIVs were further asked to state the reasons for their discrimination and stigma. From Table 13, it can be observed that 54.4 percent of the PLHIVs that were excluded from social gatherings believe it was because of their HIV status. In addition, 68.1percentof those excluded from family gatherings believed it was because of their HIV status. It can also further be observed that over 40 percent of the PLHIVs that experienced exclusion from religious activities were gossiped about and those who were verbally insulted, harassed and/or threatened perceive that these were done because of their HIV status.

Table 14 shows results of PLHIVs who were physically abused and people who inflicted the abuse. It can be observed that 61 percent of males experienced abuse from persons outside the household who they knew, while, 33 percent of females were physically abused by their partners. Also 29.6 percent of females were abused by a person outside their home and whom they knew.

Table 14: Perceived Reasons for stigma and discrimination

Reasons for Stigma and Discrimination	Nature of Stigma and Discrimination %					
	Because of your HIV status	For (an)other reason(s)	Both because of HIV status and other reason(s)	Not sure why	No response	Total
Reason for Exclusion social gatherings or activities	54.4	22.2	3.5	18.1	1.8	171
Reason for Exclusion religious activities or places of worship	44.4	20.0	17.8	15.6	2.2	45
Reason for Exclusion from family activities	68.1	12.5	9.7	8.3	1.4	72
Reason for being gossiped about	49.8	18.9	12.7	17.5	1.1	440
Reasons for being verbally insulted, harassed and/or threatened	43.9	34.3	13.5	8.0	0.3	289
Reasons for being physically harassed and/or threatened	31.7	42.9	17.4	7.5	0.6	161
Reasons for being physically assaulted	21.2	50.4	15.9	9.7	2.7	113

Table 15: Persons who physically abused

Person who physically assaulted you (N=113)	Sex				
	Male	Female	Transgender	%	Total
My husband/wife/partner	4.9	33.8	0.0	23.0	26
Another member of the household	17.1	19.7	0.0	18.6	21
Person(s) outside the household who is/are known to me	61.0	29.6	100.0	41.6	47
Unknown person	9.8	8.5	0.0	8.8	10
No response	7.3	8.5	0.0	8.0	9

3.2 Access to Social-Economic Amenities

3.2.1 Access to Accommodation/Housing

PLHIVs were asked if they were ever forced to change or leave their place of residence or unable to get place of residence because of their HIV status. Table 16 shows that 94.9 percent have never experienced such treatment.

3.2.2 Access to Employment

Table 16 further shows that 52.9 percent of males and 38.2 percent of females reported to have lost their sources of income in the 12 months preceding the survey. A further 18.5 and 13.3 percent of males and females respectively indicated that they had been refused employment in the same reference period because of their HIV status.

Table 16: Experience of stigma and discrimination, accommodation/ work in past 12 months

	Male			Female		
Experience	**No**	**Yes**	**Total**	**No**	**Yes**	**Total**
Changing place of residence or been unable to rent accommodation by force	94.1	4.9	308	94.8	5.2	686
Loss of job or other source of income	47.1	52.9	208	61.8	38.2	424
Employment opportunity refused because of HIV status in the last 12 months	81.5	18.5	157	86.7	13.3	362

3.2.3 Perceived reasons for discrimination in the contexts of accommodation and work

Table 17 show that 31.4 (16) percent of PLHIVs perceive that they were forced to change place of residence because of their HIV status while 43.1(22) percent believe it was for other reasons. Further, 7.7(21) percent of PLHIVs believe that they lost their job or source of income because of their HIV status while 21.3(58) percent perceived it was for other reasons.

Table 17: Perceptions of stigma and discrimination (accommodation/work) past 12 Months

Reasons	**Because of your HIV status**	**other reason(s)**	**Both because of your HIV status and other reason(s)**	**Not sure why**	**No response**
Reasons for changing place of residence or unable to rent accommodation by force	31.4 (n=16)	43.1 (n=22)	7.8 (n=4)	13.7 (n=7)	3.9 (n=2)
Reasons for loss of job or other source of income (self-employed, informal/casual worker) in the last 12 months	7.7 (n=21)	21.3 (n=58)	1.8 (n=5)	4.4 (n=12)	64.7 (n=176)

From table 18, results show that PLHIVs that lost income, only 4 percent were discriminated by employer or co-worker. However other factors like poor health were contributing factors.

Table 18: Reasons for HIV--related loss of income and discrimination in the workplace

	Because of discrimination by employer or co-workers	**Because you felt obliged to stop working due to poor health**	**Because of a combination of discrimination and poor health**	**Because of another reason**	**No response**
Lost job/income due to HIV status	2.2	3.8	2.2	1.6	90.2
Number	4	7	4	3	166

3.2.4 Access to Education

The respondents further answered questions on whether they or their family members had been denied access to education services. Results in table 19indicate that 96.3 percent of the PLHIVs had not been denied access to education because of their HIV status. Less than one percent of PLHIVs reported that their children were denied access to education because of their parents' status.

Table 19: Access to Education in the last 12 months

Experience	No	Yes	Total
Dismissal or suspension and deprivation for attending educational institute	96.3	3.7	428
Dismissal or suspension and deprivation of child/children for attending educational institute	99.3	0.7	860

3.2.5 Access to Health Services

In the last 12 months preceding the survey, 4 percent of PLHIVs reported to have been denied access to health care services including dental care. Furthermore, 5.6percent and 5.5percent reported to have been denied family planning and sexual reproductive health services, respectively.

Table 20: Access to health Services in the last 12 months

Experience	No	Yes	Total
Denied health services, including dental care	96.0	4.0	930
Ever being denied family planning services	94.4	5.6	638
Ever being denied sexual and reproductive health services	94.5	5.5	1040

3.3 Internalised stigma and fear

This sub-section looks at reported self-stigmatisation that is manifested through self-exclusion, over-compensation, denial, and social withdrawal. All of these behaviours affect one's ability to access services and influence the negative attitude of those around the person.

3.3.1 Feelings of shame and guilt

Table 21 shows feelings experienced by PLHIV respondents in the 12 months preceding the survey. It should be noted that proportions of males who experienced these feelings are higher as compared to that of females. 10.5 percent of males felt suicidal as compared to 6.2 percent of females. Nearly 40 percent of males blamed other while just over 31 percent of females had the same feeling. It should also be

noted over a quarter of males had feelings of guilt and self-blame while 20.2 and 17.7 percent of females had feelings of guilt and self-blame respectively.

Table 21: Feeling Experienced in the Last 12 Months

	Male		Female	
Feeling Experienced	Yes	Total	Yes	Total
Ashamed	34.5	316	23.7	689
Guilty	27.4	307	20.2	663
Self-blame	26.3	304	17.7	656
Blame others	39.6	308	31.1	671
Low self esteem	16.9	307	12.9	667
Feel should be punished	13.9	303	11.6	657
Suicidal	10.5	304	6.2	661

3.3.2 Fear

The highest proportion (23.9%) of fear among PLHIVs is observed for those who fear sexual rejection/ avoidance of sexual intimacy because of HIV status, and 20.6 feared physical abuse. Table 22 also shows that nearly 20 percent of the surveyed population feared being gossiped about, verbally insulted, harassed and/or threatened and physically harassed.

Table 22: Fears experienced in the last 12 months

Type of fear	Yes	No	Total
Fear of being gossiped about	19.8	80.2	1013
Fear of being verbally insulted, harassed and/or threatened	19.8	80.2	939
Fear of being physically harassed and/or threatened	19.7	80.3	931
Fear of being physically assaulted	20.6	79.4	929
Fear that someone would not want to be sexually intimate with you because of your HIV status	23.9	76.1	1064

3.3.3 Decisions and Avoidance

Table 23 shows people refraining to participate or deciding to engage in certain activities that could be beneficial. The most reported reaction is refraining from having children (32.3% for males and 42% for females). For males it is followed by refraining from marriage (18%) while for females is refraining from sexual activityat27.2 percent. Also 20.1 percent of females decided not to get married.

Internalised stigma and fear also affected respondent's willingness to take up educational or training opportunities (over 10% for both sexes) and about 9 percent reported to have isolated themselves from family and/ or friends. Further, over 2 percent reported to have avoided contact with health professionals.

Table 23: Decisions and Avoidance of Potentially Beneficial Activities

Type of Decision	Male		Female	
	Yes	Total	Yes	Total
Chosen not to attend social gatherings	3.5	310	5.9	676
Isolated self from the family and/or friends	9.7	300	9.2	652
Took decision to stop working	5.1	273	4.0	580
Decision not to apply for a job/work or for a promotion	7.3	262	5.8	554
Decision to withdraw from education/training or not taking up an opportunity for education/training	10.3	242	10.5	515
Decision not to get married	18.0	256	20.1	546
Decision not to have sex	14.1	291	27.2	636
Decision not to have (more) children	32.3	291	42.0	636
Decision to avoid needed local clinic visit	4.7	298	1.9	646
Decision to avoid needed hospital visit	3.7	299	2.2	647

3.4 Rights, Laws and Policies

These sub sections address knowledge of rights laws and policies that seek to protect people living with HIV. It should be noted that Lesotho does not have a law that specifically addresses people living with HIV.

3.4.1 Awareness of key documents

From table 24, we observe that51.2 percent of the PLHIVs have heard of the Declaration of Commitment on HIV/AIDS which protects the rights of people living with HIV. Also among the PLHIVs that have heard of the declaration (542) 66.4 reported to have discussed the contents of the declaration. Nearly 30 percent reported to have heard of the law that has provisions to protect people living with HIV.

Table 24: Awareness of the Declaration of Commitment and national HIV law

Awareness of Policies and Guidelines	Yes	No	Total
Heard of the Declaration of Commitment on HIV/AIDS which protects the rights of people living with HIV	51.2	48.8	1063
Have knowledge of a Lesotho law which protects the rights of PLHIV	29.8	70.2	1022
Have read or discussed content of the declaration	66.4	33.6	542

3.4.2 Discriminatory treatment by government, legal, and/or medical Institutions

Table 25 shows that nearly 8 percent of males were forced to submit to medical or health procedures which included HIV testing while 7.7 percent of females we also forced. Also, approximately 1 percent reported to have been denied health insurance

because of their HIV status. Less than one percent reported to have been subjected to arrest or court experience, disclosure of HIV status in order to enter another country, disclosure of HIV status to apply for residence or nationality and detainment, quarantine, isolation or segregation because of their HIV status.

Table 25: Discriminatory Treatment in the last 12 months

	Male		Female	
Type of Treatment	**Yes**	**Total**	**Yes**	**Total**
Have been forced to submit to a medical or health procedure (including HIV testing), in the last 12 months	8.4	345	7.7	737
Have been denied health insurance because of HIV+ status in the last 12 month	0.9	345	1.2	737
Have been arrested or taken to court on a charge related to HIV status	0.0	345	0.3	737
Have to disclose the HIV status in order to enter another country	0.0	345	0.1	737
Have to disclose the HIV status to apply for residence or nationality	0.3	345	0.7	737
Have been detained, quarantined, isolated or segregated	0.0	345	0.1	737

3.4.3 Any violation of rights

Though 10.6 percent of PLHIVs reported to have had their rights violated, it must be noted that 89.4 reported that they have not had their rights violated.

3.4.4 Seeking Redress

Of the PLHIVs that had their rights violated, 24. 5percent sought legal redress. Table 26 further shows that 56.3 percent had legal processes to address the matter started in the 12 months prior to the survey. Further, among PLHIVs that sought legal redress, 56.3 percent reported that the matter had been dealt with while nearly 19 percent reported that nothing happened or the matter was not dealt with.

Table 26: PLHIV who have addressed legal matters relating to stigma and discrimination by sex

legal matters relating to stigma and discrimination	Sex			
	Male	Female	Number	Total
Got legal redress for any abuse of rights of PLHIV				
Yes	30.0	20.4	23	24.5
No	60.0	66.7	60	63.8
Not sure	5.0	0.0	2	2.1
No response	5.0	13.0	9	9.6
Legal process begun in the last 12 months (N=32)				
Yes	57.1	55.6	18	56.3
No	28.6	5.6	5	15.6
No response	14.3	38.9	9	28.1
Result of the process (N=32)				
The matter has been dealt with	57.1	33.3	14	43.8
The matter is still in the process of being dealt with	0.0	11.1	2	6.3
Nothing happened/the matter was not dealt with	21.4	16.7	6	18.8
No response	21.4	38.9	10	31.3
Reason for not trying to get legal redress (N=2)				
Process of addressing the problem appeared too	50.0	0.0	1	50.0
None of the above	50.0	0.0	1	50.0

3.5 Effecting Change

This section addresses challenges, knowledge on how to get support and the ability to influence change as well as recommendations towards issues affecting PLHIVs.

3.5.1 Challenging Stigma and Discrimination

Nearly 40 percent of the PLHIVs reported to having confronted, challenged or educated someone who was stigmatising and/or discriminating against them in the past 12 months.

3.5.2 Knowledge of Support Organisations

Of the total PLHIVs sample, 72.4 per cent had knowledge of organisations or groups that support people living with HIV. When disaggregating by sex a slightly higher proportion of males (75.1%) than females (71.5%) had knowledge of organisations or groups that support people living with HIV.

Knowledge of organisations or groups that offer assistance in cases of stigma and discrimination is shown in table 27. It can be observed that 81 percent have knowledge about PLHIV support groups, while 43.5 percent know about a Network of people living with HIV. The table further shows that just over 10 percent have knowledge of faith-based organizations and human rights organizations; while less than 10 percent identified other types of organisations.

Table 27: Organisations Identified Offering Help in Cases of Stigma and Discrimination

Organisation type	Sex				
	Male	Female	Transgender	Number	%
People living with HIV support group					
Yes	83.4	79.9	0.0	637	81.0
No	16.6	20.1	100.0	149	19.0
Network of people living with HIV					
Yes	40.2	45.2	0.0	342	43.5
No	59.8	54.8	100.0	444	56.5
Local non-governmental organization					
Yes	5.4	7.4	0.0	53	6.7
No	94.6	92.6	100.0	733	93.3
Faith-based organization					
Yes	11.6	10.1	0.0	83	10.6
No	88.4	89.9	100.0	703	89.4
A legal practice					
Yes	6.6	8.0	0.0	59	7.5
No	93.4	92.0	100.0	727	92.5
A human rights organization					
Yes	12.0	10.4	0.0	86	10.9
No	88.0	89.6	100.0	700	89.1
National non-governmental organization					
Yes	4.2	5.1	0.0	38	4.8
No	95.8	94.9	100.0	748	95.2
National AIDS council or committee					
Yes	2.3	3.4	0.0	24	3.1
No	97.7	96.6	100.0	762	96.9
International non-governmental organization					
Yes	8.1	9.7	0.0	72	9.2
No	91.9	90.3	100.0	714	90.8
UN organization					
Yes	3.5	3.0	0.0	25	3.2
No	96.5	97.0	100.0	761	96.8
Other organizations					
Yes	3.9	2.8	0.0	25	3.2
No	96.1	97.2	100.0	761	96.8

3.5.3 Support offered by people living with HIV to others

A total of 749 PLHIVs (69%) reported to have offered support to other people living with HIV. Figure 1 depicts the type of support offered by PLHIVs. It can be observed that the high proportion of PLHIVs that offered support offered emotional support, while the least proportion of support (36.4%) is observed for those who offered physical support.

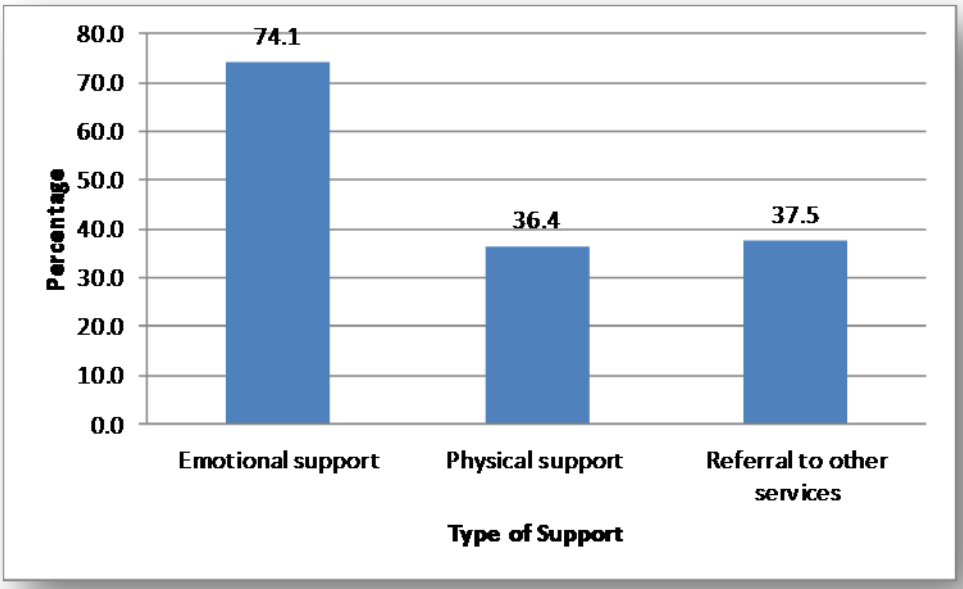

Figure 1: Form of support provided to other people living with HIV

3.5.4 Ability to influence policies, laws and programmes

Just over 200PLHIVs (18.5%) reported to have been involved in efforts to develop legislation, policies or guidelines related to HIV. Table 28 shows that 62.6percent of males and 55.1 percent of females believe that they have the ability to influence legal/rights matters affecting people living with HIV.Nearly40 percent of males and nearly 70 percent of females believe that they have the ability to influence local government policies affecting people living with HIV. It should also be noted that 26.7 percent of males believe to be able to influence national programmes/projects intended to benefit people living with HIV and over half of females believe to have influence on the same programs. It should also be noted that 11.3percentof males while 13.3 percent believe that PLHIVs could not influence any of policies and programmes mentioned.

Table 28: Power to Influence Decisions

	Male		Female	
Policies and programmes	**Yes**	**Total**	**Yes**	**Total**
Legal/rights matters affecting people living with HIV	62.6	345	55.1	737
Local government policies affecting people living with HIV	39.4	345	69.6	737
Local projects intended to benefit people living with HIV	36.8	345	36.2	737
National government policies affecting people living with HIV	35.7	345	30.9	737
National programmes/projects intended to benefit people living with HIV	26.7	345	53.3	737
International agreements/treaties	18.0	345	17.9	737
None of the above	11.3	345	13.3	737

3.5.5 Recommendations for Change

PLHIVs were also asked what recommendations they could give in order to address stigma and discrimination. Just over half of the population surveyed (549) believed in advocating for the rights of all people living with HIV as a way of addressing stigma and discrimination. About 20.6 percent believe that raising awareness and knowledge of the public about HIV and AIDS will serve as a way to decrease stigma and discrimination.

Results: Experience of HIV Testing, Disclosure, Treatment and having Children

4.1 HIV Testing and Diagnosis

The reasons for testing for HIV are shown in table 29. It can be observed that overwhelmingly the most common reason for HIV testing was that people just wanted to know their status (45.3%) followed by referral due to suspicions of HIV related symptoms (20.8%).Other reasons included for HIV testing among PLHIVs were because of employment and preparation for marriage or sexual relationship at one percent. A similar pattern of responses is observed when disaggregated by sex

Table 29: Reason for Testing for HIV

Reason for Testing for HIV	Sex			
	Male	Female	%	Frequency
Employment	1.4	0.8	1.0	11
Pregnancy	0.3	5.3	3.7	40
To prepare for a marriage/sexual relationship	0.3	1.4	1.0	11
Referred by a clinic for sexually transmitted infections	6.4	4.1	4.8	52
Referred due to suspected HIV-related symptoms (e.g. tuberculosis)	19.1	21.7	20.8	226
Husband/wife/partner/family member tested positive	6.1	1.6	3.0	33
Illness or death of husband/wife/partner/family member	8.1	11.0	10.0	109
I just wanted to know	47.0	44.4	45.3	491
Other reasons for HIV testing	12.5	11.7	12.0	130

The respondents were further asked to state what influenced them to undergo HIV testing. Table 30 shows that majority (87.9%) took a decision themselves to get tested while nearly 4 percent were tested under pressure from others and 5.9 percent reported to have been forced to take HIV test.

Table 30: Influence to Get Tested for HIV

Decision Ownership	Yes	Frequency
Yes, I took the decision myself to be tested	87.9	932
I took the decision to be tested, but it was under pressure from others	3.9	41
I was made to take an HIV test(coercion)	5.9	63
I was tested without my knowledge - I only found out after the test had been done	2.3	24
Total	**100.0**	**1060**

4.1.1 Counselling during HIV testing

On HIV testing, PLHIVs were asked if they received pre and post HIV counselling prior to receiving their results. Results in Table 31 indicate that 88.4 percent of PLHIVs received pre and post HIV counselling. Only 1.3 per cent reported not to have received any kind of counselling upon HIV testing.

Table 31: Counselling Access during HIV Test

Counselling received	Yes	Frequency
I received both pre- and post- HIV test counselling	88.4	929
I only received pre-test HIV counselling	5.6	59
I only received post-test HIV counselling	4.7	49
I did not receive any counselling when I had an HIV test	1.3	14
Total	**100.0**	**1051**

4.2 Disclosure and Confidentiality

Most respondents (over 90 %) reported to have never felt any pressure to disclose their HIV status from PLHIVs or from groups/networks of PLHIV, other individuals or PLHIV. It was also reported that in most cases, over 50 percent of the times that HIV status was disclosed, it was disclosed by a person who is also HIV positive.

4.2.1 Disclosure by health care workers and confidentiality of medical records

About 3.7 percent of PLHIVs reported that their HIV status was disclosed by a health care worker without their consent; and 75 percent said their HIV results were not disclosed without their consent and 21.3percent were not sure.

Nearly 23 per cent of PLHIV reported that it was clear that their HIV medical records were not kept confidential while 69.9 said otherwise. 6.7 percent were not sure of the confidentiality of their medical records related to HIV.

4.2.2 Reactions of other people to respondents' HIV positive status

From the table below, it can be observed that less than 10 percent of PLHIVs received discriminatory reactions except in the case of media where 12.6 percent received discriminatory reaction. Results show that there is still a lot to be done to reduce discrimination against PLHIV in a range of settings.

Table 32: Reactions of others to respondents HIV positive status

Reactions	Very discriminatory	Discriminatory	No different	Supportive	Very supportive	Total
Husband/wife/partner	5.0	1.4	5.0	13.3	75.3	738
Other adult family members	3.5	1.3	5.8	20.6	68.9	861
Children in the family	1.9	0.7	5.1	16.2	76.1	879
Friends/neighbours	3.1	3.0	16.6	38.1	39.2	801
Other people living with HIV	1.5	0.2	3.9	30.6	63.8	916
Co-workers	3.7	0.9	22.3	29.9	43.3	328
Employer(s)/boss(es)	1.0	4.6	4.0	9.2	81.1	964
Clients	3.8	0.7	26.9	31.7	36.9	290
Injecting drug partners	7.9	1.3	23.7	26.3	40.8	76
Religious leaders	3.3	1.1	24.3	29.0	42.3	366
Community leaders	1.9	0.6	19.5	38.2	39.8	513
Health care workers	2.7	0.2	3.4	27.2	66.5	925
Social workers/counsellors	2.8	0.1	2.5	24.0	70.7	931
Teachers	7.5	0.6	21.8	26.4	43.7	174
Government officials	1.2	3.7	11.4	9.6	74.1	981
The media	9.7	2.9	35.9	20.4	31.1	103

4.3 Treatment

Figure 2 shows description of respondents' health, as 34.2 percent (361) of PLHIVs described their health as excellent while 3.7 percent (39) reported their health status as poor.

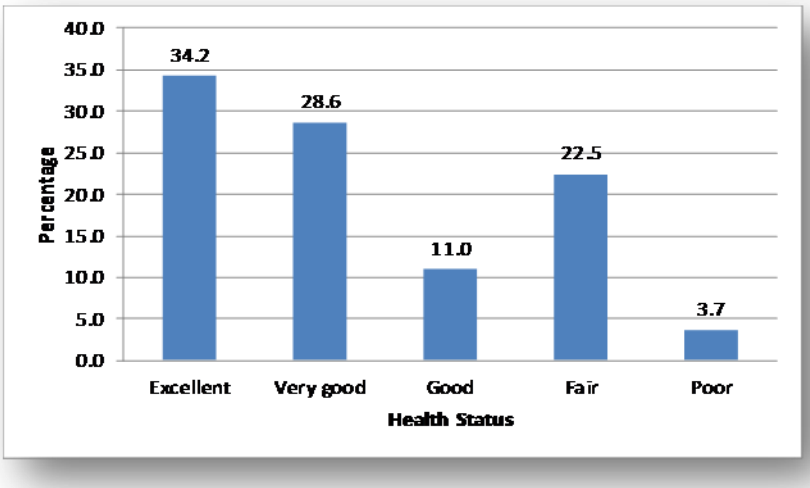

Figure 2: Description of Health at the time of the research

95.6 percent (1009) of PLHIV reported to be taking anti-retroviral therapy ART at the time of the survey. This phenomenon

could be because the surveyed population has accepted and disclosed their HIV status and are not afraid to seek medical help. Also 42.1 percent (424) of the PLHIV reported not to have access to ARV treatment while 38.2 percent (404) of PLHIVs reported to using other medication to prevent or treat opportunistic infections. Furthermore, 37.7 percent (392) of PLHIVs reported that they had no access to medication to treat or prevent opportunistic infections. In the 12 months prior to the survey, PLHIVs also reported that72.9 percent had discussion with a health care professional on the subject of their HIV related treatment optionswhile27.1 percent did not. Also 60.4 percent of PLHIVs reported to have had discussions with a health care professional on other subjects such as sexual and reproductive health

4.4 Having Children

Survey results in table 33 reveal that 85.9 percent of PLHIVs (897) have children. Further, 60.4 percent of males and 58.9 percent of females reported to have received counselling on reproductive health after being diagnosed with and 23.8 percent of males indicated that they had been advised not to have children following their HIV diagnosis, as for males 19.1 percent were also advised against having children. 3.1 and 3.0 percent of females and males respectively reported that ARV treatment was conditional on the use of certain forms of contraception.

Table 33: Counselling on Reproductive Options

	Male		Female	
Counselling experiences	**Yes**	**Total**	**Yes**	**Total**
Received counselling and reproductive options after been diagnosed of HIV	60.4	255	58.9	564
Ever been advised not to have a child since diagnosed with HIV	19.1	288	23.8	635
ARV treatment conditional on the use of certain forms of contraception	3.0	133	3.1	421

4.5 Coercion in relation to Pregnancy, Delivery Method and Infant Feeding Options

Female PLHIV respondents were asked to indicate whether they had experiencedcoercionfromahealthcareprofessionalinrelationtopregnancy, delivery method and infant feeding options in the previous 12 months:

- 0.5 (n=2) percent reported to have been forced to terminate a pregnancy
- 5.2 (n=17) percent reported to have been forced to change delivery method.
- 45.9 (n=113) percent reported that they had been coerced into changing infant feeding practices.

4.6 PMTCT services

A total of 575 women who reported to have been ever pregnant, 23.7 percent reported to have received ARV treatment to prevent mother to child transmission of HIV, while 67 percent were not yet diagnosed at the time of pregnancy. Table 34 further shows that 7.3 percent did not know about the treatment. A total of 131 (97%) females reported to have received information about healthy pregnancy and motherhood as part of the programme to prevent mother-to child transmission of HIV.

Table 34: PMTCT Services for Women

Have been given ARV to prevent mother to child transmission of HIV during pregnancy (N=737)	Percentage	Frequency
Yes - I have received such treatment	23.7	136
No - I did not know that such treatment existed	7.3	42
No - I was refused such treatment	1.0	6
No - I did not have access to such treatment	1.0	6
No - I was not HIV+ when pregnant	67.0	385
Total	100.0	575
Were given information about healthy pregnancy and motherhood as part of the programme to prevent mother-to child transmission of HIV		
Yes	97.0	131
No	2.7	4
Total	100.0	135

Conclusions and Recommendations

The study shows that Lesotho is no exception when dealing with HIV-related stigma and discrimination. Like other countries, people living with HIV still experience stigma and discrimination. This is one of the major barriers in advancing treatment and accessibility to people living with HIV, and it becomes a barrier for people to test for HIV or disclose their HIV status for fear of stigma and discrimination. The major findings of the study are outlined below.

- External and internal Stigma and discrimination towards and within PLHIVs is still widespread
- Being HIV+ was the main perceived reason for experiencing S&D in various social, religious or family gatherings or activities
- Forms of S&D include denial to accessing socio-economic amenities and services
- Knowledge about rights that protect PLHIV against infringement is relatively low
- Rights for PLHIVs to have children or seek legal redress not fully observed and therefore requires advocacy and awareness
- PLHIVs have not been widely involved in efforts to develop legislation, policies or guidelines related to HIV
- PLHIVs feel confidentiality of HIV medical records is not fully kept or adhered to
- Most of PLHIVs have access to treatment and are in good health

7.0 Recommendations

a. All stakeholders must use evidence-based strategic information results of the Stigma Index study to inform legal reforms of policies and laws that protect and promote rights of PLHIV.
b. Inform targeted programming to address specific issues of stigma and discrimination, and PHDP
c. Increase awareness, engagement and advocacy with CSOs, Government & Development Partners on issues emanating from the Stigma Index study.
d. Develop an action plan based on common issues affecting PLHIV to be used in legal reforms and programming
e. Further analysis of the data giving a more specific view according to variables such as age, sex, gender, membership of a key population and times since diagnosis.
f. Mobilisation of PLHIV across the entire spectrums of the society.
g. Enhancing coordination among LENEPWHA affiliates.

h. Mobilise resources and enhance capacity among LENEPWHA affiliates and partners for HIV stigma and discrimination prevention strategies and programs.

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Module 5 Stigma and Discrimination Related to MTCT

http://www.cdc.gov/globalaids/Resources/pmtct-care/docs/PM/Module_5PM.pdf

Module 1.4 HIV/AIDS-related stigma and discrimination R. Smart

http://www.iiep.unesco.org/fileadmin/user_upload/Cap_Dev_Training/pdf/1_4.pdf

Disclaimer

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

In this regard, the results can be said to comprise a snapshot of the level of HIV-related stigma and discrimination in a certain place and time. Through its implementation, the tool also serves to educate and empower People living with HIV on human rights related to HIV.

Survey questions therefore focus on experiences and perceptions and do not represent factual investigations, with follow up questions, into particular allegations, incidents or events nor are the answers to the questions subject to independent verification. As research participants interviewees have a right to anonymity and to confidentiality regarding their responses.

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

The data is not available as a source of allegations of individual instances of wrong-doing.