NAFOPHANU

THE PEOPLE LIVING WITH HIV STIGMA INDEX

THE PLHIV STIGMA INDEX SURVEY IN CENTRAL UGANDA

Stigma experiences based on the 2017 updated PLHIV questionnaire

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List of Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-Retroviral Therapy
CBO	Community Based Organization
FGD	Focus Group Discussions
FSW	Female Sex Workers
GNP+	Global Network of People living with HIV
HIV	Human Immune Deficiency Virus
ICW	International Community of Women living with HIV
IDU	Injecting Drug Users
IPPF	International Planned Parenthood Federation
MARPI	Most At Risk Population Initiative
MSM	Men who have Sex with Men
NAFOPHANU	National Forum of People Living with HIV/AIDS Networks in Uganda
NGO	Non-governmental Organization
ODK	Open Data Kit
PLHIV	People living with HIV
RA	Research Assistants
SOAR:	Supporting Operational AIDS Research
SRHS:	Sexual Reproductive Health Services
UNAIDS	Joint UN Program on HIV/AIDS
UNRN	Uganda Harm Reduction Network
USAID:	United States Agency for International Development
WONETHA	Women's Organization Network for Human Rights Advocacy

Acknowledgements

The 2017 PLHIV stigma experiences are based on the updated 2016 PLHIV questionnaire. This questionnaire aims to measure HIV related stigma, building on the previous 2008 PLHIV Stigma Index. NAFOPHANU would like to sincerely thank USAID for the generous funding to conduct this research. USAID's support has enabled execution of: 1) rigorous implementation research; 2) the mobilization of stakeholders around the results; and 3) building the research capacity of NAFOPHANU.

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Together for a positive difference!

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Table of Contents

List of Tables

List of Figures

Executive Summary

Background, objectives and key processes

The 2017 PLHIV stigma index report is based on the Global Network of People Living with HIV (GNP+'s) PLHIV stigma index questionnaire. Since 2008, one PLHIV standard questionnaire has been used by over 90 countries to interview approximately 100,000 PLHIV. This questionnaire was revised in 2017, after changes in HIV care, medical improvements, diversity of PLHIV and varying stages of organization structures of networks of PLHIV necessitated revisions of the original PLHIV stigma questionnaire.

Following this apparent gap, the 2008 original stigma Index developers, secured funding for the Project SOAR to lead revisions of the 2008 Standard Questionnaire. To implement the revision, a Small Working Groups, (SWG) including representatives from GNP+, ICW, UNAIDS, USAID, and stigma research experts within Project SOAR and outside worked to execute several revision processes such as: outlining the process for evaluating and updating the Stigma index, desk reviews, key informant conversations with country stakeholders by 2016. These processes, resulted into updating of the original PLHIV questionnaire, followed by pre-testing and collection of data using the revised 2017 questionnaire.

Methods

The study employed a cross-sectional mixed method using quantitative and qualitative data collection methods. All eligible participants had to have known that they were HIV positive for at least one year before enrolling in the study; resided in the study area for at least three months and be 18 years and above. Data was captured directly on mobile phones. Data analysis was conducted by the Population Council in collaboration with NAFOPHANU.

The study reached 401 respondents – 242 (60%) female and 259(40%) male. The majority of the respondents - 272(67%) - lived in small towns, with 77 (19% in rural areas and 52 (13%) in large towns or cities. Of the respondents, 339 (97%) were on ART at the time of the interview, and 245 (61%) reported that viral load suppression. On average, the majority of the respondents had known their HIV status for six to 8 years. Approximately 20% of the sample were key populations (KPs).

Key results

Disclosure

A high proportion of respondents indicated that they had shared their HIV positive status with other people. The highest proportion of people they shared their status with were healthcare workers, 392 (98%), followed by, spouse or partner, 194 (70%), family members 259 (64%), friends and family 253(63%). Employers were the least disclosed to at 15%. On average, 84% (336) of respondents indicated that they had disclosed their positive HIV status to other individuals or groups. Participants said that overall, disclosure had become simpler, and in general brought empowerment. The exception to this was disclosure to spouses - 75% of respondents who disclosed to their spouse said they received mixed reactions. About 73% of the PLHIV who disclosed to others living with HIV felt supported, whereas 12% mentioned that they were pressured to disclose by people who were not living with HIV.

External stigma

The findings indicate specific variations with respect to external forms of HIV-related stigma. For instance, 10 participants (2.5%) indicated exclusion from social gathering or activities; 6 (15%) from religious activities; and 10 (2.5%) from family activities in the 12 months before the survey. The following forms of stigma were more commonly experienced: experiences of family members making discriminatory remarks 77(19%); verbal harassment 78 (19%); physical harassment 38 (9.5%); experiences of blackmail 49 (12%); refusal of employment 27 (6.7%); and loss of a source of income 41 (10%).

Internal stigma

The rates of internal stigma were high. For instance, out of 401 respondents, 53% mentioned that it was still difficult to tell other people about their HIV status; 32% felt guilty that they had HIV, 26% were ashamed to have HIV; 22% mentioned that they experience feelings of worthlessness and 60% hid their HIV status from others.

Stigma and resilience

This category was measured based on assessing how the experiences of internal stigma had affected the respondents' abilities to meet their own psychological and personal needs in the last 12 months. The data shows (17%) were negatively affected and 60% mentioned no effect at all, reflecting a high level of resilience. Among the effects, the PLHIV desired to have children 116 (28.9%) as well as achievement of personal goals 112(27.9%) were mentioned most as negative effects on the clients. The components that were mentioned most among the positive effects included; ability to practice religion/faith 113(28.7%) and self-confidence 108(26.9%).

A few examples of those who experienced negative aspects: out of the 401 respondents, 19% mentioned that their self-confidence had been affected; 9% reported an inability to cope with stress and 23% reported an impact on their ability to find love.

Interaction with health workers and services delivery

Generally, interaction with service delivery was good except for clients who attempted to change their regular place of care. At the time of the interviews (May 2017), the majority of the respondents regarded their health as either fair 112 (28%) or good 269 (67%). This could be attributed to the wide coverage of Central Uganda's care and treatment services. Similarly, almost all respondents 387 (96.5%) were on ART treatment at the time of the interview. For respondents who did not start ART immediately (within six months after diagnosis), the main reason (for 66 respondents or 16%) was that they did not qualify as per the treatment guidelines, followed by 34 (8.5%) who felt healthy, and 15 (3.7%) who were afraid of family members/husbands finding out their HIV status. It was also noted that There was generally a high level of satisfaction - 350 (87.3%) - with sexual and reproductive health services in the area. Out of those who reported satisfaction, 311 (77.6%) were very satisfied while 39 (9.7%) were somewhat satisfied.

Human rights and effecting changes

Human rights abuses such as detention, forced disclosure, denial of citizenship in another country, and denial of residence due to HIV status were not generally experienced by participants in the last 12 months before the study. However, denial of a visa/permission to enter another country due to HIV status was still experienced by 28 (6.9%). Out of the 58 individuals who indicated that they had faced human rights abuses, 21 (36%), attempted to seek help in the past 12 months, while the rest (36 or 62%) did not. Out of those who attempted to resolve the human rights abuse, 12 (57%) said that the matter of abuse was dealt with. The data implies a big gap of clients who never sought legal redress, usually due to a limited capacity to seek justice. Through continued awareness campaigns and advocacy, such human rights abuses can be mitigated. Additionally, sensitizing the general population to avoid discrimination could prevent future violations.

CHAPTER ONE:

INTRODUCTION AND BACKGROUND

1.1 Report Overview

The People Living with HIV (PLHIV) 2017 Stigma Study in Central Uganda is part of a three-country project to determine if the revised 2017 PLHIV questionnaire can adequately collect comprehensive information that measures HIV stigma. Prior to the study, the original 2008 PLHIV stigma questionnaire was revised based on challenges that were identified during the use of the 2008 original PLHIV Index questionnaire. Some of these challenges included: questions that left out the experiences of key populations; recent changes in levels of stigma due to medical improvements such as viral load services and changes in health care settings; a too lengthy questionnaire; use of complicated concepts/ terminologies; lack of validated scales and limited coverage of rights violations.

The sole purpose of this report is to present the experiences of people living with HIV with respect to HIV-related stigma among the sampled population in Uganda.

1.2 Objective of the study

The objective of the study was to assess the empirical utility of the updated 2017 stigma index questionnaire. However, in terms of lived experiences, the study collected specific HIV related stigma information in the domain of:

1. Experience by gender identity, key populations, general population and those born with HIV
2. Experiences related to health care settings, given changes in treatment and care practices
3. Experiences related to HIV and resilience
4. Experiences related to sexual and reproductive health and rights of PLHIV
5. Access to testing, care and treatment.

1.3 Study background

This 2017 PLHIV study is a component of the Project SOAR activity entitled, "Updating of the People Living with HIV (PLHIV) Stigma Index: Phases 1, 2 and 3." Project SOAR is a 5-year cooperative agreement funded by the US Agency for International Development. The Population Council leads the Project SOAR consortium in collaboration with Avenir Health, Elizabeth Glaser Pediatric AIDS Foundation (EGPAF), the Johns Hopkins University (JHU), Palladium (formerly Futures Group) and the University of North Carolina (UNC). Project SOAR's mandate is to design and conduct high quality HIV operations research, including issues related to methods and measurement to improve programs and inform policies.

The People Living with HIV Stigma Index was developed by Global Network of People living with HIV (GNP+), International Community of Women living with HIV (ICW), International Planned Parenthood Federation (IPPF), and the Joint United Nations AIDS program (UNAIDS). The first phase (April 2016) involved consultations with individuals and organizations that were involved in implementing the Index. The second phase included synthesizing the recommendations on how to update the questionnaire, then pretesting the revised questionnaire at the International AIDS Conference in Durban (July 2016).(Council, 2014) Phase 3 involved formally pilot testing the revised questionnaire among PLHIV and analyzing the data collected resulting in recommendations for an updated PLHIV Stigma Index questionnaire. The update questionnaire also included adding questions or combining them into an indicator to monitor stigma, plus revisions to the sampling and questionnaire content sections of the User Guide.

To execute the PLHIV stigma Index study in Uganda, Population Council collaborated with the National Forum of People Living with HIV/AIDS Networks in Uganda (NAFOPHANU) through a formal sub-award implementation grant to NAFOPHANU. NAFOPHANU took the lead in executing the stigma survey.

CHAPTER TWO:

METHODOLOGY

Study design

This study utilized mixed methods, including quantitative and qualitative data collection. The quantitative data collection consisted of implementation of the updated PLHIV Stigma Index questionnaire including single-choice and multiple-choice questions covering the following domains: 1) socio-demographic information; 2) experience of stigma and discrimination (due to living with HIV or by virtue of key population membership); 3) disclosure; 4) internalized stigma and resilience; 5) interactions with healthcare services; and 6) human rights and effecting change. Qualitative data was collected through FGDs and in-depth interviews.

Sample size and characteristics

The study reached 400 PLHIV of 18 years and older. This sample size of 400 was selected to yield a representative sample with a 95% confidence interval and 95% power [CheckMarket2016]. Participants were recruited from six districts in Central Uganda: Wakiso, Luwero, Mpigi, Mukono, Mityana and Kampala. These were the same areas that area that participated in the first round of the PLHIV Stigma Index in Uganda.

This sampling provided a mixed demographic, taking into account participants from both rural and urban areas, differing education levels, gender, key populations, 'general' population and a mix of those who were accessing ART and others who were not. All eligible participants had to know that they were HIV positive for at least one year before enrolling in the study.

Recruitment

Two non-probabilistic sampling methods – venue-based and snowball - were used for recruiting study participants.

Venue-based sampling: Venue-based sampling was used to reach PLHIV who were at the time of the study accessing HIV treatment and care, those linked to PLHIV networks, and members of CBOs serving key populations, including Uganda Harm Reduction Networks (UHRN) for People who Use/Inject Drugs); WONETHA (for adult sex workers); Transgender Equality Uganda (TEU)

This was done through NAFOPHANU. The agency has a network of PLHIV with district coordinators who facilitated recruitment of participants. Some of the of the PLHIV registered with NAFOPHANU Forum are known to each other and were traced within the sampled districts and at health facilities. These venues are considered an environment where PLHIV would find it relatively easy to disclose their eligibility to participate in the study. Guided by the GIPA principle, recruitment and interviewing was led by PLHIV. District coordinators from NAFOPHANU and CBOs representing key population groups have lists of members who are registered. Initial contact about the study were made by individuals who have access to membership lists, such as district coordinators of NAFOPHANU. Once contact was made and respondents indicated willingness to be interviewed, the district coordinators arranged the interviews and served as a liaison with the respondent and interviewer.

Snowball sampling: Snowball sampling was used to recruit potential study participants outside the venues through participants' networks and was employed to reach key populations. Participants who completed the survey were encouraged to take survey coupons to share with their peers who are also living with HIV and who they thought might be interested in participating. Peer-recruiting was voluntary and did not involve any additional compensation. The main group targeted was those who were not currently accessing any care or service at any health facility or organization. The aim of snowball sampling was to increase the number of participants visiting the study sites during the enrollment period and particularly PLHIV who were not linked with networks or services at the time of the interviews.

Eligibility criteria

Study participants had to know their status for at least one year to ensure sufficient time for potentially negative consequences from this diagnosis to have occurred by the time of enrollment. However, for the purposes of this pilot implementation of the updated Stigma Index questionnaire, no one was excluded if they met the basic inclusion criteria of being aware of their status and willing to participate.

The following inclusion and exclusion criteria was used for assessing eligibility for participation:

Inclusion criteria

18 years of age or older
Self-reported living with HIV
Has lived primarily in the local community/ municipality of the study sites from which they are recruited for at least the past three (3) months
Is mentally sound and capable of giving consent
Has provided informed consent to participate in the study
Speaks English or Luganda

Exclusión criteria

Less than 18 years old
Has NOT lived primarily in the local municipality of the study sites from which they were recruited for at least the past three (3) months
Demonstrates mental incapacity, under the influence of substances, or any other illness preventing comprehension of the study procedures and informed consent
Does NOT speak any of the languages in which the study is conducted
Has already participated in the study

Translations

The modified English questionnaire was translated into Luganda, back-translated into English and pre-tested prior to using in the target population. Survey respondents were able to choose the language in which they wanted to interviewed.

2.4 Data Management

Software for data collection

Survey data was collected on updated PLHIV Stigma Index questionnaires. This was loaded on an electronic data collection smart phone using the Open Data Kit (ODK) platform.
Data was securely transmitted to the server over the cellular network. NAFOPHANU uploaded data on a bi-weekly basis to the Population Council data manager based in Kenya.

Data quality control procedures

NAFOPHANU hired a consultant to oversee data quality control procedure. The consultant deployed four quality controllers to oversee data collection. The purpose of the quality control procedures was to make sure the interviewers administered the survey correctly and maintained quality over the course of the data collection period. The quality controllers randomly selected a few respondents per interviewer to meet with after the interview to verify the accuracy of the data collected. The verification was done on a sample of questions considered complex in the tool. The results obtained by the quality controller were compared with those of the data collector. Research assistants (RAs) hired were competent in using English and Luganda. So, interviews were conducted in both languages. There was a mix of female and male research assistants.

CHAPTER THREE: RESULTS

SECTION A: BACKGROUND CHARACTERISTICS OF RESPONDENTS

The section provides descriptive information about the study respondents. The overall respondents reached were 401. Out of those, 16 (4%) were living with a disability (vision, hearing, mobility, intellectual/developmental) of some kind (not including general ill health related to HIV).

Table 1: Distribution of participants by key social demographic characteristics

Sex	**Number (N=401)**	**Percentage (%)**
Female	242	60.3
Male	159	39.7
Respondents residence status		
A rural area or village in the countryside	77	19.2
A small town	272	67.8
A large town or city	52	13.0
Marital status		
Married or cohabiting and husband/wife/partner is currently living in household	114	28.4
Married or cohabiting but husband/wife/partner is temporarily living/working away from the household	22	5.5
In a relationship but not living together	51	12.7
Single	91	22.7
Divorced/separated	79	19.7
Widow/widower	44	11.0

Sex:

Sixty percent (242) of the study participants were female and 40 % (139) male. Some of the respondents - 24 (6%) - described their gender orientation as transgender.

Residence status:

Most of the respondents - 272 (68%) - indicated that they resided in small towns. This was mainly because of the study design and sampling, which targeted an area within central Uganda. Through recent social economic developments, quite a number of areas in central Uganda have small towns where most people now prefer staying.

Marital status:

The highest proportion of respondents belonged to the category of married/living together 114 (28%), followed by those who are single 91(23%) and divorced or separated (79 or 19 %).

Table 2: Description of respondent key behaviors

Key population type	Number	Percentage
Men who have sex with men	30	7.5
Gay	6	1.5
Lesbian	9	2.2
Sex worker / person who sells sex or exchanges sex for goods	115	28.7
Person injecting or using addictive drugs on a regular basis, such as heroin, cocaine, methamphetamines	21	5.2
None of the above	13	3.2
Prefer not to answer	239	59.6
Total	433	107.9

Table 2 shows that a number of participants are key populations - 115 (28.7%) were sex workers and 30(7.5%) were men who have sex with men. Twenty-one (5.2 %) injected or used addictive drugs such as heroin, cocaine, or methamphetamines on a regular basis. This data also shows that many respondents - 239 (59.6%) - preferred not to answer or reveal either their current or past sexual practices or drug use. This question had a multiple response option, so an individual could belong to different categories.

Table 3: Education and employment profiles of the respondents

	Number N=401	Percentage (%)
Education level		
No formal education	71	17.7
Some primary/elementary/local equivalent	136	33.9
Completed primary/elementary/local equivalent	38	9.5
Some secondary/high school/local equivalent	88	21.9
Completed secondary/high school/local equivalent	25	6.2
Trade/vocational school	14	3.5
University/tertiary education and post-graduate education	29	7.2
Employment status		
Doing casual or part-time work (self-employed or paid work for others)	55	13.7
Full-time student	9	2.2
Part-time student	3	0.7
Full-time homemaker	7	1.7
Retiree	8	2.0
Volunteer (unpaid work)	12	3.0
Unemployed and not working at all	29	7.2
Other (please specify)	22	5.5
Missing	256	64.0

Education:

Table 3 shows that the largest proportion of the respondents - 136 (33.9%) - attended at least some primary/elementary/local equivalent. Next are those that completed some secondary/high school/local equivalent (88 or 21.9%). Many did not have any formal education (71 or 17.7%).

Employment status:

Of those who revealed their current employment status, the majority (55 or 13.7%) indicated that they do casual or part time work, followed by those who were unemployed and not working at all 29 (7.2%). But the majority – 256 or 64 % - did not answer the question. The most probable reason for this is that a relatively high proportion of respondents were sex workers, who may not have noted sex work as formal employment.

Figure 1: Meeting basic needs

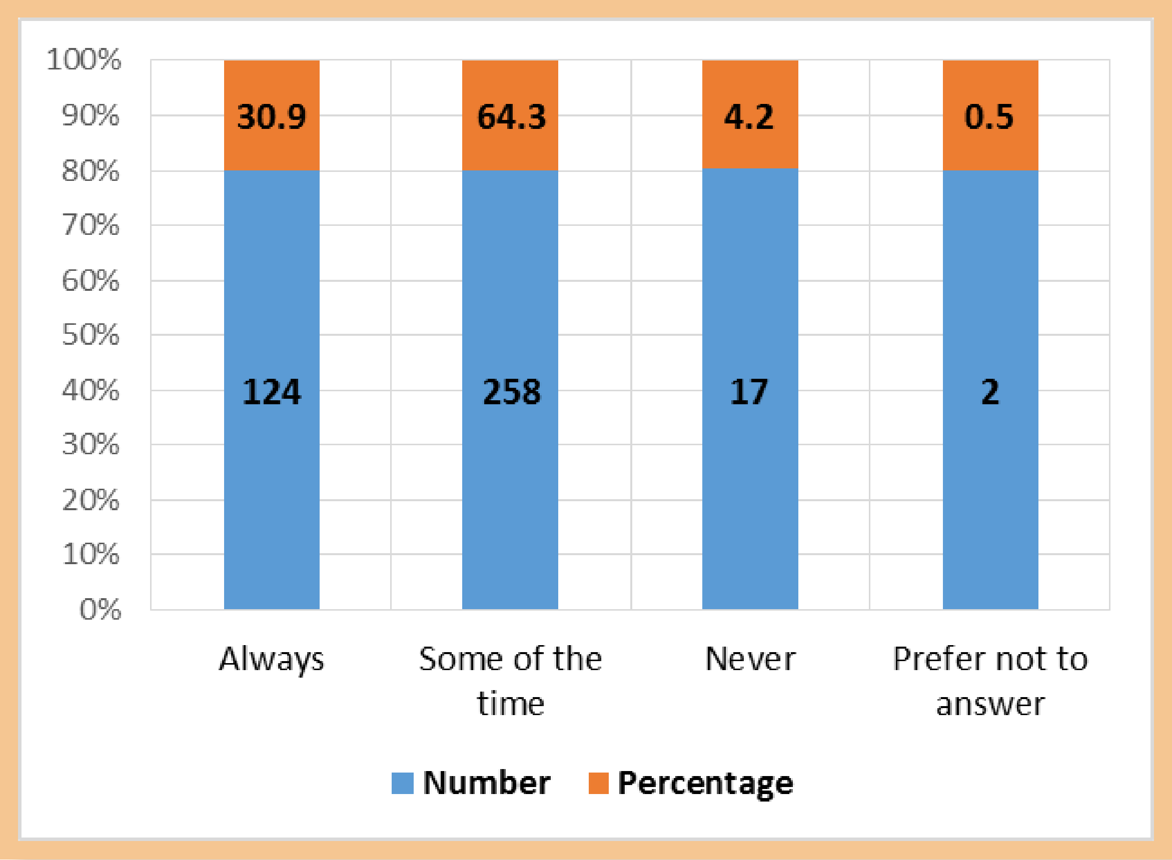


Figure 1 indicates that the majority of the respondents 258 (64.3 %) failed to meet basic needs with the last 12 months. Only 124 (30.9%) indicated that they always had the ability to meet basic needs.

SECTION B:
DISCLOSURE

Disclosure is always a challenging step in the personal management of HIV. Yet it often has multiple benefits, such as increased family support, reduction of HIV stigma, increased motivation to plan for the future, improved communication between sexual partners, reduced anxiety and increased access of health care services. This study sought to understand if the client knew if a group of persons or a particular individual knew his/her HIV current status and for those who knew, how did they get to know. Additionally, a description of how the person(s) who learnt of the client status reacted to situation during the first time they knew about the clients. This section also explores key issues around disclosure and how it influences the empowerment for the client.

Table 4: Proportion of People/group who know the client's HIV status

Category of persons disclosed to	No	Prefer not to answer	Unsure	Yes	Total valid respondents
Your husband/wife/partner	77(27.9)	1(0.2)	4(1)	194(70)	275
Your children	158(45)	1(0.2)	5(1.2)	188(56)	352
Other family members	117(29.2)	0(0)	4(1)	259(64.6)	374
Your friends	128(31.9)	2(0.5)	12(3)	253(63.1)	395
Your neighbors	246(61.3)	2(0.5)	13(3.2)	130(32.4)	391
Healthcare providers	8(2)	0(0)	0(0)	392(97.8)	400
Your employer	90(22.4)	10(2.5)	8(2)	65(16.2)	173
Your teacher/school administrator	48(12)	8(2)	3(0.7)	5(1.2)	64
Your co-workers	142(35.4)	5(1.2)	11(2.7)	94(23.4)	252
Your classmates	49(12.2)	9(2.2)	3(0.7)	1(0.2)	64
Community leader(s) (e.g. religious leader	283(70.6)	0(0)	9(2.2)	68(17)	360
Elected official/political leader(s)	297(74.1)	1(0.2)	9(2.2)	53(13.2)	360

Denominators vary depending on applicable or actual respondents who provided responses.

Out of the twelve distinct categories of individuals or persons listed, a very high proportion of health workers 392 (97.8%) were reported to know their clients' HIV status. This could be attributed to the prerogative which health workers have, but it also points to the increased uptake of health care services, including for clients seeking HIV treatment. Some years ago and particularly before the scale-up of ARVs, PLHIV used to resort to self-treatment or treatment from traditional healers for several reasons, including HIV stigma.

The other two categories of groups that were reported to know the client’s status in relatively high proportions were; husbands/wife/partners (194 or 70%), family members (259 or 64.6%) and friends (253 or 63%). The data implies that, concerningly, approximately 30% of partners did not know their partners’ HIV positive status, which can lead to negative outcomes such as lack of support, spread of the virus in case one partner is still negative, and domestic violence if a partner learns of the others’ positive status clandestinely.

Table 5: How HIV disclosure occurred

Category	I told them	I’m not sure how they found out	Prefer not to answer	Someone else told them WITH my consent	Someone else told them WITHOUT my consent	Total valid respondents
Your husband/ wife/partner	174(89.7)	7(3.6)	2(1)	8(4.1)	3(1.5)	194
Your children	180(95.7)	2(1.1)	0(0)	4(2.1)	2(1.1)	188
Other family members	220(84.9)	14(5.4)	0(0)	9(3.5)	16(6.2)	259
Your friends	217(85.8)	17(6.7)	2(0.8)	12(4.7)	5(2)	253
Your neighbors	96(73.8)	21(16.2)	1(0.8)	5(3.8)	7(5.4)	130
Healthcare providers	356(90.8)	24(6.1)	6(1.5)	3(0.8)	3(0.8)	392
Your employer	60(92.3)	2(3.1)	1(1.5)		2(3.1)	65
Your teacher/ school administrator	3(60)	0(0)	0(0)	0(0)	2(40)	5
Your co-workers	82(87.2)	6(6.4)	1(1.1)	2(2.1)	3(3.2)	94
Your classmates	1(100)	0(0)	0(0)	0(0)	0(0)	1
Community leader(s) (e.g. religious leader	53(77.9)	14(20.6)	0(0)	0(0)	1(1.5)	68
Elected official/political leader(s)	40(75.5)	8(15.1)		4(7.5)	1(1.9)	53(100)

Denominators vary depending of applicable or actual respondents who provided responses.

In Table 5, the data demonstrates that most of the individuals or groups that knew of the client’s HIV status were disclosed to by the clients themselves. Of the respondents, 180 (95.7%) had disclosed to their children; 174 (89.7%) to partners; 60 (92.3%) to employers; 356 (90.8%) to health workers, and 82(87.2%) to co-workers. Compared to past studies of HIV disclosure in 2013 and 2015, the proportion of respondents in this study who had disclosed were quite high. Despite this, some family members - 16 (6.2%) - were still told by other people about someone’s HIV status without his/her consent. The key interpretation of this data is that there is growing evidence that over time, disclosure has become easier, and has led to further benefits in the treatment and care seeking behaviors of PLHIV.

Table 6: Reported reactions from individuals or groups after disclosure

Category of people disclosed to	Mixed reaction n(%)	N/A (I don't know their reaction) n(%)	Not supportive n(%)	Other	Prefer not to know n(%)	Supportive n(%)	Total (n)
Husband/ wife/ partner	40(75.5)	8(15.1)	4(7.5)	1(1.9)	0(0)	0(0)	53
Your children	32(16.5)	3(1.5)	28(14.4)	2(1)	1(0.5)	128(66)	194
Other family members	35(18.6)	8(4.3)	7(3.7)	3(1.6)	0(0)	135(71.8)	188
Your friends	53(20.5)	9(3.5)	27(10.4)	0(0)	0(0)	170(65.6)	259
Your neighbors	52(20.6)	14(5.5)	27(10.7)	2(0.8)	0(0)	158(62.5)	253
Healthcare providers	22(16.9)	8(6.2)	24(18.5)	2(1.5)	1(0.8)	73(56.2)	130
Your employer	2(0.5)	1(0.3)	6(1.5)	1(0.3)	1(0.3)	381(97.2)	392
Your teacher/ school administrator	4(6.2)	1(1.5)	8(12.3)	1(1.5)	1(1.5)	50(76.9)	65
Your co-workers	0(0)	0(0)	1(20)	0(0)	0(0)	4(80)	5
Your classmates	15(16)	3(3.2)	13(13.8)		1(1.1)	62(66)	94
Community leader(s) (e.g. religious leader	8(11.8)	5(7.4)	8(11.8)	1(1.5)	0(0)	46(67.6)	68
Elected official/ political leader(s)	4(7.5)	4(7.5)	8(15.1)	0(0)	0(0)	37(69.8)	53

*****Different Totals*****

From Table 6, the data demonstrates that most clients experienced a supportive reaction following disclose to others for the first time. Except for the category of husband/wife, which showed that about 40 (75.5%) revealed mixed reactions (a combination of support but also blame/accusations), the rest of the categories had a proportion of 56% up to 80 % of clients who said that the reaction was supportive. Generally, these results imply the critical role of disclosure and how it links with multiple benefits. HIV programing should continue with programing that promotes safe disclosure for individuals, and they should be given the skills and knowledge to handle disclosure and reduce negative reactions during and after the disclosure process.

Table 7: Respondents views about disclosure as an empowering experience for PLHIV

Views about disclosure processes/ experiences	Agree	Somewhat agree	Somewhat Disagree	Disagree	Prefer not to answer	NA	Total
Disclosing your HIV status to people you are close to (e.g., partner, family, close friends) has been an empowering experience	295(73.6)	28(7)	0(0)	74(18.5)	2(0.5)	2(0.5)	401
Disclosing your HIV status to people you don't know very well has been an empowering experience	152(37.9)	32(8)	0(0)	193(48.1)	2(0.5)	22(5.5)	401
Disclosing HIV status has become a more empowering experience over time	247(61.6)	40(10)	0(0)	105(26.2)	2(0.5)	7(1.7)	401
Disclosing your HIV status has become easier over time	219(54.6)	36(9)	0(0)	141(35.2)	1(0.2)	4(1)	401
PLHIV have positively encouraged or supported disclosure	290(72.3)	36(9)	0(0)	66(16.5)	4(1)	5(1.2)	401
PLHIV have pressured you to disclose your HIV status	61(15.2)	46(11.5)	0(0)	273(68.1)	10(2.5)	11(2.7)	401
People NOT living with HIV have positively encouraged or supported disclosure	201(50.1)	50(12.5)	0(0)	136(33.9)	7(1.7)	7(1.7)	401
People NOT living with HIV have pressured you to disclose your HIV status	48(12)	45(11.2)	0(0)	281(70.1)	15(3.7)	12(3)	401

This data confirms that disclosure has generally become an empowering process, with some variations. Whereas the majority of respondents - 295 (73%) - agreed that disclosure to family and friends has been an empowering process, a slightly lower proportion - only 152 (37%) - said that disclosure to people who they did not know well was an empowering process.

The data also indicated that disclosure has become easier over time (287; 70.6%) as well as more empowering over time 247 (61%). Several years ago, research indicates this was not the case, with disclosure rarely occurring except to close relatives (Rachel King and et all 2007).

Amongst fellow PLHIV or other groups and networks of PLHIV, 326(81.3%) revealed that fellow PLHIV and groups/networks offer positive encouragement and support for the disclosure process.

SECTION C:
EXPERIENCE OF STIGMA AND DISCRIMINATION

External Stigma

This section explores the experiences of PLHIV with respect to HIV-related stigma and discrimination. The available literature indicates that both stigma and discrimination have a continuum of occurrence and are reinforced at multiple points; stigma and discrimination can occur in families, communities, at work places or education institutions.

So, to establish if these experiences are recent, Respondents were asked if they had experienced HIV stigma within the last 12 months or prior to the last year. Table 8 contains information about the various levels and sources of HIV stigma and discrimination, or a 'continuum of HIV stigma'. To aggregate the findings, the summations are based on proxy composite measures (two or more numerators are divided by denominators) to enable the drawing of conclusions.

Table 8: Experiences of HIV stigma, by time of occurrence

Experience	Don't know	No	Prefer not to know	Yes, but not in the last 12 months	Yes, within the last 12 months	Missing	Total
Have you ever been excluded from social gatherings or activities	2(0.5)	375(93.5)	0(0)	14(3.5)	10(2.5)	0(0)	401
Have you ever been excluded from religious activities or places of worship	0(0)	391(97.5)	0(0)	4(1)	6(1.5)	0(0)	401
Have you ever been excluded from family activities because of your HIV status	0(0)	372(92.8)	3(0.7)	16(4)	10(2.5)	0(0)	401
Have you ever been aware of family members making discriminatory remarks	17(4.2)	258(64.3)	2(0.5)	47(11.7)	77(19.2)	0(0)	401

Have someone ever verbally harassed you because of your HIV status	4(1)	268(66.8)	2(0.5)	49(12.2)	78(19.5)	0(0)	401
Has someone ever blackmailed you because of your HIV status	6(1.5)	314(78.3)	1(0.2)	31(7.7)	49(12.2)	0(0)	401
Has someone ever physically harassed or hurt you (e.g. pushed hit etc)	1(0.2)	343(85.5)	1(0.2)	18(4.5)	38(9.5)	0(0)	401
Have you ever been refused employment or a work opportunity because of your HIV status	1(0.2)	345(86)	3(0.7)	25(6.2)	27(6.7)	0(0)	401
Have you ever lost a source of income or job because of your HIV status	1(0.2)	319(79.6)	2(0.5)	38(9.5)	41(10.2)	0(0)	401
Has your job description or the nature of your job ever changed because of your HIV status	18(4.5)	326(81.3)	25(6.2)	12(3)	20(5)	0(0)	401
Has your wife/ husband or partner ever experienced discrimination because of your HIV status	30(7.5)	231(57.6)	16(4)	21(5.2)	12(3)	91(22.7)	401

According to Table 8, in the past 12 months prior to the survey 10 respondents (2.5 %) experienced exclusion from social gatherings or activities; six (15 %) from religious activities; and ten (2.5 %) from family activities. While these indicators were relatively low, many more respondents indicated still experiencing some form of HIV-related stigma in the past 12 months; 77 (19%) experienced family members making discriminatory remarks; 78 (19%) verbal harassment; 38 (9.5%) physical harassment; 49 (12%) blackmail; 27 (6.7%) were denied employment and 41 (10%) lost a source of income. In terms of HIV programing, interventions that reduce stigma are still urgently.

Internal stigma and resilience

This section explores how HIV-related internal stigma experience has affected the respondents' abilities to meet their psychological and personal needs in the last 12 months. The effects are grouped into; positive, negative or no effect whatsoever. The assumption is that the below issues are related to the respondents' HIV positive status. Generally, internal stigma is described as the way an individual feels about him/herself because of living with HIV.

Table 9: PLHIV ability to meet psychosocial and community level needs by effect of HIV positive status

Psychosocial needs	Negatively affected by my HIV status n(%)	Positively affected by my HIV status n(%)	Not affected by my HIV status n(%)	Not applicable n(%)	Prefer not to answer n(%)	Total who responded (out of 400) (n)
Self-confidence:	76(19.0)	108(26.9)	216(53.9)	1(0.2)	0(0)	400
Self-respect	36(9)	101(25.2)	263(65.6)	1(0.2)	0(0)	400
Ability to respect others	9(2.2)	99(24.7)	290(72.3)	2(0.5)	1(0.2)	398
Ability to cope with stress	82(20.4)	94(23.4)	217(54.1)	4(1)	4(1)	393
Ability to have close and secure relationships with others	58(14.5)	88(21.9)	247(61.6)	3(0.7)	5(1.2)	393
Ability to find love	91(22.7)	69(17.2)	211(52.6)	22(5.5)	8(2)	371
Desire to have children	116(28.9)	51(12.7)	196(48.9)	25(6.2)	13(3.2)	363
Achievement of personal goals	112(27.9)	83(20.7)	202(50.4)	0(0)	4(1)	397
Achievement of professional goals	72(18)	85(21.2)	171(42.6)	59(14.7)	14(3.5)	328
Ability to contribute to community	44(11)	95(23.7)	251(62.6)	6(1.5)	5(1.2)	390
Ability to practice a religion/faith as I want	23(5.7)	113(28.7)	262(65.3)	1(0.2)	2(0.5)	398

According to Table 9, the majority of respondents were able to meet key psychosocial needs and indicated high levels of resilience - 4231 (96%). Seventeen percent of respondents indicated their psychosocial needs had been negatively affected; 23% mentioned that they had been positively affected; and 60% mentioned their status had not affected their psychosocial needs in the last 12 months.

Among the negative effects were the desire of PLHIV to have children (116 or 28.9%), as well as the achievement of personal goals (112 or 27.9%). The components that were mentioned most among the positive effects included; an ability to practice religion/faith (113 or 28.7%) and self-confidence (108 or 26.9%). In terms of program implication, interventions should continue to build individual and community resilience to overcome the negative effects of living with HIV.

Actions/activities and decisions made by PLHIV in last 12 months

Owing to several effects, real or anticipated, the PLHIV respond differently to situations. Table 10 explores these reactions done by the PLHIV over the last 12 months.

Table 10: Actions/activities and decision/ choices made by PLHIV in last 12 months

Choice/ decision	Never n(%)	Rarely n(%)	Sometimes n(%)	Often n(%)	N/A n(%)	Prefer not to answer n(%)	Total number of respondents who responded
Chosen not to attend social gatherings	309(77.1)	25(6.2)	47(11.7)	16(4)	4(1)	0(0)	401
Chosen not to seek (health) care	387(96.5)	3(0.7)	5(1.2)	6(1.5)	0(0)	0(0)	401
Chosen not to apply for job(s)	305(76.1)	18(4.5)	30(7.5)	17(4.2)	31(7.7)	0(0)	401
Chosen not to seek social support	354(88.3)	14(3.5)	17(4.2)	11(2.7)	3(0.7)	2(0.5)	401
Isolated myself from family and/or friends	329(82)	19(4.7)	35(8.7)	16(4)	1(0.2)	1(0.2)	401
Decided not to have sex	254(63.3)	39(9.7)	51(12.7)	38(9.5)	16(4)	3(0.7)	401
Total	1938 (81)	118(5)	185(8)	104(4)	55(2)	6(0.002)	2406

Table 10 results are based a total summation of the responses of the specific components that measure coping or resilience. Within Table 10, these range from not attending social gatherings to deciding not to have sex. Overall, 1938 (81%) of respondents indicated that participants have not taken specific actions /decisions because of an HIV positive status. With respect to specific components, about 128 (32%) of the respondents decided not to have sex; 88(21.9%) have not attended social gatherings; 70(17.4%) have isolated themselves from family/friends; and 65 (16.2%) have not applied for employment. It is particularly noticeable that only 14 (3%) made a decision not to go on HIV treatment. Program implications include the need to continue education PLHIV on treatment literacy to increase treatment uptake; as well as interventions that reduce internal HIV stigma so that PLHIV can continue to seek employment, engage in sex and have active social lives.

Specific feelings about key aspects of HIV internal stigma

Many PLHIV find that their HIV status changes their attitude towards life in general. These feelings often influence the person's general outlook and response to situations, including their ability to disclose their HIV positive status. These statements are intended to measure feelings and opinions about key aspects of internal stigma.

Table 11: Specific feelings about being HIV positive (by level of agreement)

Feeling	Disagree n(%)	Agree n(%)	Prefer not to answer n(%)	Total n(%)
Difficult to tell people about my HIV infection	214(53.4)	186(46.4)	1(0.2)	401(100)
HIV positive status makes me feel dirty	52(13)	349(87)	0(0)	401(100)
I feel guilty that I am HIV positive	130(32.4)	270(67.3)	1(0.2)	401(100)
I feel ashamed that I am HIV positive	105(26.5)	296(73.8)	0(0)	401(100)
I feel worthless sometimes because I am HIV positive	90(22.4)	306(76.3)	5(1.2)	401(100)
Hide my HIV status from others	241(60.1)	157(39.2)	3(0.7)	401(100)

According to Table 11, most respondents tended to agree with the statements posed. For instance, 270 (67%) felt guilty because of their HIV positive status; 296 (73.8%) felt ashamed; and 306 (76%) felt worthless. The data also indicates that 157 (39%) revealed that they hide their status from others.

This result points to the persistence of internal stigma among PLHIV. Interventions are required over time to build aspects of PLHIV self-esteem and to overcome negative feelings.

SECTION D:
INTERACTIONS WITH HEALTHCARE SERVICES

This section relates to clients self-reported issues about: HIV and general health status; HIV testing and seeking care; and experiences with recent developments in HIV treatment, such as viral load testing.

HIV and general health status

At the time of the interview (May 2017), the majority of the respondents regarded their health as either fair - (112 or 28%) - or good (269 or 67%). This could be attributed to the wide coverage of Central Uganda's care and treatment services. In addition, about 184 (44%) revealed that they had been diagnosed with a specific infectious disease over the last 12 months before the survey. Diagnoses included sexually transmitted diseases (92 or 23%), followed by Tuberculosis (45 or 11%), Hepatitis B and C (20 or 5%), and others (55 or 14%). Almost all of those who reported having a diagnosis had sought care and treatment. The program implication is that HIV services should continue to be integrated with broader health services.

HIV testing, care and treatment

Respondents were asked if it was their choice to be tested for HIV. According to the results, the majority - 337 or 84% - independently made the choice to be tested, followed by 34 (8.5%) people who tested because they were pressured from others. For 15 respondents (3.7%), they were tested without their knowledge and only found out after the test was completed. Within this subset, 7 (1.7%) were tested prenatally (just after birth), whereas 8 (2%) were forced to undertake an HIV test.

Table 12: Specific reason for undertaking an HIV test

Reason	Number	Percentage
I just wanted to know	215(n)	53.6 (%)
Provider recommended it/part of other health care (e.g. antenatal, health screening, medical male circumcision)	26	6.5
To prepare for a sexual relationship/marriage	10	2.5
Trying to get pregnant	3	0.7
I believed I was at risk for HIV	50	12.5
I felt ill or had symptoms that I thought might be HIV-related	103	25.7
My husband/wife/partner or family member tested positive, was ill or passed away/died	42	10.5
Requirement (e.g. for employment, visa/citizenship, incarceration, marriage)	1	0.2

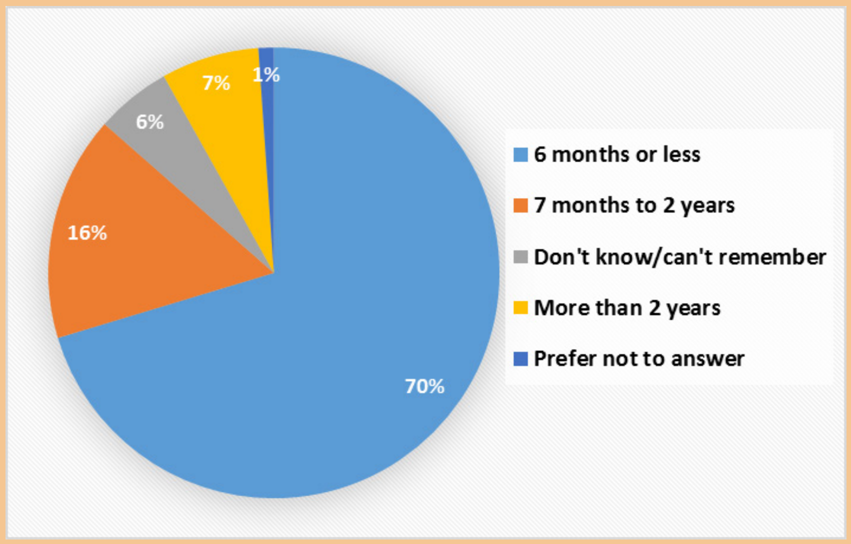
The results in Table 12 are consistent with other previous studies in terms of specific reasons for undertaking an HIV test. Most people - 215 or 53% - mentioned that the HIV test was done because of an individual desire to know their HIV status. Other reasons included feeling ill (103 or 25%), because they believed they were at risk of HIV (50 or 12.5%) and having a family member who passed away or tested positive (42 or 10.5%). The findings also revealed that about 153 (41%) of all the respondents hesitated to test for fears about how other people such as friends, family, employers or their community would respond if they tested HIV positive.

This implies that health communication interventions that promote an individual's choice for HIV testing should be maintained.

From making the decision to test to obtaining a test – how long does it take?

There is often a time lapse between an individual's decision to take a HIV test and actually receiving the test. This lag is largely attributed to HIV-related stigma. This questionnaire explored the actual time gap between the respondents' decision to test and when the test occurred.

Figure 2: Time between when to test and when test was done



According to Figure 2, the majority (70.4%) took six months or less between the time they first thought they should get an HIV test and the time they actually took it. Twenty three percent took 7 months or longer to take an HIV test.

Antiretroviral treatment and viral load experiences

This thematic area explores the proportion of respondents who were on ART at the time of the survey and aspects of their treatment experience. According to the results, almost all respondents - 387 or 96.5% - were on treatment at the time of the interview. The proportion of those on treatment has remained relatively stable over the last four years in Central Uganda.

Respondents were also asked the reasons why they did not start on ART immediately or within six months after diagnosis. Those who were not on ART were also asked why (Table 13).

Table 13: Reason for not starting HIV (antiretroviral) treatment

Reason	Number	Percentage
Not eligible for treatment (e.g. CD4 count too high/above threshold; not pregnant/no longer pregnant)	66	16.5
Treatment (or particular regimen needed) not affordable for me	3	0.7
Treatment (or particular regimen needed) not available at the clinic (based on policy or stock outs)	7	1.7
Unable to collect medications at the clinic or pharmacy	5	1.2
Afraid of partner/family/parents/friends finding out my status	11	2.7
Worried about treatment side effects	5	1.2
Worried about inability to comply with drug regimen or take pills	6	1.5
Did not feel sick so did not feel treatment needed	15	3.7
Other reason (please specify)	34	8.5
Don't know/can't remember	10	2.5
Prefer not to answer	5	1.2
Total	167	41.4

Multiple response options

Eligibility criteria for starting ART was the main reason that the majority of the respondents - 34 or 8.5% - were not on ART. This was followed by those who said they did not feel sick (15 or 3.7%; and 11 (2.7%) who were afraid of family members/partners finding out their HIV status.

The study also looked at issues of adherence and disclosure. In this pursuit, Respondents were asked to reveal times when they missed doses of medication in the last 12 months and the reasons why.

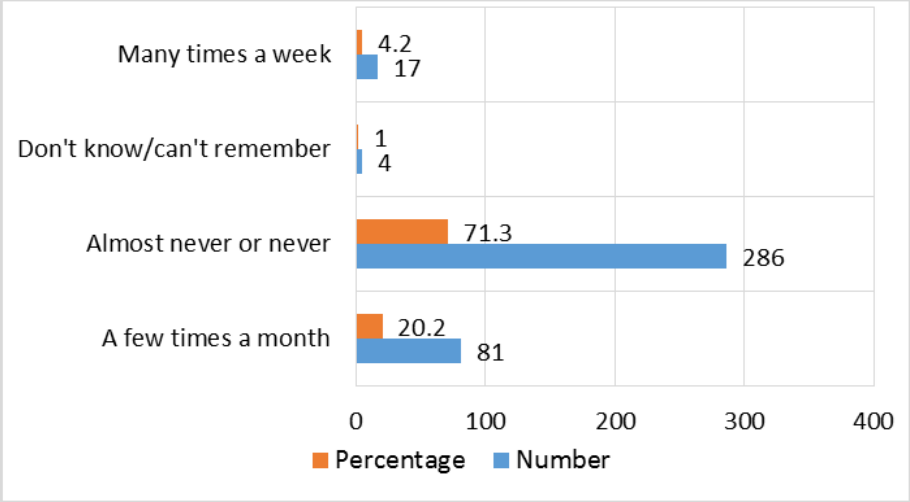


Figure 3: Proportion that missed medication for fear of disclosure in the last 12 months

Figure 3 illustrates that although the majority - 286 or 71.3% - had almost never missed doses of medication for fear of possible disclosure, some respondents - 98 or 24.4% - said they had missed medication a few times for this reason, whereas 17 (4.2%) had missed their medication 'many times' in the past 12 months for fear of disclosure. These findings show that HIV-related stigma continues to affect adherence, and that treatment and care programs should continue to have disclosure components.

Table 14: Viral load testing in the last 12 months

Response	Number	Percentage
Don't know	49	12.2
No, I have not had a viral load test in the last 12 months	72	18.0
No, the virus was detectable / I am not virally suppressed	33	8.2
Prefer not to answer	1	0.2
Yes	246	61.3
Total	401	100.0

According to Table 14, more than half - 246 or 61.3% - had an undetectable viral load in the past 12 months, compared to 33 - 8.2% - whose viral load was detectable and 72 (18%) that had not yet taken a viral load test. The current targets for viral load suppression are 90%, so more effort needs to occur particularly regarding mobilization of PLHIV in their respective communities or in associations.

Among those who reported not having taken a viral load test, 27 (37.5%) did not give a specific reason, 17 (23.6%) were not eligible for viral load testing based on their CD4 count despite the availability of a viral load test kit and 7 (9.7%) chose not to be tested. This indicates that viral load testing has yet to benefit the majority of PLHIV in Uganda. More health communication campaigns that promote use of viral load testing, in combination with health system efforts to ensure availability, should be advocated for.

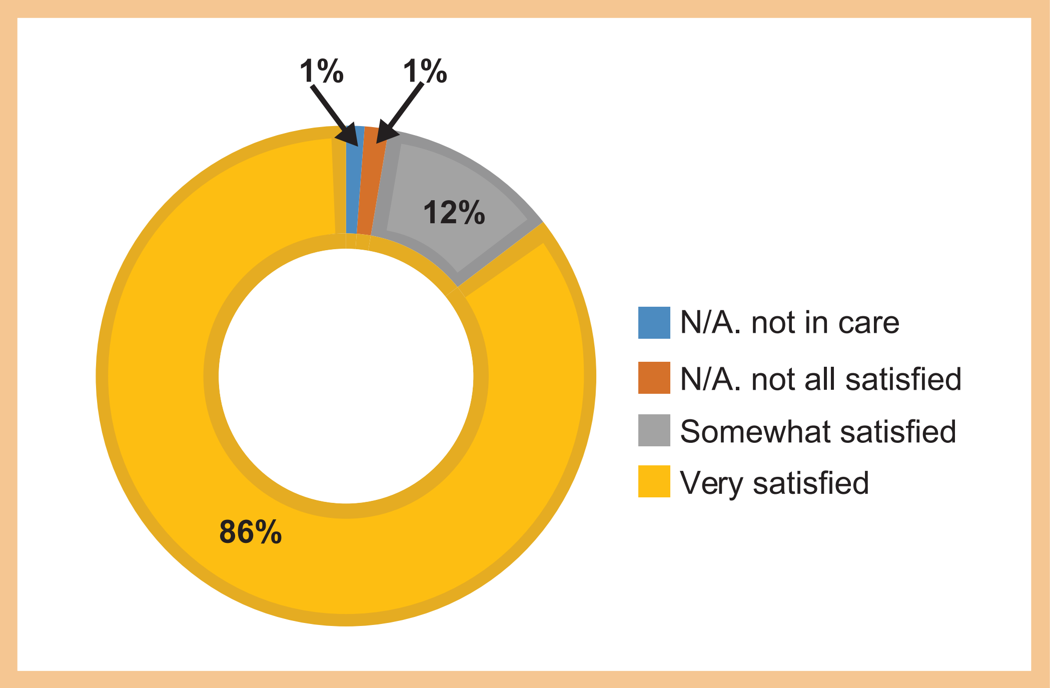
Service delivery experiences

The service delivery issues explored included access to health services for HIV related care and treatment; satisfaction with the available services; and support services and health worker and client interactions.

Experiences of seeking health care at regular health facilities

The data shows that 245 (61.1%) of the PLHIV sampled received their regular HIV care from government facilities. The rest – 147 or 36.7% - received HIV care from private or NGO facilities. Though the reasons for why services were sought at different places were not explored, PLHIV often prefer government facilities because they are more affordable. Figure 4 shows the respondents' level of satisfaction with the services at the regular place where they seek HIV care services.

Figure 4: Satisfaction with the regular HIV services received (to get figure)



According to Figure 4, the findings reveal that the majority - 390 or 97.2% - were satisfied with the regular HIV services they had received in the past 12 months, with 85.5% indicating they were 'very satisfied' and 11.7% indicating they were 'somewhat satisfied'.

Table 15: HIV-specific service experience at a regular HIV care center

Experience	Don't know	No	Prefer not to answer	Yes	Total
Feeling able to freely make your own decisions about treatment or care	4(1)	143(36.1)	2(0.5)	247(62.4)	396(100)
Provision of respectful and welcoming supportive care	1(0.3)	37(9.3)	1(0.3)	357(90.2)	396(100)
Denial of health services, including dental care because of your HIV status	4(1)	354(89.4)	2(0.5)	36(9.1)	396(100)
Being advised not to have sex because of your HIV status	2(0.5)	289(73)	4(1)	101(25.5)	396(100)
Being talked badly or gossiped about because of your HIV status	19(4.8)	307(77.5)	2(0.5)	68(17.2)	396(100)
Verbal abuse (yelling scolding or being otherwise verbally abusive) because of your HIV status	9(2.3)	333(84.1)	1(0.3)	53(13.4)	396(100)
Physical abuse (pushing hitting or being otherwise physically abusive)	1(0.3)	362(91.4)	0(0)	33(8.3)	396(100)
Avoidance of physical contact with you/taking extra precautions because of your HIV status	1(0.3)	357(90.2)	1(0.3)	37(9.3)	396(100)
Telling other people about your HIV status without your consent	39(9.8)	319(80.6)	0(0)	38(9.6)	396(100)

Table 15 shows that more than half – 247 or 62.4% - revealed that they feel able to freely make their own decisions about treatment; 375 (90.2%) reported respectful and welcoming supportive care; and 101 (25.5%) reported being advised not to have sex because of their HIV status. On a positive note, experiences such as denial of health services (such as dental care), physical abuse, and avoidance of physical contact with PLHIV because of their HIV status were minimal. It is key that interventions continue to tackle the myths and misconceptions around sexual activity for PLHIV. Media articles on HIV should also dedicate time to write about and dispel these misconceptions.

Seeking care outside the regular health care facility

Results revealed that some respondents (79 or 19.7%) had sought health care outside their regular HIV care facility. A comparative analysis was made about treatment experiences for the same individuals who had sought care outside their regular care facility.

Table 16: HIV service experience outside a regular HIV healthcare facility

Experience	Don't know	No	Prefer not to answer	Yes	Total
Feeling able to freely make own decisions about treatment or care	0(0)	40(50.6)	0(0)	39(49.4)	79
Provision of respectful and welcoming supportive care	0(0)	15(19)	1(1.3)	63(79.7)	79
Denial of health services including dental care because of your HIV status	1(1.3)	70(88.6)	1()1.3	7(8.9)	79
Denial dental care because of your HIV status	2(2.5)	54(68.4)	2(2.5)	21(26.6)	79
Being talked badly about or gossiped about because of your HIV status	2(2.5)	58(73.4)	1(1.3)	18(22.8)	79
Being talked badly or gossiped about because of your HIV status	1(1.3)	61(77.2)	0(0)	17(21.5)	79
Verbal abuse (yelling, scolding or name calling or being otherwise verbally abusive) because of your HIV status	0(0)	71(89.9)	0(0)	8(10.1)	79
Avoidance of physical contact with you/taking extra precautions because of your HIV status	0(0)	67(84.8)	1(1.3)	11(13.9)	79
Telling other people about your HIV status without your consent	4(5.1)	62(78.5)	1(1.3)	12(15.2)	79

The experiences of PLHIV at health care facilities contrast with those at HIV-specific health care facilities. For instance, the feeling of being able to freely make their own decisions about treatment or care was reported by 63 (79.7%) at their regular HIV health facility compared to only 39 (49.4%) at the non-regular health facility. Provision of respectful and welcoming supportive care was 357(90.2) at the regular healthcare facilitiy compared to only 63(79.7%) at the non-regular facility. However, being gossiped about because of ones HIV status was experienced by 68 (17.2%) at their regular place of care compared to 17 (21.5%) at the non-regular health care facility. Programs should, in general, encourage PLHJIV to seek care from their regular health facilities, as these offer multiple advantages compared to seeking care from other facilities, including access to treatment history and a better relationship with the service provider.

Medical Records and Confidentiality

The study also assessed client's opinions on whether their medical records were kept with utmost confidentiality.

Table 17: Confidentiality of medical records relating to HIV status

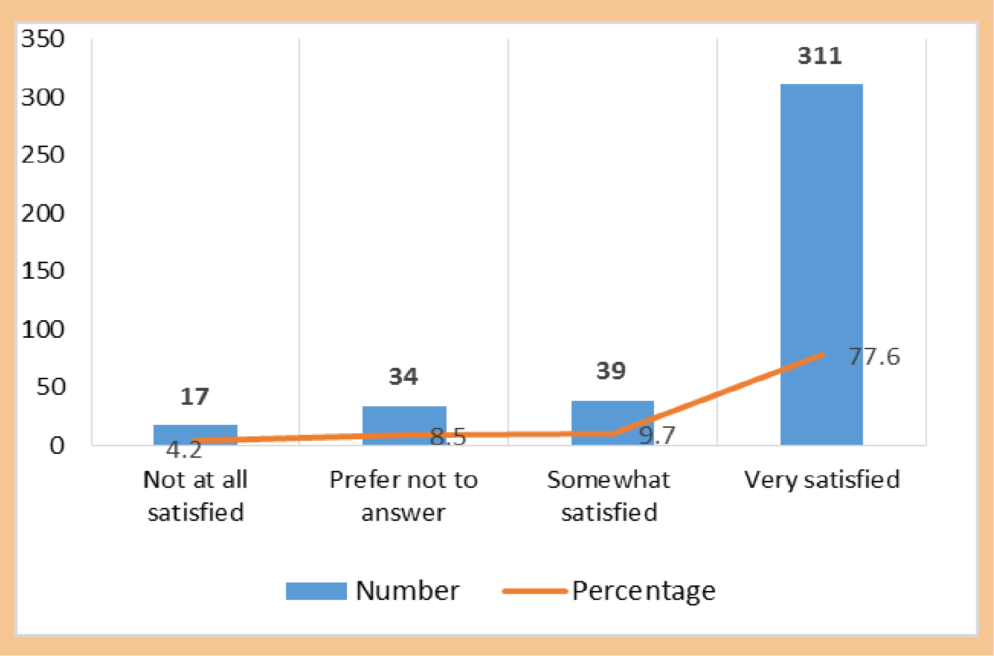
How confidential do you think the medical records are relating to your HIV status?	Number	Percentage
I am sure that my medical records will be kept confidential and will not be shared without my written informed consent	253	63.1
I don't know if my medical records are confidential	80	20.0
It is clear to me that my medical records are not being kept confidential	67	16.7
Prefer not to answer	1	0.2
Total	401	100.0

According to the results in Table 17, the majority 253 (63%) were sure that their medical records were kept confidential. However, 20% do not know if their medical records are kept confidential. Health care workers continue to need refresher courses on the importance of keeping individual HIV records confidential at all times.

Satisfaction with sexual and reproductive services at health facilities

This sub-section relates to respondents' satisfaction with sexual and reproductive health services in the past 12 months. Some of the key components of sexual and reproductive health services explored include: family planning/contraceptive provision; antenatal care and maternal care.

Figure 5: Levels of satisfaction with sexual reproductive health services in the past 12 months



According to Figure 5, there is a generally high level of satisfaction – 350or 87.3% - with sexual and reproductive health services. Out of those who reported satisfaction, 311 (77.6%) were very satisfied, while 39 (9.7%) were somewhat satisfied.

Table 18: Actions taken by healthcare professionals with respect to SRHS

Action/advise	No	Prefer not to answer	Yes	Total
Advised you not to have a child	360(89.8)	8(2)	33(8.2)	401
Forced pressured or paid you to get sterilized	373(93)	21(5.2)	7(1.7)	401
Advised you to terminate a pregnancy	356(88.8)	41(10.2)	4(1)	401
Forced or pressured you to use a specific type of contraceptive method	358(89.3)	36(9)	7(1.7)	401
Denied you contraception/family planning services	367(91.5)	31(7.7)	3(0.7)	401
Told you that in order to get your HIV (antiretroviral) treatment you had to use contraception	363(90.5)	32(8)	6(1.5)	401
WOMEN ONLY: Forced or pressured you to use a particular method of giving birth/delivery option	230(95.4)	9(3.7)	2(0.8)	241
Forced or pressured you to use a particular infant feeding practice	221(91.7)	14(5.8)	6(2.5)	241
Forced or pressured you to take antiretroviral treatment during pregnancy to reduce the chance of HIV transmission rather than counseling you on this as an option	220(91.3)	12(5)	9(3.7)	241

The findings show that 33 (8.2%) PLHIV were advised not to have children. The majority were not forced or pressured to get sterilized, denied contraception or family planning services or told to use specific contraception to obtain HIV treatment (93%, 91.5%, and 90.5% respectively). With reference to women only, 241 (60.1%) women of reproductive age reported that despite being HIV positive, they were not forced to use particular methods of giving birth; 230 (95.4%) were not forced to use a particular infant feeding method; 221 (91.7%) were not forced to take antiretroviral treatment during pregnancy to reduce HIV transmission 220 (91.3%).

The findings generally imply that interactions between patients and health care workers are progressively improving compared to 2013 HIV stigma results that indicated over 10% of PLHIV have had several negative experiences, including coercion of female patients into sterilization or family planning decisions.

SECTION E.
HUMAN RIGHTS AND EFFECTING CHANGE

The subsection relates to human rights and human rights violations experienced by PLHIV. This includes whether PLHIV are aware of their rights and if the respondents have tried to resolve human rights abuses.

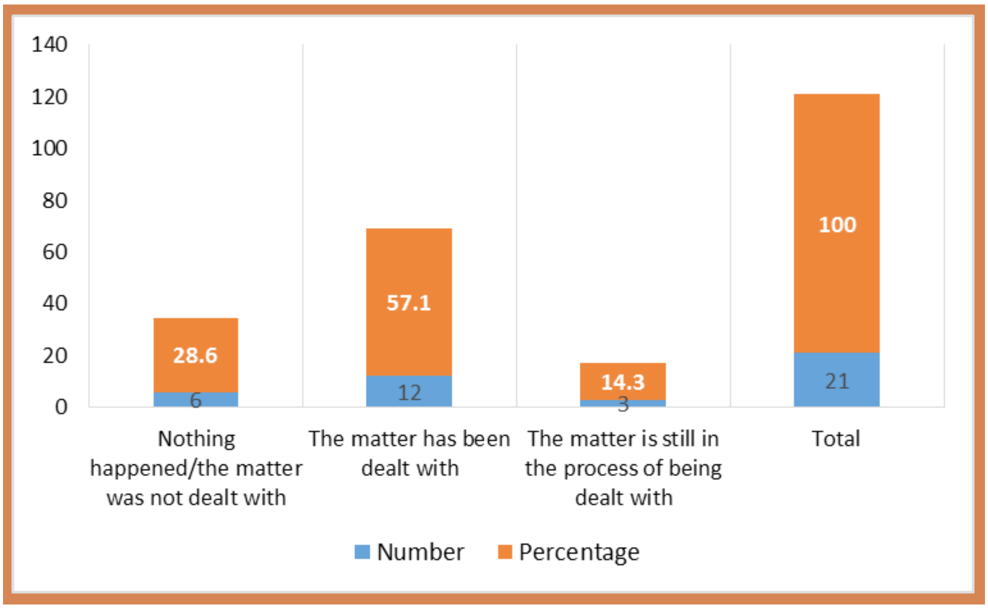
Table 19: Human rights abuses experienced by PLHIV in the last 12 month

Abuse	**Don't know/ can't remember**	**No**	**Prefer not to answer**	**Yes, but NOT in the last 12 months**	**Yes, within the last 12 months**	**Total Sum the row totals**
I was arrested or taken to court on a charge related to my HIV status	0(0)	380(94.8)	0(0)	8(2)	13(3.2)	401
I was denied a visa/ permission to enter another country because of my HIV status	1(0.2)	371(92.5)	1(0.2)	13(3.2)	15(3.7)	401
I had to disclose my HIV status in order to apply for residence/citizens	0(0)	385(96)	1(0.2)	6(1.5)	9(2.2)	401
] I had to disclose my HIV status to apply for a job or get medical insurance	0(0)	384(95.8)	1(0.2)	8(2)	8(2)	401
I was detained or quarantined because of my HIV status	0(0)	393(98)	1(0.2)	4(1)	3(0.3)	401
I was forced to disclose my HIV status publicly	0(0)	396(98.8)	1(0.2)	2(0.5)	2(0.5)	401
I was denied citizenship or was not able to apply for citizenship because of my HIV status	0(0)	395(98.5)	1(0.2)	1(0.2)	4(1)	401
I was denied permission to travel because of my HIV status	0(0)	379(94.5)	0(0)	9(2.2)	13(3.2)	401
I was denied residency because of my HIV status	1(0.2)	393(98)	0(0)	2(0.5)	5(1.2)	401

According to Table 19, findings illustrate that HIV status has not resulted in high rates of: detention, forced disclosure, denial of citizenship, or denial of residence. However, denial of a visa/permission to enter another country because of HIV status remains a human rights violation, with 28 respondents (6.9%) experiencing such a denial. In terms of advocacy, UNAIDS should continue to conduct global advocacy to remove visa barriers.

Out of the 58 individuals who faced some form of human rights abuse, 21 (36%), attempted to seek some help in the past 12 months, while the rest 36 (62%) did not. Out of those who attempted to resolve the human rights abuse, 12 (57%) mentioned that the matter of abuse was dealt with (Figure 6). The data implies a big gap between clients who experience an abuse and those who seek legal redress. One reason may be that PLHIV do not have the resources to seek justice. Through continued awareness campaigns and advocacy, such human rights abuses can be prevented. Additionally, sensitizing the general population to avoid discrimination could yield additional benefits.

Figure 6: Action taken to address abuse of rights



Those who feared taking action mentioned multiple reasons for not taking action (Table 20).

Table 20: Reason for not addressing abuse of rights

Reason for not taking action	Number	Percentage
Did not know where to go/how to take action	22	5.5
Insufficient financial resources to take action	4	1.0
Process of addressing the problem appeared too complicated	3	0.8
Felt intimidated or scared to take action	2	0.5
Was worried taking action might lead people to learn about my HIV status	2	0.5
No/little confidence that the outcome would be successful	2	0.5
Lack of evidence for the abuse	2	0.5
Other, specify:	3	0.8
Total	**40**	**10.0**

According to Table 20, the majority (22 or 5.5%) that did not try to seek redress did not know where to go and what action to take. Some PLHIV cited other reasons, like insufficient funds to enable them to take action, bureaucracy involved in the process, etc.

Awareness campaigns on the rights of PLHIV should continue to include information about how to take action if human rights violations occur. NAFOPHANU should also provide regular information about facilities that offer free services.

Table 21: Knowledge about laws protecting PLHIV in Uganda

Response	Number	Percentage
I do not know if there is a law	179	44.6
No, there are no laws	92	22.9
Yes, there are laws	130	32.4
Total	**401**	**100.0**

Table 21 indicates that the majority – 179 or 44.6% - do not know if there is any law that protects PLHIV; 130 (32.4%) said that there were laws; and 92 (22.9%) said that there are no laws. Overall, this shows a lack of knowledge about the legal environment, and more efforts should occur to inform PLHIV about relevant laws.

Table 22: Positive actions taken to effect change

Action	Don't know/can't remember n(%)	No n(%)	Prefer not to answer n(%)	Yes, but NOT in the last 12 months n(%)	Yes, within the last 12 months n(%)	Total n(%)
Supported others living with HIV in relation to stigma and/or discrimination	0(0)	166(41.4)	2(0.5)	139(34.7)	94(23.4)	401(100)
Confronted, challenged or educated someone who was stigmatizing and/or discriminating against a person living with HIV	5(1.2)	209(52.1)	2(0.5)	104(25.9)	81(20.2)	396(100)
Participated in an organization or group that works to address stigma and discrimination against people living with HIV	2(0.5)	248(61.8)	0(0)	80(20)	71(17.7)	401(100)

Action	Don't know/can't remember n(%)	No n(%)	Prefer not to answer n(%)	Yes, but NOT in the last 12 months n(%)	Yes, within the last 12 months n(%)	Total n(%)
Tried to get a community leader to take action about issues of stigma and discrimination against people living with HIV	2(0.5)	299(74.6)	5(1.2)	48(12)	47(11.7)	396(100)
Tried to get a government leader or a local/national politician to take action about issues of stigma and discrimination against people living with HIV	2(0.5)	326(81.3)	4(1)	36(9)	33(8.2)	401(100)
Spoke to the media about issues of stigma and discrimination against people living with HIV	6(1.5)	338(84.3)	7(1.7)	34(8.5)	16(4)	401(100)
Other (Specify)	52(13)	254(63.3)	59(14.7)	22(5.5)	14(3.5)	401(100)

Table 22 shows that more than half – 233 or 58.1% - had supported other PLHIV to confront stigma and discrimination. PLHIV remain a powerful force for challenging misconceptions, increasing knowledge about human rights and effecting change. PLHIV-led groups should continue to be supported to engage in stigma reduction efforts.

Key findings analyzed by theme and sampled audience

The qualitative findings are presented below by key themes such as disclosure, internal stigma and resilience, interaction with health care workers and human rights, as well as divided by key audiences.

Table 23: Theme1: Disclosure

Audience	Key findings
FSW	For most of the FSW surveyed, disclosure has been an empowering process, leading to increased access to HIV treatment and support from close friends and families. "Disclosure is good because when you disclose to someone, they get to know what you are going through. You get relief and this helps you to get determined. For instance, you're told to swallow drugs every day - you get that determination of swallowing without any hindrances inside you.'' Participant in FSW group in MARPI clinic.
MSM	Most MSM agreed that disclosure had enabled them to get support, courage and had become easier over time. "I am of the view that you can disclose to a person you don't know [more easily] than a person you know. This is because a person un-known to you might have a good heart to support you, compared to a person known to you". Participant in MSM group in MARPI clinic.
Transgender	To some disclosing was rewarding as they received encouragement, counseling and support from family and friends. Others felt disclosure was a negative experience, especially disclosing to people who were HIV negative. Participants mentioned not disclosing for fear of rumors and gossip. " Through the process of being open, I will save many souls because I was a victim of circumstance. Being open is going to help the family members in case of falling sick. They will know how to help, because they will know what exactly happened."
IDU	Disclosure has been an empowering process, but some disagree with disclosing to friends because they will gossip about them so they rather disclose to people they know this makes them strong.
Heterosexual men	Disclosure presented mixed benefits and challenges to this group. "There is a certain place I went in Gomba district, I got my ARVs and swallowed them but the person who was seated next to me had not known that I have HIV. When he saw that I had swallowed them, he approached me and started asking me many questions and in the end I realized they were not getting the services in their area very well". Others would say disclosing my status just worsened the situation "When I disclosed to people whom I did not know very well and were not related to me and not my friends, they just made my life more difficult. I was expelled from the job I had applied for because they got to know that I was HIV positive and yet they were those who were negative thus losing my job and a lot of words were said"
Heterosexual women	Since we have lived with HIV for a long time we are experts and many people run to us for counseling because we disclosed to them and we are experienced and every time you disclose you become more skillful. "Yes, it empowered me, and we believein disclosure to people. It has helped me so much, because previously, they did not know and they could not help me. I also could not help them"

Table 24: Theme 2: Interaction with health care services

Audience	Key findings
FSW	All could define what viral load is and knew that if one does not take his/er drug well, the viral load goes high. Most of them have never received care outside their usual HIV care, however when one of them ran out of drugs and went to access them in another facility she was denied the drugs.
MSM	All understood what viral load is and what it means when it is high or low.
Transgender	All of them understood what viral load meant. All have ever received care outside their usual HIV care facility. In contrast, they received away from the regular facility was much more different. The health workers where friendly and could give much attention to us.
IDU	All could not define what viral load means, however they were informed by the health worker that the viral load is high or low/ dormant and encouraged to adhere to their drugs well.
Heterosexual men	The majority have never received care outside their regular HIV care, however the few who went outside their usual place report that the health workers took long to attend to the clients and provide less treatment (few drugs) and rest the drugs had to be bought outside the facility.
Heterosexual women	All were able to define what viral load was and added that visuals of smiling face and annoyed face used to explain better to the client. The rest have never received care outside their usual HIV care, however when one of them ran out of drugs and went to access them in another facility she was denied the drugs.

Table 25: Theme 5: Human rights and effecting change

FSW	They have never experienced human rights abuses, but disclosed that there are instances when an employer wants you to be tested..
MSM	Most of them have never experienced any human rights violation, however one participant was denied VISA to go to Sweden because she was HIV positive,
Transgender	All report to not have experienced any violation of their human rights.

STUDY LIMITATIONS

The study had one major limitation in contrast to the previous stigma studies conducted in Uganda in the recent past. Unlike the previous studies that set out explore and quantify PLHIV experiences with HIV and related topics, this study generally set out to assess the empirical utility of the updated Stigma Index questionnaire in detecting the causes, extent, manifestation and impact on care service uptake, of stigma and discrimination experienced by PLHIV in Uganda. Since the details explored related more to improving the questionnaire in terms of: variability of responses, there are possibilities of missing data, association between questions and specific understanding of the questions. Therefore, this data may not be so much comparable to other studies.

RECOMMENDATIONS

1. Owing to regular changes in HIV care policies and treatment guidelines, changes to the questionnaires and implementation of the modified questionnaire is justified and recommended to capture emerging trends.

2. The results based on the updated questionnaire should be shared widely, particularly the data around PLHIV interactions with health care workers. NAFOPHANU is specifically tasked to share the results widely through several platforms.

3. Awareness campaigns that aim to bust myths and misconceptions about ‘appropriate’ sexual behaviors for PLHIV are still paramount. These awareness programs should emphasize accurate knowledge about positive living.

4. The mobilization of PLHIV for available services in the respective communities needs to be sustained through the existing networks of PLHIV within the districts. NAFOPHANU secretariat should channel logistical and other forms of support to the networks.

5. Training or providing refresher courses to health care workers to adopt or maintain positive attitudes towards PLHIV is highly recommended, as it contributes to PLHIV long-term ability to manage their health.

6. PLHIV need support around the disclosure process, particularly disclosing to families and sexual partners.

7. NAFOPHANU should work with other implementing partners, AIDS Control Program, local government entities and grass root agencies to encourage PLHIV to seek care from regular facilities for continued quality of services and easy coordination of the care and support system affiliated with the facilities.

REFERENCES

NAFOPHANU (2013), The PLHIV Stigma Index, Country Assessment, Uganda

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