

## The People Living with HIV Stigma Index -The Gambia

### STIGMA AND DISCRIMINATION: A DETERRENT TO UNIVERSAL ACCESS- EXPERIENCED BY PEOPLE LIVING WITH HIV IN THE GAMBIA



National AIDS Control Programme



Gambia Network of AIDS Support



National AIDS Secretariat

**Dedication**

This report is dedicated to the people who participated in the People Living with HIV (PLHIV) Stigma Index Surveys but have since lost their lives to AIDS. You remind us of the urgent need for universal access to quality and comprehensive HIV prevention programmes, treatment, care and support services. We are further motivated to ensure that Zero New Infections, Zero HIV Related Stigma and Zero AIDS Related Death becomes a reality, and we shall never relent until this vision is attained by all in need and for all who need care.

**Disclaimer**

The People Living with HIV Stigma Index is designed as an evidence-gathering and advocacy tool led by and for people living with HIV to raise awareness of stigma and discrimination as experienced by people living with HIV.

To that end, the methodology is designed to capture respondent perceptions and experiences of stigma and discrimination, external as well as internalised.

As research respondents those participating in the research have a right to anonymity and to confidentiality regarding their responses. Survey questions are limited to this focus and the methodology does not include follow-up questions to re-confirm perceptions or to take action to respond to individual instances of stigma and discrimination documented.

As a result, while the data present information and evidence on perceived and experienced stigma, the survey is not intended to be used as a fact-finding tool or a source of allegations of individual instances of wrong-doing.

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**Acronyms**

AIDS	-	Acquired Immunodeficiency Virus
ARV	-	Anti-retroviral
FGD	-	Focus Group Discussion
GAMNASS	-	Gambia Network of AIDS Support Societies
GNP+		
HC	-	Health Centre
HIV	-	Human Immunodeficiency Virus
IDI	-	In-Depth Interview
IDU	-	Injecting Drugs User
KII		Key Informants Interview
MRC	-	Medical Research Council
MSM	-	Men Having Sex with Men
NACP		
NAS	-	National AIDS Secretariat
PI		Principal Investigator
PLHIV	-	People Living with HIV and AIDS
PMTCT	-	Prevention of Mother to Child Transmission
RVTH		
VCT	-	Voluntary Counseling and Testing
UNAIDS		Joint United Nations Programme on AIDS

## Executive Summary

### Background

In 2009, HIV1 and HIV2 prevalence were estimated as 1.6% and 0.4%, respectively, in The Gambia. Stigma and discrimination limit the ability of people living with HIV to cope with their condition because it hinders HIV prevention, disclosure and care-seeking. In 2009, the UNAIDS Gambia Country Office partnered with the nine People Living with HIV support groups in the country, the Gambia Network of AIDS Support Societies (GAMNASS) and the National AIDS Secretariat (NAS) to characterize stigma and discrimination and its related impacts on Universal Access.

### Methods

This is a sequential explanatory study, which investigated stigma and discrimination related problems amongst people living with HIV/AIDS and its implications on the uptake of services. To address the research objectives the study embraced a mixed methodology approach. Qualitative and quantitative methods were used.

A survey was conducted with 317 PLHIVs at various support groups where they are registered members using a structured questionnaire. A standardized questionnaire was administered to each participant that included socio-demographic characteristics, perceived stigma, discrimination, disclosure practices and access to work and health care services. Answers were coded; double entered and analyzed using SPSS v.16 and R statistical computing environment. Frequencies were calculated and bivariate and multivariate analysis used to investigate the relationship between demographic factors and types of stigma experienced, as well as between types of stigma experienced and key health outcomes.

Twenty six Focus Group Discussions (FGDs) were conducted with support group members, twenty four FGDs with community members, eight in-depth interviews (IDIs) with health workers and three IDIs with social workers. Each FGDs consist of six to eight participants. Qualitative data was recorded in local language and translated into English. Two researchers coded each transcript and analyzed the data using a grounded theory-based analysis. PLHIVs were trained as research assistants and they conducted some of the surveys and were moderators in some of the FGDs,

### Results

#### *Quantitative Results*

Sixty-four percent of interviewees had experienced enacted stigma in their household or community at least once during the previous year. Forty-five percent had experienced

some sort of stigma in the health care setting in the previous years, including 6% being denied health services and 13% being advised not to have a child due to HIV status. 17.4% of respondents had had their status disclosed without their consent. Of those who did disclose their status personally, 64% found it to be an empowering experience.

Respondents experienced shame (46%), low self-esteem (20%), guilt (19%), blame by others (29%) and self-blame (14%). Guilt was more common among men (33%) than women (15%). Participants isolated themselves from family or friends (21%) and social gatherings (24%). The greatest fears of PLHIV included being gossiped about (55%), sexual rejection (40%), verbal insults (35%), physical harassment (15%) and physical assault (12%).

### *Qualitative Results*

The people living with HIV interviewed, perceived high levels of stigma and discrimination including gossip, social shunning, and divorce upon suspicion or disclosure of HIV status. Both perceived and enacted stigma lead to a pervasive fear that their status will be disclosed. Most community members condemned discrimination against PLHIV; however, health and social workers reported that PLHIV experienced a high level of HIV stigma and discrimination from the community. Community beliefs that HIV is primarily caused by promiscuity and that PLHIV will die immediately after diagnosis caused many PLHIV to only disclose to a limited number of people. Women infected with HIV face a higher risk of divorce than men and often feared disclosing to their husbands.

Study participants reported both positive and negative experiences when seeking health services. Some reported that health workers did not maintain confidentiality or refused to treat them.

## **Conclusions and Recommendations**

The people living with HIV interviewed in this study:

- Experienced fear and rejection from their families and communities; Gambian communities need empowerment to openly discuss HIV and its impact on families. Sensitization campaigns to improve HIV knowledge and reduce stigma and discrimination are urgent
- Had variable experiences when accessing health services; health facilities should protect PLHIV from involuntarily disclosing their status in addition to shortening waiting times for drugs and structuring the clinic and protocols in such a way to reduce the chances of other patients or personnel not involved in their care discovering their status

- Enactment of HIV/AIDs , and STIs control and prevention bill
- Engagement of law enforcement officers on HIV Human rights and law.
- Advocacy with opinion and religious leaders on elimination of HIV related to stigma and discrimination.
- Treatment literacy and positive deviance targeting PLHIVs
- Impact mitigation and Social protection for PLHIVs and orphans and vulnerable children.

**Keywords: People living with HIV (PLHIV), Stigma, Discrimination, HIV Prevention, The Gambia**

## Introduction

### HIV-related stigma and discrimination

Stigma is a discrediting attribute that reduces individuals into degraded persons and can be conceptualized in different ways<sup>1</sup>. Internalised stigma, felt stigma, or “self-stigmatization” is what an individual perceives about him or herself, i.e. the way a person living with HIV feels about themselves and specifically if they feel a sense of shame about being HIV-positive. Enacted stigma includes acts of discrimination<sup>1</sup>.

Stigma and discrimination play significant roles in the development and maintenance of the HIV epidemic. At an individual level, stigma undermines the person’s identity and capacity to cope with the disease. Stigma introduces a desire not to know one’s own status, thus delaying testing and accessing treatment. Fear of discrimination limits the possibility of disclosure even to potentially important sources of support such as family and friends. Also, stigma impacts on behavior change as it limits the possibility of using certain safer sexual practices. For example, behavior such as wanting to use condoms could be seen as a marker of HIV, leading to rejection and stigma<sup>3</sup>.

The impact of HIV-related stigma and discrimination goes beyond individuals infected with HIV to reach broadly into society, both disrupting the functioning of communities and complicating prevention and treatment of HIV. Generally, stigma hinders HIV prevention, disclosure, and care-seeking and is linked to harmful unnecessary social policies<sup>4-6</sup>.

HIV-related stigma often builds upon and reinforces other existing prejudices, such as those related to gender, sexuality and race. Furthermore, HIV is highly stigmatized because it is associated with groups that are perceived as deviant, related to sex, linked to what is considered irresponsible behavior and perceived to be contagious and dangerous<sup>7, 8</sup>.

### PLHIV related stigma and discrimination in The Gambia

The Gambia is the smallest country on mainland Africa (11,295 sq km) with an estimated population of 1.7 million in 2009. The capital city is Banjul with approximately 50 000 inhabitants. The Gambia is made up of several ethnic groups, including the Mandinka (the largest), the Fula, the Wolof, the Jola and the Serahuli. English is the official language, but Mandinka, Wolof, Fula, and other local languages are widely spoken. The Gambia is predominantly Muslim, but there is a significant Christian community and indigenous beliefs are also practised. The average life expectancy is 54 years for men and 57 years for women. The number of PLHIV and HIV prevalence are depicted in Table 1.

**Table 1: HIV and AIDS estimates in The Gambia**

Indicator	Estimated value in 2011
Number of people living with HIV	14 000 [7,300 - 28 000]
Adults aged 15 to 49 prevalence rate	1.5% [0.70% - 2.90%]
Adults aged 15 and up living with HIV	12,000 [6,600 - 25 000]
Women aged 15 and up living with HIV	7,700 [4,000 – 15,000]
Deaths due to AIDS	<1000 [<200 – 1,600]
Orphans due to AIDS aged 0 to 17	4,500 [1 500 – 10,000]

The fourth Multiple Indicator Cluster Survey (MICS), a nationally representative household survey, was conducted in the Gambia in 2010. When women were questioned on HIV-related stigma, HIV comprehensive knowledge and acceptance of voluntary counseling and testing, they yielded the following answers:

- 36.7 % would buy vegetables from a shopkeeper with AIDS;
- 52.5% would allow a seropositive teacher (but not sick) to continue teaching in school;
- 77.7% correctly identified two major ways of preventing the sexual transmission of HIV (using condoms and having sex only with one faithful uninfected partner), rejected major common misconceptions about HIV transmission (by mosquito bites, by supernatural means and issues on mother to child transmission) and responded that a person who looks healthy may be HIV-infected; and,
- 31.8% had ever received an HIV-test and 7.5% had ever voluntarily requested an HIV test, received the test and received their results.

Survey results support that fears of their HIV-status being disclosed without their consent could be common among Gambians and could prevent seeking testing.

Furthermore, the stigma attached to HIV and the resulting discrimination towards people living with the virus (PLHIV) has been previously reported as a major barrier for people with HIV to search for care, treatment and support<sup>9</sup>. These two hypotheses need to be further documented and quantified in order to inform the development and implementation of national policies that protect the rights of people living with HIV in the Gambia and to shape the design of programmatic interventions so that they consider the issue of HIV-related stigma and discrimination within the Gambian context.

## Methods

In 2009, the UNAIDS country office of Gambia, in partnership with the nine PLHIV Support Groups in the country, initiated a survey on “Stigma and discrimination experienced by the PLHIV in Gambia” following the methodology suggested in *The People Living with HIV Stigma Index User Guide, 2008*<sup>1</sup>.

**Aim: To investigate stigma and discrimination problems amongst people living with HIV/AIDS and its implications on the uptake of services.**

## Study Objectives

The study objectives included the following:

1. To identify the different forms of stigma and discrimination experienced by PLHIV;
2. To explore the perceptions of PLHIV on stigma and discrimination;
3. To explore the opportunities and challenges in treating PLHIV amongst health workers;
4. To explore the perceptions of social workers on stigma and discrimination related problems;
5. To explore the communities' perception on HIV/AIDS related issues; and,
6. To provide information on stigma and discrimination that will facilitate the preparation of a best practices guide that can be used by other countries.

## Data Collection and Analysis

This study used a mixed methods approach. All quantitative and qualitative instruments were administered by trained, HIV-positive moderators, supported by experienced data collectors not necessarily living with HIV.

A structured questionnaire on socio-demographic characteristics, perceived causes of stigma and discrimination, access to work and services, internalised stigma, testing, disclosure and confidentiality of medical records, medical and reproductive health and discrimination within the health care system was administered to PLHIVs who are registered members of the various support groups across the country. (See map) Since it was not possible to take a representative sample of the whole population of people with HIV in the Gambia due to confidentiality issues and problems surrounding disclosure, participants were recruited by inviting PLHIV from each of the nine support groups to the study. The sample size was estimated as 310 respondents and 317 people living with HIV took part in interviews. Answers were properly coded and double

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<sup>1</sup> GNP+, ICW, IPPF, UNAIDS 2008. The guide is available at [www.stigmaindex.org](http://www.stigmaindex.org)

entered in Excel. After cleaning, the two independent data sets were compared and inconsistencies were checked against the answers in the hard-copy of the questionnaires.

(Can we include a map of locations of various support group.)

Data analysis was conducted using SPSS v.16 and R statistical computing environment. Sample proportions for key attributes were calculated and t-tests and chi-squared tests run to determine if stigma items differed significantly by gender, residence, and education.

A total of twenty-six focus group discussions (FGDs) were conducted with PLHIV support group members at the nine support group sites. Twenty-four FGDs were conducted with people from the communities surrounding the support group location. Moderators conducted eight in-depth interviews (IDIs) with health care workers, three IDIs with social workers, and key informant interviews with religious leaders, teachers, and UN system representatives. FGDs and IDIs were conducted and recorded in local languages, such as Mandinka or Wolof, and translated and transcribed in English. The rationale behind these sample size was to ensure credibility allowing, for flexibility with the sample size until a saturation point was reached with no new information emerging. Two researchers coded each transcript and analyzed for key themes. All the transcripts were coded systematically using themes from the thematic framework.

### **Ethical Considerations**

The study protocol obtained clearance from The Gambia Government/Medical Research Council Joint Ethics Committee. Prior to enrollment in the study, interviewers explained to candidates they could refuse to participate in the survey, withdraw from the interview at any time or decline to answer particular questions. Written consent was obtained from all the participants. Only one participant refused to participate.

To ensure confidentiality, the names of participants were never written in their answers and a system of uniquely identifying codes was defined.

An important aspect of the Stigma Index Study is that data collection was conducted by people living with HIV trained in research techniques as part of the study, ensuring that the study is both by and for PLHIV. Although PLHIV moderators underwent training, their relative lack of experience led to some issues in a few of the FGDs and administering of survey questions. Additional support and capacity building for community based researchers should be a feature of similar future research

## Results

### Quantitative Results

#### Demographics

A total of 317 people living with HIV participated in the questionnaire survey. The majority were women (76% N=242), urban residents (64% N= 202), married (67% N=212), and employed (58% N= 184). The median age was between 30 and 39 years old and the median number of years living with HIV was between 1 and 4 years. A summary of the socio-demographic characteristics of the participants by gender is provided in Table 2. Men and women differed significantly on key attributes, including age, marital status, sexual activity, and employment ( $p<0.05$ ); women were generally more likely to be younger, divorced or widowed, sexually abstinent, and unemployed or employed in petty business.

**Table 2: Socio-demographic characteristics of participants by gender**

Characteristic		Proportion		
		<b>Overall n=317</b>	<b>Male 23.7% (75/317)</b>	<b>Female 76.3% (242/317)</b>
Location:	Urban	63.7% (202/317)	57.3% (43/75)	65.7% (159/242)
	Rural	36.3% (115/317)	42.7% (32/75)	26.2% (83/242)
Age**:	15-19	0.9% (3/317)	1.3% (1/75)	0.8% (2/242)
	20-24	4.4% (14/317)	0.0% (0/75)	5.8% (14/242)
	25-29	14.2% (45/317)	4.0% (3/75)	17.4% (42/242)
	30-39	36.9% (117/317)	29.3% (22/75)	39.3% (95/242)
	40-49	27.1% (86/317)	30.7% (23/75)	25.6% (63/242)
	50+	16.4% (52/317)	34.7% (26/75)	11.2% (26/242)
Number of years living with HIV	<1	17.7% (56/316)	17.3% (13/75)	17.8% (43/241)
	1-4	50.9% (161/316)	53.3% (40/75)	
	5-9	20.9% (66/316)	18.7% (14/75)	50.2% (121/241)
	10-14	7.0% (22/316)	9.3% (7/75)	21.6% (52/241)
	15+	3.5% (11/316)	1.3% (1/75)	6.2% (15/241)

				4.1% (10/241)
Marital status**	Married	67.1% (212/316)	80.0% (60/75)	63.1% (152/241)
	Divorced or separated	13.3% (42/316)	5.3% (4/75)	15.8% (38/241)
	Widowed	13.3% (42/316)	5.3% (4/75)	15.8% (38/241)
	Single	6.0% (19/316)	8.0% (6/75)	5.4% (13/241)
Sexually active**	Yes	67.4% (213/316)	77.3% (58/75)	64.3% (155/241)
Education**	No formal education	37.0% (117/316)	17.3% (13/75)	43.2% (104/241)
	Arabic school	23.7% (75/316)	36.0% (27/75)	19.9% (48/241)
	Primary school	17.4% (55/316)	16.0% (12/75)	17.8% (43/241)
	Secondary school	17.7% (56/316)	21.3% (16/75)	16.6% (40/241)
	College/university	4.1% (13/316)	9.3% (7/75)	2.5% (6/241)
Employment**	Unemployed	41.8% (132/316)	36.0% (27/75)	43.6% (105/241)
	Self-employed	13.3% (42/316)	28.0% (21/75)	8.7% (21/241)
	Petty business	28.5% (90/316)	12.0% (9/75)	33.6% (81/241)
	Part-time employment	3.2% (10/316)	6.7% (5/75)	2.1% (5/241)
	Full-time employment	12.0% (38/316)	16.0% (12/75)	10.8% (26/241)
	Business person	1.3% (4/316)	1.3% (1/75)	1.2% (3/241)
Self-reported health status	Excellent	16.8% (53/315)	12.0% (9/75)	18.3% (44/240)
	Good	59.0% (186/315)	64.0% (48/75)	57.5% (138/240)
	Fair	21.3% (67/315)	22.7% (17/75)	20.8% (50/240)
	Poor	2.9% (9/315)	1.3% (1/75)	3.3% (8/240)

\*\* = Characteristic differs significantly by gender, Pearson's chi-squared test of independence or Student's t-test,  $p < 0.05$

### Enacted stigma in the Household and Community

The table below shows key forms of enacted stigma in the household and community for people living with HIV, including being gossiped about (52.2% N=164); being insulted, harassed, or threatened (26.3% N=83); and being psychologically pressured by a spouse or partner with the HIV positive status of the respondent used against them

(18.1% N=57;). Sixty-four percent N=200; of respondents had suffered at least one of the eight forms of enacted stigma in their household and community during the year prior to the interview. There were no significant differences on the frequency of experienced enacted stigma by sex, age, or location. However, men were significantly more likely to be excluded from religious activities ( $p < 0.05$ ) and women were somewhat more likely ( $p < 0.1$ ) to be insulted, harassed, or threatened, due to their HIV status.

**Table 3: Enacted stigma, experienced by survey participants**

In the last 12 months, due to HIV status...	overall	male	female
Excluded from religious activities	6.0% (19/315)	13.3% (10/75)	3.8% (9/240)**
Excluded from family activities	17.8% (56/315)	17.3% (13/75)	17.9% (43/240)
Excluded from social activities	11.7% (37/316)	13.3% (10/75)	11.2% (27/241)
Were gossiped about	52.2% (164/314)	52.7% (39/74)	52.1% (125/240)
Insulted, harassed, or threatened	26.3% (83/315)	18.7% (14/75)	28.8% (69/240)*
Physically assaulted	6.6% (21/317)	5.3% (4/75)	7.0% (17/242)
- Assaulted by spouse/partner	28.6% (6/21)	25.0% (1/4)	29.4% (5/17)
- Assaulted by other household member	52.4% (11/21)	50.0% (2/4)	52.9% (9/17)
- Non-Household member acquaintance	14.3% (3/21)	0/0% (0/4)	17.6% (3/17)
- Stranger	4.8% (1/21)	25.0% (1/4)	0.0% (0/17)
Psychologically pressured by spouse or partner with your HIV+ status used against you	18.1% (57/315)	21.3% (16/75)	17.1% (41/240)
Another member of your household experienced discrimination	14.3% (45/315)	20.0% (15/75)	12.5% (30/240)
<b>Any of the above:</b>	<b>63.5% (200/315)</b>	<b>61.3% (46/75)</b>	<b>64.2% (154/240)</b>

\*\* = Characteristic differs significantly by gender, Student's t-test,  $p < 0.05$ .

\* = Characteristic differs moderately significantly by gender, Student's t-test,  $p < 0.1$

Of those who experienced some form of HIV-related stigma or discrimination in the last 12 months, the perceived reasons for the stigma were:

**Table 4: Perceived reasons for HIV related stigma and discrimination**

	overall	male	female
People are afraid of getting infected with HIV from me	33.7% (56/166)	39.0% (16/41)	32.0% (40/125)
People don't understand how HIV is transmitted and are afraid	48.2% (80/166)	48.8% (20/41)	48.0% (60/125)
I will infect them with HIV through casual contact	14.5% (24/166)	17.1% (7/41)	13.6% (17/125)
I look sick with symptoms associated with HIV	10.2% (17/166)	4.9% (2/41)	12.0% (15/125)
<b>Any reason relating to fears of casual contact:</b>	<b>75.3%</b> <b>(125/166)</b>	<b>65.9%</b> <b>(27/41)</b>	<b>78.4%</b> <b>(98/125)</b>
People think that having HIV is shameful and they should not be associated with me	6.6% (11/166)	7.3% (3/41)	6.4% (8/125)
Religious beliefs or moral judgments	12.0% (20/166)	14.6% (6/41)	11.2% (14/125)
People disapprove of my lifestyle or behaviour	16.3% (27/166)	24.4% (10/41)	13.6% (17/125)
<b>Any reason relating to moral judgment</b>	<b>31.9%</b> <b>(53/166)</b>	<b>43.9%</b> <b>(18/41)</b>	<b>28.0%</b> <b>(35/125)*</b>
Not sure of the reasons	12.0% (20/166)	17.1% (7/41)	10.4% (13/125)
<b>Both casual contact and moral judgment</b>	<b>19.3%</b> <b>(32/166)</b>	<b>26.8%</b> <b>(11/41)</b>	<b>16.8%</b> <b>(21/125)</b>

Fears related to being infected through casual contact were the most common, with 75.3% of participants citing misunderstandings about HIV transmission, fear of HIV transmission, or the fact that they look sick as reasons why they were being stigmatized. Factors relating to moral or religious judgment were also prevalent though less common, with 31.9% of participants citing a reason relating to moral judgment. Men were somewhat more likely than women ( $p < 0.1$ ) to cite reasons related to moral judgments as an explanation for why they were being stigmatized.

### Internalised stigma

Shame (46%) was the most common type of internalised stigma experienced by respondents (see table below). Some of these feelings differ between sexes. Guilt was significantly more common among men (33%) than among women (15%), while women

were significantly more likely to blame others ( $p<0.05$ ). In keeping with this, men were also somewhat more likely to have felt they should be punished ( $p<0.1$ ).

The most common fear of PLHIV was of being gossiped about (55%), followed by fear of being sexually rejected (40%), being verbally insulted (35%), physically harassed (15%) and fear of being physically assaulted (12%). There were no significant differences by gender..

Many participants had made the decision to exclude themselves from social gatherings (24%) or from family or friends (21%). Furthermore, 31% decided to stop sexual relations and 34% decided not to have more children. Deciding not to have sex was significantly more common among women than men ( $p<0.05$ ).

**Table 5: Internalised stigma experienced by PLHIV**

Due to your HIV status...	overall	male	female
Ever felt ashamed	46.3% (146/315)	45.3% (34/75)	46.7% (112/240)
Ever felt guilty	19.4% (61/315)	33.3% (25/75)	15.0% (36/240)**
Ever blamed myself	13.7% (43/315)	17.3% (13/75)	12.5% (30/240)
Ever blamed others	28.6% (90/315)	16.0% (12/75)	32.5% (78/240)**
Ever had low self esteem	21.0% (66/315)	24.0% (18/75)	20.0% (48/240)
Ever felt I should be punished	1.6% (5/315)	5.3% (4/75)	0.4% (1/240)*
Feared being gossiped about, last 12 months	55.2% (174/315)	56.0% (42/75)	55.0% (132/240)
Feared being verbally insulted, harassed, and/or threatened, last 12 months	35.2% (111/315)	33.3% (25/75)	35.8% (86/240)
Feared being physically harassed and/or threatened, last 12 months	15.2% (48/315)	13.3% (10/75)	15.8% (38/240)
Feared being physically assaulted, last 12 months	11.7% (37/315)	10.7% (8/75)	12.1% (29/240)
Feared someone would not have sex with you, last 12 months	40.4% (127/314)	41.3% (31/75)	40.2% (96/239)
Chosen not to attend social gatherings, last 12 months	24.4% (77/315)	20.0% (15/75)	25.8% (62/240)
Isolated self from family or friends, last 12 months	21.3% (67/315)	20.0% (15/75)	21.7% (52/240)
Decided not to get married	17.8%	18.7%	17.5% (42/240)

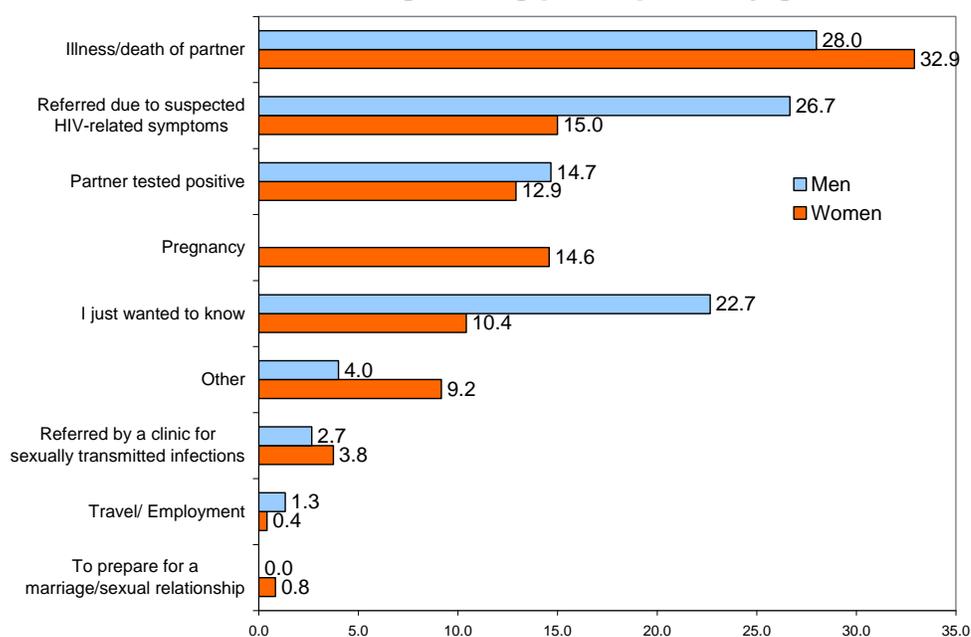
	(56/315)	(14/75)	
Decided not to have sex, last 12 months	30.8% (97/315)	21.3% (16/75)	33.8% (81/240)**
Decided not to have (more) children, last 12 months	33.7% (105/312)	34.2% (25/73)	33.5% (80/239)

### Testing and disclosure

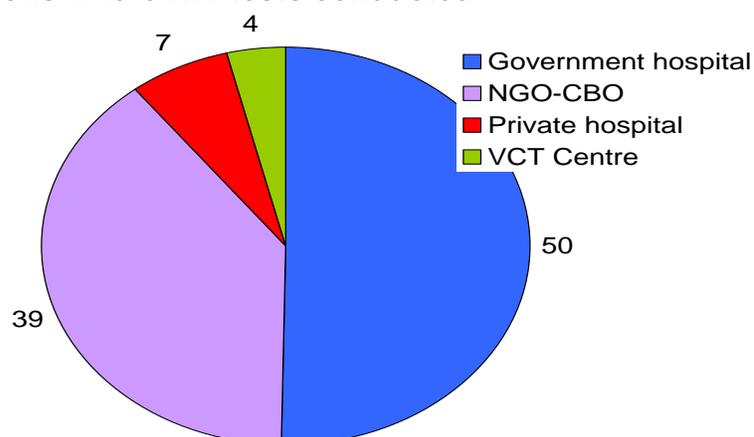
The questionnaire survey highlighted that 32% (N=101) of respondents decided to get tested because of the illness or death of their partner. Reasons for getting tested were different between men and women as shown in Figure 2. The proportion of participants getting tested as their own decision differed by gender ( $p < 0.05$ ), 50% (N=38) of male participants compared to 35% (N=84) of female participants. Four percent of men compared to 9% of women were tested as part of some form of mandatory check. Three percent of women referred were tested without their knowledge.

Regarding informed consent, 12% of respondents reported being tested without informed consent being previously obtained. This proportion did not differ by sex but by residence: 16% of urban versus 4% of rural residence ( $p < 0.05$ ).

**Figure 1: Reasons for HIV testing among participants by gender**



Half of respondents were tested for HIV in a government hospital and 39% were tested by NGOs (see Figure 3).

**Figure 2: Institutions where HIV tests conducted**

More than two thirds (70%) (N=223) of respondents received pre- and post-test counselling but 3% (N=9) did not receive any counselling at all. There were no differences by gender but counselling practices differed between urban and rural residents. Seventy-seven percent (77%) (N=85) in rural settings versus 66% (N=137) in urban locations received pre- and post-test counselling while 5% of urban residents did not get any counselling (compared to 0% of rural residents).

Seventy-two percent (N=227) of respondents had the opportunity to discuss stigma and discrimination with a counsellor at the time they were HIV-tested or when they got their results and 88% (N=278) were referred to a support group for PLHIV.

### Disclosure

The table below shows the percentage of people who had their HIV status disclosed without their consent to their spouse, adult members of their household, their children, friends and neighbours, religious leaders, community leaders, co-workers, and employers; 17.4% (N=55) of participants have had their HIV status disclosed without their consent to at least one of these groups of people. Women were significantly more likely ( $p < 0.05$ ) to have their HIV status disclosed to their spouse and to their friends and neighbours than were men.

**Table 6: Percentage of people who had their HIV status disclosed without their consent**

HIV Status disclosed without consent to:	Overall	Male	Female
Spouse	2.9% (8/275)	0.0% (0/67)	3.8% (8/208)**
Adult members of household	5.1% (16/311)	4.1% (3/74)	5.5% (13/237)
Children	3.6% (11/302)	2.9% (2/68)	3.8% (9/234)
Friends and neighbors	7.1% (22/309)	1.4% (1/73)	8.9% (21/236)**
Religious leaders	2.4% (7/292)	4.4% (3/68)	1.8% (4/224)
Community leaders	3.0% (9/298)	5.6% (4/72)	2.2% (5/226)
Coworkers	6.5% (10/153)	2.4% (1/42)	8.1% (9/111)
Employers	10.0% (8/80)	7.1% (2/28)	11.5% (6/52)
<b>At least one of the above:</b>	<b>17.4% (55/317)</b>	<b>13.3% (10/75)</b>	<b>18.6% (45/242)</b>

In addition to having their status disclosed without their consent, approximately one-fifth of PLHIV experienced pressure from other PLHIVs to disclose their status to others, with a similar percentage reporting pressure from individuals not living with HIV, such as family members and NGO workers, to disclose (see table below). Almost 10% of respondents have concealed their status from their spouses, other adults in the household, and their friends and neighbours. Overall, 63.9% of respondents who actively disclosed their status to someone else found disclosure to be an empowering experience; however, men were significantly more likely than women ( $p < 0.05$ ) to find disclosure to be empowering.

**Table 7: Percentage of PLHIV who experienced pressure to disclose status**

	Overall	Male	Female
Felt pressure from PLHIVs or groups of PLHIVs to disclose	20.7% (65/314)	26.7% (20/75)	18.8% (45/239)
Felt pressure from individuals not living with HIV (including family members and NGO workers) to disclose	19.4% (61/315)	17.3% (13/75)	20.0% (48/240)
Friends, neighbors, spouses, and adults	9.8% (31/317)	6.7% (5/75)	10.7% (26/242)

in household do not know status			
Found disclosure an empowering experience	63.9% (177/277)	75.0% (51/68)	60.3% (126/209)**

About 67% (183/275) of participants personally disclosed their status to their partners, 26% (77/317) to their children and 13% (39/309) to their friends and neighbours.

### **Stigma and discrimination experienced within the healthcare setting**

Regarding treatment, 67% are currently on antiretroviral treatment. Eight percent of participants reported having no access to treatment, i.e. antiretroviral treatment (ARVs) was not available and free or they could not afford it. Similarly, 85% of participants were currently taking medication to prevent or to treat opportunistic infections and 10% had no access to medication for opportunistic infections.

Seventeen percent of participants had not talked about HIV-treatment options with their health care professionals in the last 12 months and 15% neither had a discussion about treatment options nor other subjects such as sexual and reproductive health, sexual relationship(s), emotional well-being, etc.

The large majority of the participants (91%) had children and 13% were aware of at least one of their children being HIV-positive. Twenty eight of participants had never received counseling about their reproductive options since their diagnosis.

Of the 235 women who had been pregnant, 91 (39%) had been HIV-positive at the time of their pregnancy. Of these 91 women, 70% (64) received ART to prevent vertical transmission of HIV. The remaining 30% reported not having access to ART (n=8), not knowing that such treatment existed (n=18), or being refused treatment (n=1).

Respondents were asked about the confidentiality of their HIV-related medical records. While 81% (255/315) were certain that their records were kept confidential, 5% (16/305) were certain of breaches of confidentiality and 14% (44/305) were unsure about whether their records were confidential.

The table below includes key types of enacted stigma experienced in the healthcare setting, including disclosure of HIV status without consent by a health worker (10.5%), being denied health services (5.1%), conditioning treatment on the use of contraception (9.6%), and refusal of a health worker to treat the patient (6.4%). Excluding the three forms of discrimination in the health care setting exclusive to women (being coerced to

terminate a pregnancy, give birth in a certain way, or feed an infant in a certain way), differences in experiences between men and women were not statistically significant, with 37.2% of the overall sample reporting experiencing at least one of the nine forms of discrimination. However, when including forms of discrimination exclusive to women, women reported experiencing at least one of the twelve forms of discrimination in the healthcare setting significantly more often than men, with 47.5% of women reporting experiences of discrimination and 34.7% of men reporting discrimination.

**Table 8: key types of enacted stigma experienced in the healthcare setting**

Ever experienced the following in the past 12 months as a result of your HIV status:	Proportion % (n/N)		
	Overall	male	female
A health professional disclosed your status without your consent	10.5% (33/314)	9.5% (7/74)	10.8% (26/240)
Denied sexual and reproductive health services	4.8% (15/315)	5.3% (4/75)	4.6% (11/240)
Denied health services or dental care	5.1% (16/315)	6.7% (5/75)	4.6% (11/240)
Advised not to have a child	12.9% (39/302)	11.1% (8/72)	13.5% (31/230)
Coerced you to be sterilized	2.2% (6/273)	0.0% (0/69)	2.9% (6/204)**
Ability to obtain ARVs conditional on the use of certain forms of contraception	9.6% (24/249)	12.1% (8/66)	8.7% (16/183)
Health worker ever refused to attend to you	6.4% (20/314)	10.8% (8/74)	5.0% (12/240)
Health worker ever used latex gloves for non-invasive exam	8.9% (28/314)	13.3% (10/75)	7.5% (18/239)
Ever denied treatment, drugs, or tests	6.3% (20/315)	10.7% (8/75)	5.0% (12/240)
Coerced by health worker to terminate a pregnancy	0.8% (2/239)	-	0.8% (2/239)
Coerced to follow particular infant feeding practices	15.9% (38/239)	-	15.9% (38/239)
Coerced to follow a method of giving birth	8.8% (21/239)	-	8.8% (21/239)
Experienced any of the above	44.5% (141/317)	34.7% (26/75)	47.5% (115/242)**
Experienced any of the above, excluding terminating a pregnancy, giving birth, or	37.2% (118/317)	34.7% (26/75)	38.0% (92/242)

feeding infant			
Ever avoided seeking treatment due to attitudes of healthcare team toward PLHIVs	10.2% (32/315)	14.7% (11/75)	8.8% (21/240)
Ever travelled to a clinic further away due to concerns about confidentiality or people discovering your status	10.2% (32/315)	10.7% (8/75)	10.0% (24/240)
Avoided going to local clinic when I needed to, last 12 months	15.3% (48/314)	18.7% (14/75)	14.2% (34/239)

Ten percent of participants (N32) have avoided or delayed seeking treatment because of the attitudes of health workers, 10%(N=32) have travelled to a clinic or hospital other than the one closest to their home due to concerns about confidentiality or concerns that someone in their community may discover their status, and 15% (N=48) have avoided going to their local clinic when they needed to go in the past 12 months.

## Qualitative Results

People living with HIV reported experiencing a high level of stigma and discrimination from family, community members and, to a lesser extent, in the health care setting. They reported a high level of fear that others will learn of their status and that disclosure would lead to negative consequences.

Community beliefs regarding HIV strongly influence the stigma and discrimination experienced by PLHIV. From early sensitizations, community members learned about the transmission of HIV through sexual contact and that HIV did not have a cure. These two beliefs strongly influenced enacted stigma and health seeking behaviours including testing and disclosure.

## Perceived stigma

People living with HIV reported a high level of perceived stigma, and commonly reported fear of being pointed at. For some, this caused them to remain at home and avoid some normal interactions with community members and participation in cultural activities. "Pointing fingers" was a commonly reported term used to describe a wide variety of behaviours, including gossiping about people with HIV, identifying them as HIV-positive, and laughing at them. Finger-pointing as a common practice is corroborated by both health workers and community members.

*"How people [interpret] this is if you are sick and weak, they will say you have HIV. They will point at you."- PLHIV*

*"If people know that you have HIV, they will be pointing at you and you won't feel good." - Health worker*

*"People running away from you is the only reason - the shyness and shame you feel when people point fingers at you that you suffer from this disease, is the reason why they hide it from people. If you go to the hospital frequently, people start to suspect." - Community member*

Many community members agreed that they should come near to PLHIV to support them and prolong their lives.

*"If you run away from a PLHIV and don't care for him, it means you are digging his grave. If we come closer to them, they tend to feel better."- Community member.*

The experiences of those with HIV who were part of this study did support that this always occurs. Some of the people with HIV interviewed described family and friends refusing to greet them and avoiding social interaction. One woman described how relatives in her compound would talk to her children and keep them away from her. Stigma resulted in feelings of isolation, abandonment and concern for self and children's future.

### Internalised Stigma

Families are the primary caregivers when someone falls ill. However, not all family responses are supportive. HIV positive members can find themselves stigmatised and discriminated against within the home. Enacted stigma was commonly reported by study participants. PLHIV commonly reported people “running away” from them. “Running away”, included deprivation of housing, exclusion from the food bowl, not including them in social events and withholding psychological support.

*“Am on my own, I live alone. Sometimes my family will throw my food by the side-door”*

*“If their children try to play with you and hold on to your wrapper, then their mothers call them to say “hey” come here. Don’t go near her she is sick.”-*



***PLHIV assaulted by her own sister in the presence of her mother***

The photo above shows a PLHIV whose own sister poured hot boiling water on her in the presence of their mother as a result of a dispute and told her “*go and die with your AIDS*”

It was reported by some PLHIVs who are local food vendors that community members will stop buying you food once they suspect or are aware of your HIV status.

*“I sell pancakes and fish balls at the market but, since I fell sick No one touches or eat what my hands have touched. I stopped selling ever since I had this disease.*

*“I went to the school, the head master said there is blood sample test at the school and I did it, he told me you are infected with HIV, you should stop selling, at home I used to sell pancake but parents stop their kids from buying”.*

Health and social workers and community members corroborated the stigma perceived by PLHIV. They reported that both stigma and discrimination remain at high levels. Community stigma and discrimination towards PLHIV is found all over the world and this can manifest in various ways forcing PLHIVs to change some of their daily activities such as shopping and socializing. They also substantiate that communities believe that promiscuity is the primary cause of HIV, which causes some PLHIV to fear disclosure.

*“People might know that you are not promiscuous and that the virus can be transmitted through different means, but as soon as people find out that you are living with the virus, they conclude that it was contacted through sexual intercourse.” - PLHIV*

Divorce is one of consequences of stigma and discrimination affecting mostly women. Increase cases of divorce indicate that stigma and discrimination is dominant in our society. Divorce was mentioned by PLHIV, health workers and community members as having an association with disclosure.

*“When I disclose my status to my husband, he said get out of my house and I don't want to have any business with you this world and the hereafter”*

A social worker even reported going to great lengths to deceive husbands into believing that they had been tested first. The social worker instructed the wife to tell the husband that he needed to go in for blood and urine testing because of an STI test. If the husband was found positive, the social worker would give the husband his results and then suggest that the wife get tested, thus avoiding the woman being blamed for introducing HIV into the compound.

*“Now we present the husband to be the first person to be positive, that would save the wife from divorce.” - Care team member*

Despite the gender bias, both men and women reported marital partners leaving them following disclosure.

Even if disclosure did not result in divorce, some PLHIV, mostly women, reported being thrown out of the compound or given inadequate housing. For example, one woman's brother sent her to stay in the small chicken house behind the main house. Women separated from the family face difficulties in finding food for themselves and their children.

Some family members supported the HIV positive members in their family, while others excluded them from daily activities. The low level of knowledge about HIV caused some family and community members to exclude PLHIV from the food bowl or sharing a common drinking cup. Others describe family members fearing to come near them. In addition to physical neglect, PLHIV often experienced low emotional support.

Some PLHIV received emotional support from the people they disclosed to. One PLHIV disclosed to her daughter who replied:

*"What can you [do]? I can't do anything. You can't do anything. Let's trust in God and believe in him and know that [if there is] anything that you need, I will support you until we have any other support." I told her, thank you." - PLHIV*

PLHIV reported that support groups provided a supportive environment for PLHIV. Some PLHIV initially feared attending the groups because they feared that group members would disclose their status. PLHIV who attended meetings reported the reassurance of meeting other PLHIV who were facing and overcoming similar challenges and discussing their experience. PLHIV found psychological support from other support group members.

*"Example like myself, when I confessed I have this disease to the people who were told of their HIV status at the hospital come join to this group you will see people with the disease.*

*Moderator: That would help them to steady their mind.*

*Respondent: Yes that would help them to steady their mind and help them to be brave to their situation."*

*~PLHIV*

*"When I join the support group, I met people who said they are living with the virus fourteen years plus, that give me peace of mind. May be before I live with it for fourteen years, God will help me for the medicine to be available."*

*Since I started taking ARVs, I have no difficulties and I am in the support group. NAS is also helping me.” - PLHIV*

*“We do not encounter any form of discrimination in our groups here in Basse. We might not know where each one comes from but we have to be friendly and helpful to one another. As for me, I greet anyone I meet with here irrespective of which language you speak. As for here, we live as one people.”*

Support groups also provide a venue for health education on how to prevent the spread of the disease, drug adherence and other health promotion lessons.

*“Those who are in [a support group] thank God, they know how to live with it and they know how to protect themselves... If you see the disease is spreading, it is not from our supports groups but from those who are not in any support groups, because we already knew the safety precaution measures ourselves.”*

### **Disclosure and testing**

Participants cited fear of stigma and discrimination as one of the main reason why they are reluctant to disclose their status. Factors attributing to lack of disclosure are fear of divorce, abandonment, social ostracism and lack of care and support was a common reason given for not disclosing to partners and family members.

It was reported by some support group members that *“An HIV patient committed suicide after disclosing his status to his family due to their adverse reaction”. “When I disclose my status to my biological mother, I was ostracize completely by her and now by the community”-PLHIV*

*“When I was informed of my status by healthcare workers, I was shock and I cried lot thinking about how I managed to contract this disease. I am very young. I thought about my marriage and my husband’s compound is big, how would people see me? Since I left the hospital, I did not tell my husband”.- Woman living with HIV*

Due to the level of fear of finger pointing and enacted stigma, most PLHIV disclosed to only a very small number of people and some disclosed to no one.

*“I am never been gossiped or pointed at because of this disease. The reason is that I have never disclosed to anyone and I will not.” - PLHIV*

There was a strong belief that their life would be over if people knew their status. PLHIV feared that disclosure would lead to divorce, make everyone think that they were

promiscuous and cause them to lose their job. PLHIV also feared being blamed for introducing HIV into the household. In addition, PLHIV reported that they did not want to disturb their family by disclosing their status.

*“If you see the reason why we are afraid of [disclosing our status], the whole world is just one friend. If I trust you and tell you my secret, you also trust someone to whom you are going to tell my secret, who also trusts someone else, and that is how it will go until everyone comes to know about it. This is the reason why people are fearful.” – PLHIV*

Although some PLHIV experience positive reactions after disclosing their status and this has helped them to live comfortable with the disease.

*Since I disclose my status to my husband and family members, I am being supported fully. Thank god..... I am lucky.*

The belief that HIV is a disease without cure has caused some to worry a lot about their condition. Several respondents referenced this fatalistic belief that community members viewed HIV as a killer disease based on early health education campaigns that predated more effective ARV treatments.

*“I was afraid of the way they will look at you, because we do hear that when you have HIV that is the end of you, of everything. That is why I did not tell anybody.” PLHIV*

*“It kills easily, because when you have it the next thought is ‘I will die.’ That is always in your thinking. That is why they hide from people - the reason is that when you tell people they all abandon you, even me, I have a friend who is an AIDS patient, but I ran away from him. I said it is a killer disease; everybody is afraid of death.” - Community member*

*“Wrong signals were sent out in the beginning, so we have to clear the misconceptions and treat HIV as any form of infection. To be HIV positive does not mean you are less of a human being”.-key informant*

Health and social workers corroborated the fear of disclosure and the consequence of disclosure reported by the people living with HIV interviewed. Additionally they emphasized that women do face greater challenges disclosing their status, but still encouraged disclosing to partners so that they could be tested.

People living with HIV primarily sought testing after recognizing unfamiliar signs and symptoms in themselves. Having a spouse disclose his/her status was also a common reason for being tested. PLHIV also commonly reported being tested as part of antenatal services, due to sensitizations, upon learning that their spouse was having an

affair and after being encouraged by a friend or relative. One participant noted that stigma and discrimination were a primary cause of not getting tested.

*“There is a Mandinka proverb which says “IKA KUTU SUWOILONU YETA KUTO FA WOLOKONO” - when you see disease, it should be disclosed. But AIDS, if you see people do not even attempt to do VCT, it is because of stigma and discrimination.” - PLHIV*

PLHIV identified fear of imminent death as the most common response to learning that they have HIV, a “killer disease.”

*“Now I will die and who will take care of my children and who will have the sympathy, love and care for my children? Who will be that person?” – PLHIV, woman*

Acceptance was also a common response to testing. Belief that having HIV was “God’s will” facilitated many PLHIV to accept their test results.

*“I met a doctor but I feel shy that day, he called me and said why are you keeping quiet? He reassured me and told me to see it as God's wish. Is not a disease for bad people or whatsoever, those whom it's God's wish for them to be infected will be. He told me not to isolate myself and always mingle with people. I listen to his advices and reduced thinking about the disease.” - PLHIV*

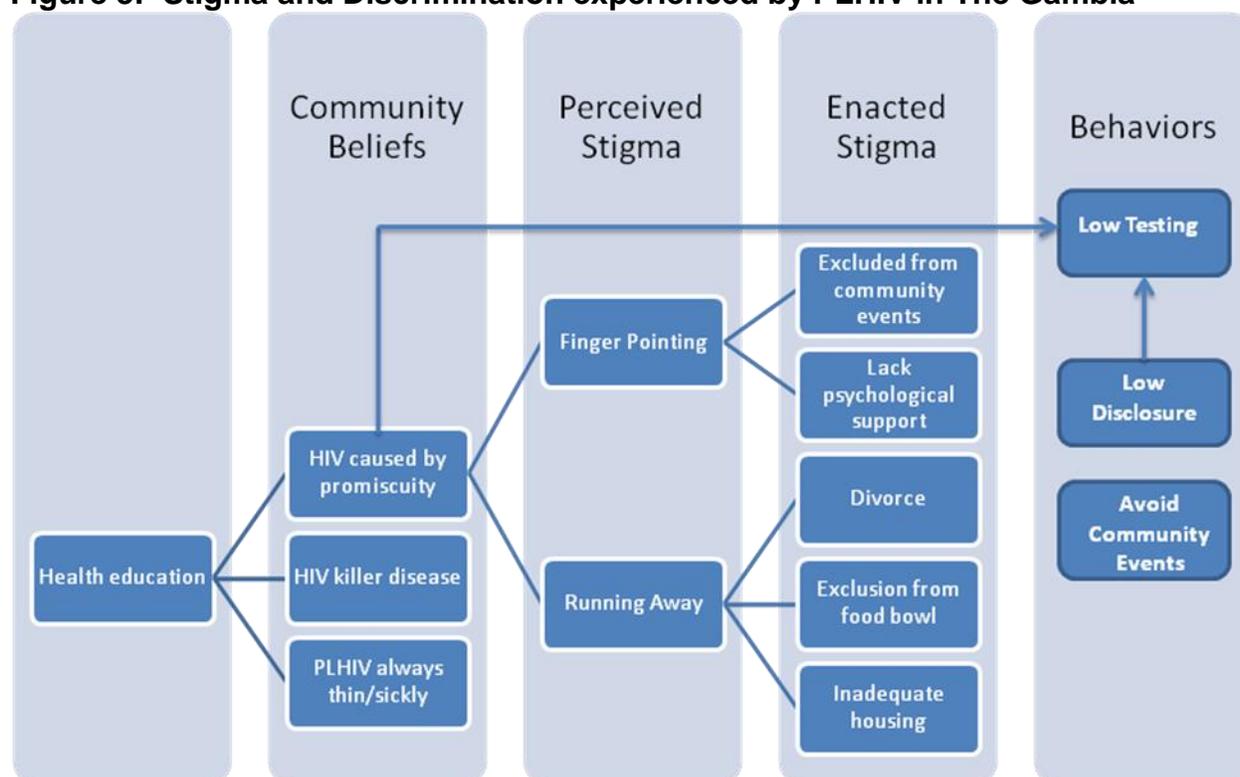
Other reactions to testing include refusing or disagreeing with the results, concern about what other people will think and confusion about how they were infected. A social worker reported that the pervasive belief that promiscuity is the primary cause of HIV incites shame and fear in PLHIV.

Appropriate counselling can help PLHIV regain hope and accept their situation. PLHIV described how the counsellor told them about available treatments and that having HIV does not mean that they would die immediately.

*“The way they react now is different compared to those days. If you remember, they used to say when you have HIV that’s the end of you. I believe, with the good counselling that I am offering them, they are able to live with the disease.”*

*~ Social Worker*

Figure 4 outlines the primary causes and consequences of stigma and discrimination as reported by PLHIV in the Gambia.

**Figure 3: Stigma and Discrimination experienced by PLHIV in The Gambia**

### Stigma and discrimination experienced within the healthcare setting

PLHIV reported differing experiences at health facilities. Confidentiality and access to drugs and services were two key issues related to overall satisfaction with health services.

Maintaining confidentiality at health facilities included the behaviour of health facility staff and the design and construction of the health facility. Many PLHIV described very positive encounters with doctors and social workers who "joke and smile" with them, especially during voluntary counselling and testing. The counselling experience appeared to be a significant factor in a person's acceptance and recovery from the initial shock of learning their positive status. Explaining the efficacy of drugs was an especially important component to allaying fears.

*"As for me, I have not disclosed to my people, friends, not even my mother, except my stepmother. She was the one to whom I disclosed, then I took her to RVTH and the doctor explained to her that it is not a disease that can kill instantly. It is a disease that can stay long in your body, but when you fight it, it can be reduced in your body."*

~PLHIV

*“They encouraged me to encourage people come to the lab. The person that went to counsel me said that he didn’t hide his status and he has lived with it for a long time and is still standing strong.”*

*~PLHIV*

PLHIV appreciated doctors who treated them respectfully and did not use gloves when examining them. Other doctors were criticized as lacking empathy and using excessive precautionary measures (e.g. using gloves when the risk of contamination was minimal).

*“When you meet a good doctor it motivates you, but when you meet with a bad doctor it discourages you so much that you don’t want to come back to that hospital. When they are treating you [they wear] gloves or feel that they are better than you...When people come they should show that oneness between them and the patients.” - PLHIV*

PLHIV criticized some health facility staff including nurses and guards for treating PLHIV disrespectfully. Some PLHIV described health workers disclosing their status by discussing their status in front of community members, family members or other health staff. In addition, some non-care team members refused to see PLHIV, saying that they were the patients of the care team doctor. In addition, some guards questioned who PLHIV were coming to see at the health centre with excessive interest and insinuated that they must be HIV positive because only PLHIV visited the social worker.

*“is just too crazy, I was sick and admitted. I had pimples all over my body and the nurse refuse to give me injection or touch me. I became very angry”.*

*“I gave birth to my eldest son at this .....hospital. The doctor that delivered me told another doctor that I suffer from this disease. They remove me from where I was to a side corner. This was because they did not want me to be with others in the same place”.*

*“At the facility, once health workers know the status of a woman, they tend to be extra careful even to the point of wearing double gloves”- Key Informant.*

*We encounter stigma at the hospital, you see people telling each other, look at [care team member]’s people.”*

*. “Doctors they told us in secret but is between us and Allah. Sometimes you go there to take your medicine you see somebody who is not in our support group and if you find out they will know why we come there and if you are sick and admitted the nurses will say you are different from the other people.*

The layout of the health facility either exposed or maintained the privacy of the PLHIV. The confidentiality of rooms was especially important.

*“The place where I was being counseled was a very conducive area and very confidential.”*

Some respondents preferred a private place where they could wait without being seen or approached by other community members; however, sometimes these places were identified as locations for only HIV/AIDS patients.

*“Definitely Farafenni hospital is properly built. I like medical treatment, where we go, and [social worker] has his own place ...when we come, we go direct to that room.” - PLHIV*

*Before, where I collected my medicine is very secretive, but now when some people see you entering there they will say this place is for AIDS patients. If your people see you going there every time, they say you also have AIDS. It used to be secretive but now it is not. - PLHIV*

PLHIV were especially concerned with “bantaba” style waiting areas where patients would sit in the open on a platform without privacy.

*“Before the waiting has privacy, when we enter you close the door behind you. If you meet with anyone there then s (he) must meet you inside. That is the type of privacy we want, but now where we are moved is more like a “bantaba” which is at the children’s hospital.” – PLHIV*

*Stigma and discrimination is not only experience by PLHIV but some of the care team members face certain challenges in treating PLHIVs.*

*“Those who are not faithful to their partners get this disease. Most people in this community refer to the social worker as someone who is promiscuous and follows people’s wives whilst, he is just doing his routine home visits and advising people how to live with the disease”.-PLHIV*

PLHIV emphasized the importance of having drugs and doctors made readily available as long waiting times required them to sit longer and risk disclosure. Some participants expressed difficulties in seeing doctors when they visit the health facilities.

*“I do not want to meet people there, because some people could not keep their mouths shut, and they will go and reveal your secret.” - PLHIV*

*“I came here three times this year, I could not see a doctor. They keep telling me to come back: the doctor is in Banjul. PLHIV*

Although some health centre staff describe the use of discrete codes to identify PLHIV, PLHIV reported at least one health centre using different coloured forms for PLHIV.

*“We do have difficulties from the clinics and some doctors... [people] are pointing at people who have HIV/AIDS, or you see this one with yellow paper is having HIV/AIDS.” - PLHIV*

Figure 4 shows fear of disclosure as the central concern of PLHIV when at health centres.

**Figure 4: PLHIV experience at health centres**



Despite their fears, PLHIV prioritized their treatment and praised its effects. PLHIV commonly discussed the importance of drug adherence in order to improve strength and health, to do work and to care for others. PLHIV were willing to find the money needed to seek treatment; however some people were not able to get medicine because they did not have the *fare*.

*“Didn't we want to live? Because when we take the drugs it helps to suppress the disease and prolong our lives.” - PLHIV*

*“The intention is to have good health, to have good health intention will encourage you to go for medication to enable you to have permanent health and do your normal activities.” – PLHIV*

Respondents highlighted one social worker whose work exemplified his commitment to improving the lives of his patients

*“We do have our medicine accordingly in now that I know how - before I come I call [social worker] and tell him am coming at this time before I collect it... Sometimes you will call him and explain your problem, and he will collect the medicine and bring it to you with his rider.” - PLHIV*

**Some of the key coordinating agencies responsible for the fight against HIV/AIDS also mention some of the challenges they are being faced with:**

*“There is high staff attrition rate, health workers leave for greener pastures or better paid. Others leave for better conducive working environments. We have trained a lot of staff but retaining them in the system is a challenge which has increased the workload”- Key informant*

## **Discussion**

Despite significant improvements in HIV knowledge in The Gambia, evidence here shows stigma and discrimination against PLHIV remain significant barriers to future progress toward universal access in Gambia. Almost three out of four interviewees had experienced enacted stigma at least once during the previous year, half of them had problems finding or keeping jobs and one out of four had difficulties finding a place to live. Health workers and community members corroborate the stigma and discrimination reported by PLHIV. The stigma and discrimination stem from incomplete and inaccurate beliefs in the community regarding HIV. Specifically, many Gambians believe that PLHIV are promiscuous and that HIV causes near immediate death. These beliefs discourage many Gambians from seeking testing and from disclosing to partners, family and friends.

The relatively low level of HIV knowledge that persists in The Gambia increases the burden of internalised stigma suffered by PLHIV. Half of participants reported a feeling of shame because of their status and fear of being discriminated. One out of three participants renounced all sexual activity, and one out of four excluded themselves from familial activities (and also from social or even religious activities). A better understanding of the disease would allow PLHIV to engage in social activities and a more normal lifestyle.

Fear of the finger pointing and enacted stigma was a pervasive theme with significant consequences in disclosure behaviours. PLHIV only disclose their status to a limited number of people, usually partners and family members. PLHIV report not disclosing their status due to fears of divorce, sexual rejection, social isolation and exclusion from community activities. Fear of the consequences of disclosing to friends and family members limits the number of partners who seek testing because having a partner disclose is a primary reason for seeking testing.

The results of this study support current studies that suggest that the face of HIV is increasingly female and that the empowerment of women and girls is key to a successful response. Internalised stigma and the nature of enacted discrimination differed significantly by gender in some specific regards. Women expressed greater fears of divorce from disclosing their status, which was also noted by health workers. In the quantitative data, women were also shown to be vulnerable to additional types of stigma, such as coercion around infant feeding practices and giving birth. Women were more likely to have their status disclosed without their consent to spouses and friends and neighbors, and were less likely to find disclosure an empowering experience. Men, on the other hand, were more likely to feel guilt for having HIV or excluded from religious activities. Gender specificities should be accounted when designing activities for stigma reduction.

The access to and use of health services by PLHIV highlight areas for improvement. The fact that 5% of PLHIV had been directly denied services because of their status and that one in six had travelled to a far-off health facility over concerns about confidentiality underscores the stigma that still exists in health services. PLHIV report a high level of fear that their status will be disclosed when waiting for services or by health center staff.

### **Recommendations**

The high level of ignorance evident from the contributions from PLHIV, health and social workers and community members call for the immediate design and implementation of a targeted, nation-wide health education campaign that emphasizes the following:

- HIV can be transmitted in ways other than sexual activity;
- current treatments are effective in decreasing the signs and symptoms of HIV in the body, and PLHIV can live for many years, even decades, if consistently taking anti-retroviral drugs;
- everyone should be tested prior to signs and symptoms becoming unbearable in order to limit transmission and increase treatment success rates; and,
- women especially should be protected from the negative consequences of revealing their HIV status.

Stigma within the health system in The Gambia calls for increased training and sensitization of all health center staff including:

- the transmission of HIV and appropriate use of universal precautions;
- stigma experienced by PLHIV;
- necessity and means of protecting the confidentiality of PLHIV;
- ways to support PLHIV; and
- particular attention to the sexual and reproductive health and rights of PLHIV, particularly positive women

In addition, all health center buildings and protocols should be critically examined for areas and practices that may cause the involuntary disclosure of HIV status.

This study also highlights the importance of promoting Support Groups as a means of psychological support and health education for PLHIV.

This study highlights the urgency of addressing and reducing stigma and discrimination experienced by people living with HIV in Gambia. The PLHIV community demand more empowerment to enable them to undertake more advocacy actions and sensitise the communities they are residing.

## **Limitations**

Given that the quantitative survey is based on a convenience sample drawn from members of PLHIV support groups, it is not possible to extrapolate conclusions to the whole population of those living with HIV in Gambia. Support groups may be systematically different from the total population of Gambian PLHIV with regards to experiences of stigma, awareness of stigma, responses to stigma, or other attributes. However, efforts were made to diversify the sample by recruiting from support groups based in regions throughout the Gambia to make it as representative as possible.

Despite these limitations this study has strictly followed a well-planned methodology with highly rigorous standards, and these findings highlight numerous challenges that urgently need to be addressed.

## References

1. Goffman E. Stigma: Notes on the management of a spoiled identity. Englewood Cliffs, New Jersey : Prentice Hall. 1963.
2. Herek GM, Capitanio JP. Symbolic prejudice or fear of infection? A functional analysis of AIDS-related stigma among heterosexual adults. *Basic Appl Soc Psych*. 1998; 20 (3): 230-241.
3. Skinner D, Mfecane S. Stigma, discrimination and the implications for people living with HIV/AIDS in South Africa. *Journal des aspects sociaux du VIH/SIDA*. 2004; 1: 3: 157-164.
4. Chin D, Kroesen KW. Disclosure of HIV infection among Asian/Pacific Islander American women: Cultural stigma and support. *Cultur Divers Ethnic Minor Psychol*. 1999; 5(3): 222-235.
5. Fortenberry JD, Yebei VN, Egessah O, Einterz RM. Multiple dimensions of stigma and STD-related care-seeking in western Kenya. 2003 July 27-30; Ottawa, Canada: International Society for Sexually Transmitted Disease Research; 2003. Abstract 0255, p. 90. ISSTD website 2006 [cites 2006 Oct 9], Available from: URL: [http://www.med.uotawa.ca/isstdr/2003\\_ISSTD/media/2003\\_ISSTD\\_Abstracts.pdf](http://www.med.uotawa.ca/isstdr/2003_ISSTD/media/2003_ISSTD_Abstracts.pdf)
6. Herek GM, Capitanio JP, Widaman KF. HIV-related stigma and knowledge in the United States: Prevalence and trends, 1991-1999, *APJH*. 2002; 92: 371-377.
7. Fife BL, Wright ER. The Dimensionality of stigma: A comparison of its impact on the self of persons with HIV/AIDS and cancer. *JHSB*. 2000 Mar 41:50-67.
8. Quam MD. The sick role, stigma and pollution: the case of AIDS. In: Feldman DA, editor. *Culture and AIDS*. New York: Praeger; 1990.p. 29-44.
9. GNP+ / ICW/ IPPF / UNAIDS. *The People Living with HIV Stigma Index*, 2008.