NAFOPHANU

PEOPLE LIVING WITH HIV STIGMA INDEX SURVEY AMONG YOUNG PEOPLE LIVING WITH HIV IN EAST CENTRAL UGANDA

2017

GET UP SPEAK OUT for youth rights

SRHR ALLIANCE UGANDA

aidsfonds

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Names used in case studies are not real names of the respondents

The survey documents (User's Guide and Questionaire) were developed by GNP+, ICW, IPPF and UNAIDS

PEOPLE LIVING WITH HIV STIGMA INDEX SURVEY AMONG YOUNG PEOPLE LIVING WITH HIV IN EAST CENTRAL UGANDA

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF ACRONYMS

CEHURD	Center for Human Rights and Development
CSO	Civil Society Organization
FLEP	Family Life Education Program
FSW	Female Sex Worker
GIPA/MIPA	Greater / Meaningful involvement of Persons Living with HIV/
GUSO	Get Up Speak Out
HIV/AIDS	Human Immune Virus/Acquired Immuno Deficiency Syndrome
IDU	Injecting Drug User
IPPF	International Planned Parenthood Federation
MSM	Men who have Sex with Men
MUREC	Mildmay Uganda Research Ethics Committee
NAFOPHANU	National Forum for People with living HIV/AIDS Networks in Uganda
ODK	Open Data Kit
PLHIV	People Living With HIV
PMTCT	Prevention of Mother to Child Transmission
RAHU	Reach a Hand Uganda
RHU	Reproductive Health Uganda
STF	Straight Talk Foundation
SRHR	Sex Reproductive Health and Rights
UGX	Uganda Shilling
UNYPA	Uganda Network of Young People Living with HIV
YPLHIV	Young People Living with HIV

ACKNOWLEDGEMENT

The People Living with HIV Stigma Index Survey among Young People Living with HIV in East Central Uganda is part of the Get Up Speak Out” For Youth Rights (GUSO) Project (2016-2020). The project aim is that “All young people, especially girls and young women10-24years, are empowered to realize their sexual and reproductive health and rights (SRHR) in societies that are positive towards young people’s sexuality”.

The National Forum of PLHA Networks (NAFOPHANU) is so grateful to Aidsfonds for the financial and technical support provided to entire project through the Sexual Reproductive Health & Rights Alliance Uganda (SRHR-A Uganda).

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Together for a positive difference.

Stella Kentutsi
Executive Director NAFOPHANU

EXECUTIVE SUMMARY

Introduction

The report presents findings from the Stigma Index Baseline Survey among Young People living with HIV (YPLHIV) in East Central Uganda conducted in three districts of East Central Uganda; Jinja, Iganga, and Bugiri. The survey was linked to a series of stigma index surveys in Uganda and other countries and as such used the standard Persons Living with HIV (PLHIV) stigma index methodology. The overriding purpose of the study was the need to gather baseline data to support measurement of changes for the planned four-year project titled "Get Up Speak Out" (GUSO) for youth rights project funded by Aidsfonds. The project that runs from 2016—2020 is implemented in a consortium of Sexual Reproductive Health Rights Uganda Alliance comprising of eight partners including; Family Life Education Program (FLEP), Straight Talk Foundation (STF), National Forum for People with living HIV/AIDS Networks in Uganda (NAFOPHANU), Uganda Network of Young People Living with HIV (UNYPA), Reach A hand Uganda (RAHU), Restless Development (RD).

During the study, NAFOPHANU worked closely with UNYPA to execute the YPLHIV stigma index. The YPLHIV stigma index was planned to document the level of stigma and discrimination as a critical structural barrier to access and utilization of sexual reproductive health services (SRHS) and HIV services among young people living with HIV. The results will aid programming of SRH/HIV services for the young people as well provide a basis for measurement of changes in respect to GUSO project outcomes and impact as well as guide stigma reduction interventions generally in the region and the country.

Methods

The study adopted a cross-sectional design to collect and synthesize data from the three districts. The study had mixed methods approach using both quantitative and qualitative. The data was collected using electronic SMART phone devices. Quantitative data analysis followed the standard 2008 PLHIV stigma questionnaire thematic areas: experiences of internal and external stigma, knowledge and practices relating to governing laws, experiences of effecting change, disclosure, HIV testing, seeking care and treatment experiences. However, given the nature of the planned intervention with a major focus on reproductive health services, the main synthesis of the data and interpretation focused more on sexual reproductive health as per the stated project objectives. To compute the overall levels of HIV stigma for both external and internal forms, selected data elements were combined.

The empowerment processes

The study design adhered to the PLHIV stigma index empowerment standard programmatic requirement for PLHIV (Federation, 2008). This standard and principle requires active participation of the PLHIV in the entire research execution process. Therefore, the YPLHIV were recruited as research assistants to adhere to the requirement. The age factor was greatly emphasized and only Research Assistants (RAs) categorized as young people living with HIV participated.

Socio- Demographics characteristics

A total of 223 respondents were reached, comprising 84 (37%) males and 139 (53%) females in the three districts of Jinja, Iganga and Bugiri. Almost half 109 (49%) of the respondents were in the age category of 20-24 years and the rest were 15-19 years and half were married 111(50%). The proportion that completed primary education was small 24(18%) females Vs. 3(3.8%) males. Overall, the respondents reached were generally sexually active. In terms of program implication, the YPLHIV reached demonstrated the need for sexual and reproductive health services (SRHS) as per the Get Up Speak Out (GUSO) planned interventions.

Key findings

The proportion of YPLHIV who expressed internal and external forms of HIV related stigma was almost equal (19.1% vs. 20.8%) respectively.
With reference to internal HIV stigma, feeling ashamed because being a YPLHIV was the most mentioned form of internal reported by 133 (59.6%). Other components that measure internal stigma such as feeling guilty, blaming others having low self-esteem, feeling of being pushed and suicide were mentioned by small proportion between 24.7% to 6.8%). Several gender differences with respect to internal forms of HIV related stigma among YPLHIV manifested. Except for proportions that blame others: 24% male vs. 27% females. All other forms of internal HIV related stigma (blaming self, feeling suicidal, feeling of being punished, and feelings of guilt) were more reported by male's respondents.

Regarding external HIV related stigma, being gossiped about was the most mentioned by experience by 109(49%), followed by verbal insult 65(29%), physical assault 45(20%) and physical threats 31(14%). The proportions that revealed exclusion experience were 22 (10.4%) with respect to social gathering,18 (2.7%) family activities 17(8%), religious places or places of worship. Overall, discriminatory practices were high among YPLHIV unlike exclusion from places of worship. Therefore, factors related to external and internal stigma have a bearing on deterring YPLHIV access to SRH/HIV services.
From the qualitative data, the external forms of HIV related stigma were mentioned to cause several barriers to accessing sexual reproductive health services.

HIV stigma was revealed to pose several barriers to accessing sexual and reproductive health services by YPLHIV. Whereas most 147 (69%) YPLHIV self-reported to be sexually active and 63(30%) already have biological children, the proportion who reported to have received counseling about reproductive options was generally low at 34 (43%) males' vs. 77 (58%) females on the contrary.
The findings further indicate 79 (37.1%) of the females were receiving PMTCT while still 29 (13.7%) were not aware of whether such treatment existed. Others 22(10.4%) did not have access to such treatment and the same proportion reported to have not had HIV when they were pregnant. This data implies the need for comprehensive sensitization program to create demand for services in addition to promotion of desirable behaviors among the target audiences.

Access to reproductive health services

The data revealed that over 50% of the respondents were sexually active, married and some had produced children. Though almost all (97%) YPLHIV were accessing ART, those who were accessing SRH services were quite low- 116 (52%), 34(43%) males, 77(58%). Like other adolescent and young people programs, advocacy to ensure provision of reproductive health services for YPLHIV is critical. This means that internal and deliberate integration of SRH should level on the momentum created by ART program for YPLHIV.

Recommendations

From a program perspective, the role of the NAFOPHANU and other Civil Society Organizations (CSOs) is very vital in creating an enabling environment for the GUSO project to meet the intended objectives. Through NAFOPHANU stewardship, CSOs should be strategically engaged as the first significant step toward resources mobilization, advocacy, for YPLHIV to gain milestones in programs that will make it possible for integration of SRHS and ART.

Strengthening dialogues amongst groups of YPLHIV should be fostered to empower fellow peers to seek SRHR and HIV valid information hence equipping them with skills, knowledge and solutions pertaining to structural barriers faced in accessing SRHR services. Dialogues are anticipated to support a peer-to-peer approach that will potentially contribution to motivating YPLHIV to demand for SRHR and HIV services. The peer-to-peer approach has beneficial effect of reducing specific forms of HIV stigma. The Government should work with CSOs and other administrative units to enforce local laws that protect rights of YPLHIV. The government and other service providers should collaborate to ensure adequate and appropriate provision of SRH products and services in the most comprehensive way to the YPLHIV. This will enhance preferential consumption of the services and products. In addition government should ensure creation of human rights awareness pertaining to SRH rights, health rights, access to information and justice among YPLHIV.

Health facilities and communities should advocate for the strengthening of the role of expert clients as a supportive structure to establish the facility-family linkage at grass root level.

Stakeholders particularly those in health services should be tasked to operationalize existing guidelines of SRHR service provision in general but specifically the Uganda National Guidelines and Services standards for SRHS. This will generally empower the YPLHIV and ensure quality services.

CHAPTER ONE: INTRODUCTION

Get Up Speak Out for Youth rights (GUSO) is a five-year (2016-2020) project implemented in a consortium of eight partners. The consortia members are coordinated by the Uganda Sexual Reproductive Health & Rights (SRHR) Country Alliance.

The project is supported by six Northern partners including Aidsfonds, Choices for Youth & Sexuality, Dance 4 life, International Planned Parenthood Federation (IPPF), Rutgers & Simavi. The SRHR Uganda country Alliance has eight program implementing partners including National Forum of People Living with HIV/AIDS Networks in Uganda (NAFOPHANU), Uganda Network Young People living with HIV and AIDS (UNYPA), Restless Development (RD), Straight Talk Foundation (STF), Reach a Hand Uganda (RAHU), Family Life Education Program (FLEP), Reproductive Health Uganda (RHU) and the Center for Human Rights and Development (CEHURD).

The primary beneficiaries of the project are young people aged 10-24 years, PLHIV both in and out of school in the four participating districts of Bugiri, Mayuge, Jinja and Iganga. It also targets young people's key gate keepers and district-based stake holders. The program is built on cross cutting principles such as; Meaningful Youth Participation, Youth Centered Approach, Gender Transformative Approach and Multi-component Approach.

The GUSO programme is implemented under five outcome area including;

1. Strengthened sustainable alliance to comprehensively address the SRHR of young people
2. Empowered young people increasingly voice their rights
3. Increased utilization of comprehensive SRHR information and education by all young people
4. Increased utilization of quality and youth friendly SRHR services that respond to the needs and rights of all young people
5. Improved socio-cultural, political and legal environment for gender-sensitive, youth-friendly SRHR

Therefore, the project aims at ensuring that young people have access to SRHR education and related services that match their needs and choices.

1.2 ABOUT NAFOPHANU

The National Forum of People Living with HIV Networks in Uganda (NAFOPHANU) is an umbrella organization for networks of People Living with HIV (PLHIV) with membership spread across the country and in specific national level cohort groups of uniformed personnel, Young PLHIV, Women, Men, religious leaders and teachers living with HIV. Established in May 2003, to provide systematic and all-inclusive coordination for PLHIV networks

NAFOPHANU with support from Aidsfonds came into this consortium to ensure meaningful involvement of young people living with HIV, integration of HIV information and services into SRHR and national level advocacy.

1.3 Main baseline survey objective

To provide data to guide interventions aimed at stigma reduction among YPLHIV, development of future advocacy interventions to promote the rights of YPLHIV and facilitate measurement of changes.

1.3.1 Specific Objectives of the Baseline Survey

i. To find out the experiences of YPLHIV regarding stigma and discrimination in three districts.
ii. To assess the extent to which stigma and discrimination is a critical structural barrier to access and utilization of SRHR and HIV services by YPLHIV in the three districts.
iii. To provide evidence for programmatic interventions to effect change.

1.4 Study Scope

The baseline was conducted in the three districts of East Central Uganda (Jinja, Iganga and Bugiri). The study population were young people living with HIV between 14 to 24 years old. These were deemed to have unique challenges with regard to SRHR owing to transition issues from childhood, through adolescent and the anticipated adulthood.

CHAPTER TWO: APPROACH AND METHODOLOGY

2.1 Approach

The PLHIV Stigma index uses a participatory consultative approach where discussions with the project consortia members and different stakeholders; women, men, boys, girls, district, health facility were held. The recommended methodological approaches for any HIV related stigma studies is an empowerment process of the PLHIV. This requirement was adhered to during the processes and engagements before and during data collection; particularly the data collection was conducted and supervised by YPLHIV from the three participating districts.

2.2 Study design

Given the general approach and methodological requirements, the study adopted a cross sectional design. Data was collected at a single point-in time. Cross sectional was the most appropriate because, the planned intervention was not tagged to a cohort but a general population of young people living with HIV. The survey activities were undertaken through a participatory approach. For instance, before commencement of data collection, NAFOPHANU arranged a preliminary consultative meeting with representatives of Uganda Network of Young People Living with HIV (YPLHIV) to ensure that there was mutual understanding of the expectations of PLHIV survey and key deliverables. The consortia members were informed about the approval process at the institutional review board and registration with Uganda National Council for Sciences and Technology (UNCST). Note- Mildmay Uganda Research Ethics Committee approved the previous two protocols for the PLHIV stigma index and was therefore approached to approve this study too because of the similarity of the protocols used.

2.3 Target population, Sample Size and Sampling Procedures

2.3.1 Target population

The survey targeted young people living with HIV in East Central Uganda. Anecdotes from YPLHIV representatives indicated that approximately 200 YPLHIV would be interviewed during the survey. These were already registered with YPLHIV groups. Given this background information, the three districts were expected to provide about 200 respondents including females and males. Because of lack of a clear estimated sample of the YPLHIV, this background information formed the basis for calculating the sample size.

2.3.2 Quantitative Samples

Though a representative quantitative sample is often required to generate precise estimates, the level of homogeneity among the YPLHIV in these districts was considered high and a relatively small sample of 200 YPLHIV was justified. However, current records in registered HIV Network lacked actual numbers of target population living with HIV in the three districts to permit proportionate sampling and allocation per district.

2.3.3 Sampling frame and enlisting the respondents

The sampling is district based. This is because the YPLHIV are registered within the district:

Stage 1	District selection was pre-determined to focus on three districts where the GUSO project was undertaken
Stage 2	A sample of at least 70% respondents from rural and 30% from urban was determined to help document stigma level among the two locations.
Stage 3	To address gender balance, usually females are more than the males. Depending on the registration in the network at districts, appropriate samples based on the sampling plan were determined.
Stage 4	Probability Proportion to Size (PPS) approach to determine the number of females/males within the age group targeted was done. The minimum sample size was fixed at 200 in total.
Stage 5	District sampling frames were obtained from the registered membership network. This list was used to randomly sample eligible respondents.

2.3.4 Final list of Respondents for interviews

The research team closely worked with field mobilizers at the district level to identify those randomly chosen off the sampling list. The randomness was executed by the data manager using a computer function called Rand Between in Microsoft Excel software. The respondents were mobilized to convene at the nearest health facilities or other safe places for interviews.

2.4 Data Collection Instruments

The English PLHIV stigma index tool was translated to Lusoga, a popularly spoken language in East Central Uganda and particularly in the three districts.

2.5 Data management, analysis and reporting aspects

2.5.1 Data Collection

During data collection, a YPLHIV served as the local guide and mobilizer. Upon agreeing on venue for the interview, appropriate permission including consent and assent were done, while ensuring confidentiality throughout the interview process. Data collection was done through face-to-face interviews using the standard PLHIV stigma index tool.

2.5.2 Software for data collection

Survey data was collected on standard structured questionnaire, loaded on an electronic data collection device. The platform on the Smart phone was Open Data Kit (ODK). The use of electronic platforms for data collection means that, no data entry procedures were expected for the survey data upon completion of data collection phase.

The Open Data Kit (ODK); an open-source set of tools for mobile data collection solutions, was used for developing data collection forms, gathering data on mobile devices, and sending the data to a server. he current ODK Aggregate was configured to receive data sets for this project.

2.5.3 Data Analysis Plan -Quantitative

Much as the PLHIV Stigma Index standard questionnaire was adopted, the questionnaire does not contain a standard analysis plan and a general recommendation to use basic statistics and ease to understand measurements is recommended. Given the relatively small sample size, it was suggested that the Social Behavioral Change framework, be adopted to help in contextualization (Socio-ecological model, (McKee N et al. 2000). The frame work targets the individual (self) but is cognizant of the influencing factors beyond the individual in adoption of positive behaviors. In adopting the McKee model, interpretation of data was contextualized using aspects of: information/knowledge, experiences, motivation, and ability to act, gender and social norms as they relate to the nine thematic areas in the stigma index.

2.5.4 Data collection teams: Recruitment, Training and Deployment

Training of the data collection team was done by a consultant and the representatives of YPLHIV. Data collectors received ethics training as is emphasized for PLHIV related studies. Part of the gender integration was achieved by having female and male research assistants where appropriate. All those recruited were competent in English and the local language (Lusoga).

2.6 Quality Control

For purposes of quality control, a team of three research assistants and a supervisor were allocated per district. One overall quality controller who was well versed with the protocol procedures and phone technology was allocated as the overall data collection supervisor. Before submission of data, the supervisors allocated per district verified the entries on the spot. Additionally, the data manager at the data management center verified entries and provided instant feedback for any errors that were detected immediately. This entire process ensured that very reliable data was obtained.

2.7 Ethical Considerations:

The sensitivity of executing the PLHIV stigma index among the minors below 18 is acknowledged. Therefore, ethical approval was mandatory and all aspects of protection of YPLHIV were adhered to. Participation in the exercise was voluntary without “benefit” attached whatsoever. The research team sought formal consent keeping all data gathered confidential and private. Normally, in conducting PLHIV stigma Index, part of the empowering process includes working with PLHIV as data collectors and key actors in the study process. YPLHIV with competence in data collection were trained and later collected the data.

CHAPTER THREE: RESULTS

3.0 Report Structure:

The PLHIV stigma index conventional way of presenting results follows the three major sections reflected in the PLHIV standard HIV stigma questionnaire. These include: 1) Respondents background characteristics, 2) Experiences of stigma and discrimination and 3) Experiences of HIV testing, disclosure, treatment and having children. Within each of these sections, there are three to five distinct sub topics that are embedded. At the beginning of every section, a brief introduction is provided in relation to the content expected within that section. Owing to the length of the information, the report uses disaggregated tables and selected figures to condense such information for easy reading. After presentation of the major findings, additional sections such as conclusions, study limitations, study strengths and recommendation follow.

SECTION 1: BACKGROUND CHARACTERISTICS OF RESPONDENTS

This section presents summary statistics about the sample reached during the study and key socio-demographic characteristics of the respondents. A total of 223 respondents participated in the survey. The total minimum pre-determined sample was 200 respondents. Out of the 223, 84 (37%) were males and the rest female 139(63%).

Table 1: Background characteristic of the sampled respondents by gender

Categories of belonging	Male n (%)	Female n (%)	Total n (%)
Men who have sex with men	1(0.4)	NA	1(0.4)
Sex worker	1(0.4)	8(3.6)	9(4)
Injecting drug user	5(2.2)	0	5(2.2)
Refugee or asylum seeker	1(0.4)	1(0.4)	2(0.9)
Internally displaced person	3(1.3)	0	3(1.3)
Migrant worker	8(3.6)	3 (1.3)	11(4.9)
Prisoner	5(2.2)	3(1.3)	8(3.6)
I don't belong to and have not in the past belonged to any of these categories	60(71)	124(89)	184(82.5)
Total	**84 (37.7)**	**139 (62.3)**	**223(100)**
Age grouping			
10-14	5(6.3)	11(8.3)	16(7.5)
15-19	37(46.8)	50(37.6)	87(41)
20-24	37(46.8)	72(54.1)	109(51.4)
Total	**79 (100)**	**133 (100)**	**212(100)**
Marital relationships			
Married or cohabiting and husband/wife/partner is currently living in household	12 (15.2)	31(23.3)	43(20.3)
Married or cohabiting but husband wife/partner is temporarily living/working away from the household	2(2.5)	8(6.0)	10(4.7)
In a relationship but not living together	0	20(15.0)	20(9.4)
Single	56(70.9)	55 (41.4)	111(52.4)
Divorced/separated	9(11.4)	17(12.8)	26(12.3)
Widow/widower	0	2(1.5)	2(0.9)
Total	79(100)	133 (100)	212 (100)
Education level attained			
No formal education	3 (3.8)	24 (18)	27(12.7)
Primary school	48(60.8)	66(49.6)	114(53.8)
Secondary school	26(32.9)	41(30.8)	67(31.6)
Technical college/university	2(2.5)	2(1.5)	4(1.9)
Total	**79(100)**	**133(100**	**212(100)**

3.1.1 Description of the sub groups and other social demographic characteristics

Population Categories: As per table 1, majority 184(82%) of the respondents reported not to have belonged to any of the categories listed by the stigma index (MSM, FSW, IDU, Asylum seeker, prisoner, Migrant worker etc.). The unique differences to note about the categories and gender are three. Overall, more females 124(89%), vs. 60(71%) reported not currently belong or to have belonged in the past to any of the categories listed above. Among the females, 3.6% revealed belonging or having belonged to sex work (FSW) category compared to 0.4% among the males. By contrast, more males revealed belonging to or having belonged to categories of migrant workers 8 (3.6%) and injecting drug user 5(2.2%).

Age grouping of the sampled respondents:

The predominant age categories were 15- 19 and 20- 24 years (table 1). This was mainly because of the targeted sample of YPLHIV. The proportion of males and females within the two age categories varied. For instance, there are 37 (46.8%) males vs. 72(54%) females in age category of 20 to 24 years. Thought it cannot be confirmed, the higher proportion of females to males could explained in terms of reproduction health services that often more gills seek compared to boys especially after age 18. During these services, HIV testing has been mandatory and so more girls ending up knowing their HIV status.

Marital relationships of sampled population:

Slightly over half of the respondents 111(52%) were single. This is expected given the relatively young ages. However, more males 56 (70%) vs. 55 (41%), reported to be single. This indicates that females marry off or are engaged at a much young age than males. Similarly, the proportion of married/cohabiting was 31(14.6%) female vs. 12 (5.7%) males, where as those who were divorced/separated had 17(8%) female's vs. 9 (4.2%) males. These findings reveal that the target population is sexually active hence justifying the need for SRHR targeting young people living with HIV.

Education level attained

The majority of the respondents 114 (53.85) attained primary school education, followed by secondary 67 (31.6%) and very few 4(1.9%) attained college/ university. Female respondents 24(18%) were the majority among those with no formal education. These education differences mean that aspects of sensitization for the target groups should in all cases categorize and factor the audience level of understanding given the relative diversity in education attainment.

3.1.2 Wealth related respondent's characteristics

The wealth related components explored included; employment, income levels and food availability.

Table 2: Employment status by Gender

Response	Male n (%)N=79	Female n(%)N=133	Total n (%) N=212
Employment status			
In full-time employment (as an employee)	5(6.3)	8(6)	13(6.1)
In part-time employment (as an employee)	6(7.6)	2(1.5)	8(3.8)
Working full-time not as an employee (self-employed)	4(5.1)	13(9.8)	17(8)
Doing casual or part-time work (self-employed)	21(26.6)	20(15)	41(19.3)
Unemployed and not working at all	43(54.4)	90(67.7)	133(62.7)

Employment status:

Regarding employment status, majority of the respondents 133(62.7%) were unemployed. Overall the proportion of unemployed females was higher 90 (67.7%) vs. 43 (54.4%). Among those who were employed, majority 21(26.6%) vs. 20 (15%) reported working on causal activities or part-time work (Self-employed). The rates of unemployment could be attributed to the relatively young ages. Ordinarily most before the age of 24 years are in Uganda are expected to be in school. Even those who are working are mainly in part time to compliment school fees and other domestic requirements.

Table 3: Distribution of respondents by average monthly income of their households and number of days' respondent's household have not had enough food.

Income levels	Frequency n (%)
1- 50,000	49(23.1)
100,001- 150000	16(7.5)
150,001- 2000,00	6(2.8)
200,001- 3000,00	20(9.4)
300,001- 4000,00	13(6.1)
400,001- 5000,00	15(7.1)
500,001- 600,000	28(13.2)
600,001- 700,000	4(1.9)
700,001- 800,000	5(2.4)
800,001- 900,000	8(3.8)
900,001- 1,000,000,	3(1.4)
Above 1,000,000	26(12.3)
None	3(1.4)
Total	212(100)
Availability of enough food	
1 - 7 days	123 (58)
8 - 15 days	20(9.4)
16 - 21 days	7 (3.3)
22 - 30 days	8(3.8)
None	54(25.5)
Total	**212 (100)**

The income levels directly measure poverty at household level. The greatest number of respondents 49 (23%) fall in categories that reflect low income levels of less than UGX 50,000 per month on average. The reported incomes don't show a consistent trend because some respondents reported that their average household incomes ranged between UGX500,000 and UGX600,000 where others 26(12.3%) have over UGX1,000,000 on average. This finding should be interpreted from the perspective of average household income note necessarily the interviewee who could be in a lower age category of less than 24 years.

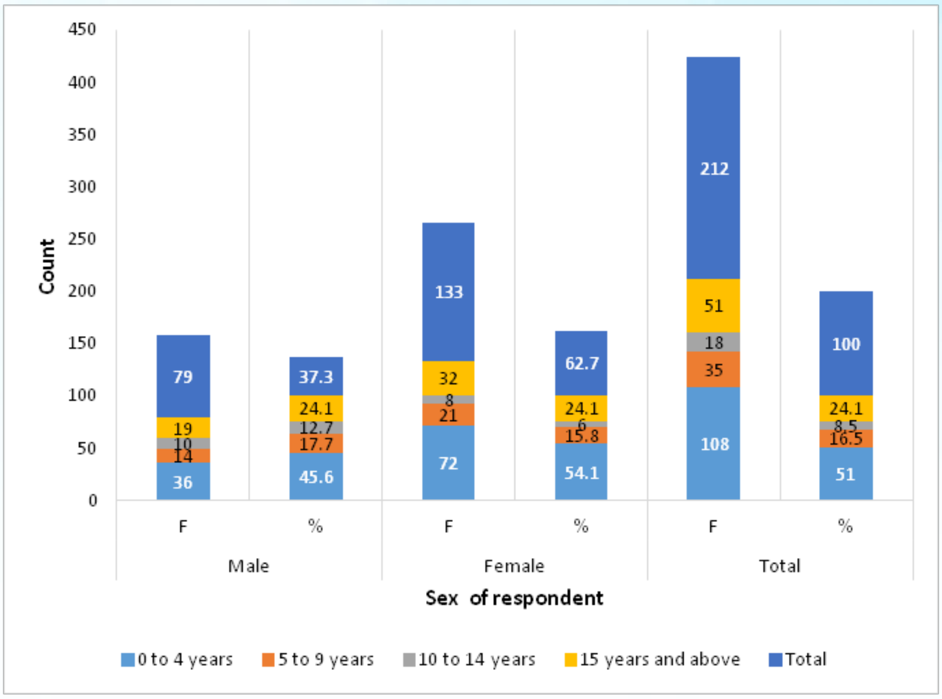
Access to three meals a day (breakfast, lunch and dinner) was a proxy indicator for enough food. This was computed in days within a month as per the categories in table 3. Overall 74.5% of respondents reported that members of their household had not had enough food in the last one month. Within the referenced month, 123 (58%) did not have enough food in the last 1-7 days, followed by 20(9.4%), who did not have enough food between 8-15 days. These figures should be interpreted with caution that at the time of the survey, Uganda as a country and the East Central region were experiencing severe dry spells which could have increased the food crisis and access to food by households in general. In contrast to the Stigma reduction study in Central and South Western Uganda in 2015, the proportion that reported not to have enough food were 51% in the last one month. Regarding enough food, it is generally known that most YPLHIV depend on their care takers for basic needs including food. So, the ability of the caretaker directly impacts on the YPLHIV.

3.1.3 Respondents profile related to HIV and sexual activity

Duration lived with HIV

The length of time an individual has lived with HIV is often associated with the magnitude of HIV related stigma. The time duration refers to time since the respondents knew their status. It may/may not reflect time since infection.

Figure 1: Length of time respondents have lived with HIV



F= Frequency derived from the count and total sample which responded

Figure 1 shows that the majority 108(51%) of the respondents had known living with HIV between 0 and 4 years. This could be associated with a possibility of recent infections among the young people or delayed disclosure process from care takers to children for fear of negative consequences upon disclosure. Those who had known living with HIV for 15 years and above were 51(24.1%). The proportions are similar for both males 19(24%) vs. 51(24%) females. Given the relatively young ages, those who had lived with HIV for 15 years, could have contracted it prenatally.

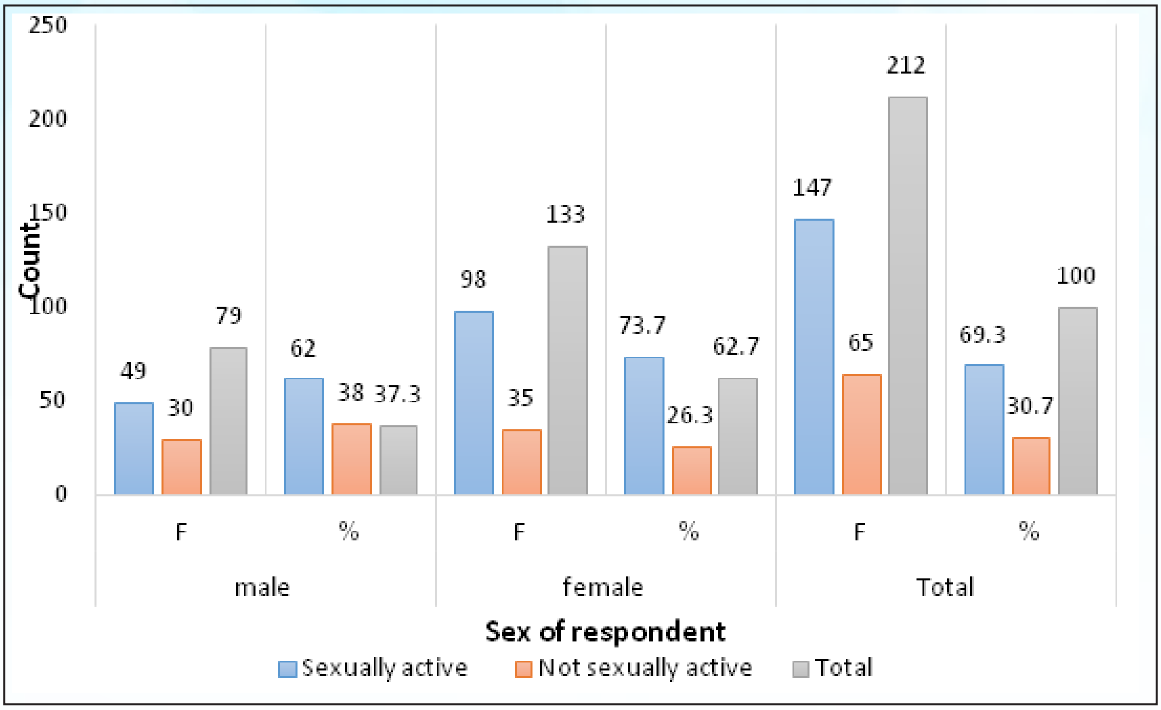
Below are quotes from young people who participated in the FGD and discussed the issues of how they found out their HIV status the first time. They gave varying accounts that either depict fear disclosure or the age factor that might have obscured the care givers from disclosing to them.

- "I got to know my status at university, I fell sick and went to the sick bay and was advised to take an HIV test, so I discovered I was positive"
- "I discovered in p.7, I was very sick. My young bother was born with HIV and we used to share sharp instruments because I didn't know. I tested and was positive"
- "My mum took me for a test at 8years but was told I am positive at 14years"
- "I went for family planning; I was tested and told I had HIV"
- "I was very sick at school and my teachers were concerned and I was told to go home and found out" from my parents that's when my mom told me that I was positive, so I went to hospital for checkup".

Sexual activity

Owing to the project goal and objectives, understanding of sexuality issues was paramount to refining the proposed interventions.

Figure 2: Percentage of respondents who were sexually active by gender



F= Frequency derived from the count and total sample which responded

Figure 2 indicates that most 147 (69.3%) respondents revealed being sexually active in the last 12 months; 49 (62%) males and 98 (73.7%) females and early initiation of sex activity among YPLHIV. These findings imply a need for focused SRH interventions for young people including those of 18 years and above, and those below.

Having biological children

Data indicated that 83 respondents; 20 (9%) males and 63 (30%) females admitted to having biological children. Only 2 females and 1 male respondent mentioned to have adopted children. Specific support systems will be required to address anticipated challenges regarding child care as well as seeking HIV care by adolescent parents. Similarly, sexual reproductive health services particularly family planning for those with children need to be provided. These services will enable this target audience to adopt the right spacing or number of children that they can optimally provide care for will be required. Those who currently have not given birth will be helped to delay pregnancy or child birth.

SECTION 2: EXPERIENCES OF STIGMA AND DISCRIMINATION FROM OTHER PEOPLE

This section presents external forms of HIV-related stigma and discrimination experiences in the last 12 months preceding the survey. The experiences measured include: exclusion from social activities and the frequencies of such exclusion, the possible reasons for exclusion for those individuals that reported such experiences, awareness of external stigma and a reflection of experiences with people who are reported to have stigmatized or discriminated the respondents.

Table 4: Percentage of respondents who reported stigmatization and discrimination at family and community level by the frequency in the previous 12 months

3.2.1 Stigma experiences at family and community levels

Table 4: Percentage of respondents who reported stigmatization and discrimination at family and community level by the frequency in the previous 12 months

HIV external stigma forms	Never n (%)	Once n (%)	A few times n (%)	Often n (%)	Total n(%), N=212
Excluded from social gatherings or activities (e.g. weddings, funerals, parties, and clubs)	190 (89.6)	6(2.8)	8(3.8)	8(3.8)	212 (100)
Excluded from religious activities or places of worship	195 (92)	10 (4.7)	4(1.9)	3(1.4)	212(100)
Excluded from family activities (e.g. cooking, eating)	204(96.2)	4(1.9)	2(0.9)	2(0.9)	212(100)
Been aware of being gossiped about	108(50.9)	24(11.3)	47(22.2)	33(15.6)	212(100)
Been verbally insulted, harassed and/or threatened	151(71.2)	18(8.5)	37(17.5)	6(2.8)	212(100)
Physically harassed and/or threatened	183(86.3)	17(8)	11(5.2)	1(0.5)	212 (100)
Physically assaulted	170(80.2)	22(10.4)	15(7.1)	5(2.4)	212(100)

From Table 4, external forms of HIV stigma are most revealed in the category of gossip, 104 (49.1%) verbal insult, 61(29%), and physical threats 29(14.1%). The frequency of these external stigma experiences occurs a few times.

3.2.1.1 External stigma and discrimination experiences and sources

Many times, PLHIV face stigma and discrimination owing to the social groups such as sexual orientation, migrant status, sex work, people who use/inject drugs, refugee status and several others that they belong to or have belonged to in the past. For those whose stigma and discrimination experiences were not linked to any of the social related groups, their experiences about selected potential stigma and discrimination sources were explored. (Table 5).

Table 5: Percentage of respondents who reported selected forms of stigma in last 12 months

Response	Never	A few times	Often	Once
Discriminated against by other people living with HIV	192(90.57%)	10(4.72%)	7(3.30%)	3(1.42%)
Experienced sexual rejection because of my HIV Positive status	167(78.77%)	20(9.43%)	10(4.72%)	15(7.08%
My wife/husband or partner, or any members of my household experienced discrimination because of my HIV-positive status	172(81.13%)	22(10.38%)	2(0.94%)	16(7.55%)
Psychological pressure or manipulation by my Husband/wife or partner in which my HIV-positive status was used against me	186(87.74%)	6(2.83%)	8(3.77%)	12(5.66%)

Results in table 5 depict several experiences, source of HIV stigma and frequency of occurrence. It is particularly important to take note of the 20(9%) who reported experience of stigma and discrimination that emanate from other PLHIV.

3.2.1.2 Perceived reasons about stigma and discrimination

There are multiple reasons why YPLHIV perceived linked it with HIV positive status. (Table 6).

Table 6: Percentage of respondents by reason for experiencing some form of HIV-related stigma and /or discrimination in the last 12 months by gender.

Response	Male n =79	Female n=133	Total N=212
People are afraid of getting infected with HIV from me	30 (14%)	51(24%)	81(38%)
People don't understand how HIV is transmitted and are afraid	32(15%)	11(5%)	43(20%)
People think that having HIV is shameful and they should not be associated with me	19(9%)	15(7%)	34(16%)
Religious beliefs or "moral" judgments	0	4(2%)	4(2%)
People disapprove of my lifestyle or behavior	5(2%)	10(5%)	15(7%)
I look sick with symptoms associated with HIV	7(3%)	4 (2%)	11(5%)
I don't know/I am not sure of the reason(s)	24 (11%)	48 (23%)	72(34%)

Multiple response options and total percentages may not total up to 100%.

Per Table 6, the highest proportion 81(38%) of the respondents perceived fear of getting infected with HIV from the PLHIV as the most prevalent reason for stigma and discrimination; additionally, about 43(20%) mentioned that "people don't understand how HIV is transmitted and are afraid". Generally, a relatively big proportion 72(34%) said they don't know or were not sure of the reasons. The findings show differences in this perception by gender 30(14%) males vs. 51(24%) females. These findings reflect gaps in awareness of the causes of HIV and awareness about the transmission routes among the communities calling for massive community sensitization.

3.2.2 Access to Work, Health and Education Services

The section presents findings linked with institutional level discrimination faced by YPLHIV. The section highlights aspects of; changes in job location because of job loss, suspension and non-promotion due to HIV and denial of either health or educational services (Table 7).

Table 7: Access to work, health and education services and frequency of occurrence

Response	Male N=79	Female N=133	Total N=212
Forced to change your place of residence or been unable to rent accommodation	79(100%)	133(100%)	212 (100%)
Job description or the nature of your work changed, or have you been refused promotion	79(100%)	133(100%)	212(100%)
Lost a job or another source of income	11(14%)	10(8%)	21(10%)

Multiple response options

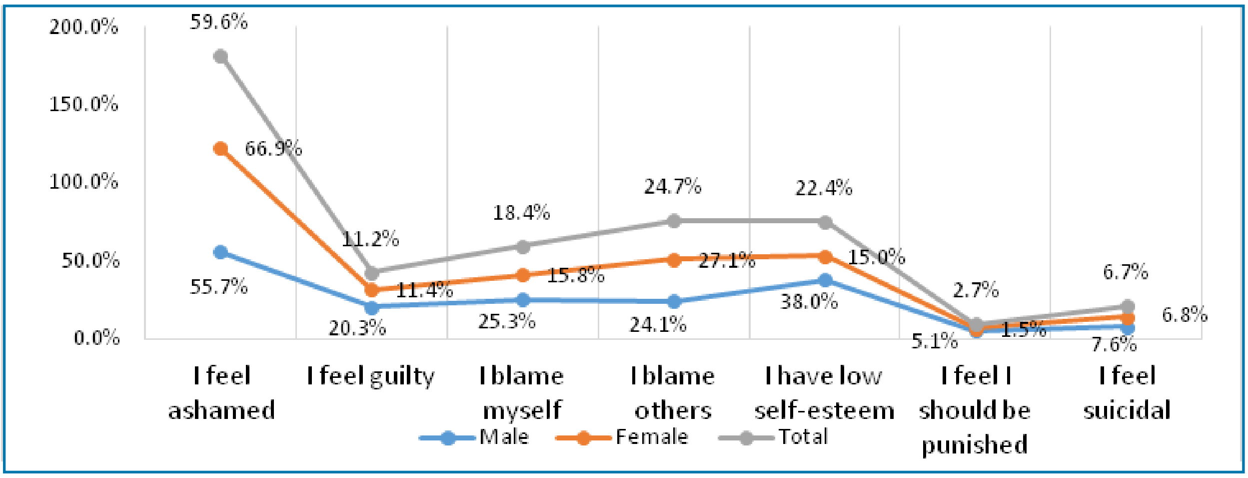
The findings relating to access to work are generally worrying, as several respondents 79(100%) males, Vs. 133 (100) have been forced to change their places of residence or been unable to rent accommodation, while others have had to change their job description or nature of their work or have been denied a promotion in the past 12 months. The data also reveals that about 21%, (14% males vs. 8% females) lost a job or another source of income. Approximately 14(6%) think these experiences occurred to them because of HIV positive status, where 19(9%) think these experiences occurred to them because of living with HIV and other reasons. Generally, the majority 32(15%) of those who experienced the mentioned institutional level stigma revealed it was other reasons.

3.2.3 HIV Internal Stigma

This sub section presents information about the way individuals feel about themselves because they are living HIV (internal HIV stigma). The follow up sub section, presents findings about the reactions that they report to have emerged because of internal stigma. The operation definition of internal stigma adopted for this survey is the degree to which YPLHIV endorse the negative feelings associated with HIV and apply those feeling to him/herself. Usually internalization of feelings, often result into negative consequences in form of the decision they make or the reactions that follow.

In the survey, internal stigma was measured based on an seven item HIV stigma scale. Several sub categories are presented in this section to synthesize stigma and guide intervention development to reduce internal stigma.

Figure 3: Percentage distribution of perception and fears respondents had about themselves because of living with HIV by gender



Multiple response option

From figure 3, there are varying levels of internal stigma within the different measurement components and by gender. The findings indicate that, feeling ashamed 133(59.6%) was the most mentioned internal stigma component. The proportions are different for both 44(55.7)-males vs. 89(66.9%) females. Except for proportions that blame others; 24% male vs. 27% females, all other forms of internal HIV stigma including ;blaming self, feeling suicidal, feeling of being punished, and feelings of guilty were more reported by male respondents.

3.2.3.1. Individual level reactions and coping mechanisms

There are often several ways of coping and reactions adopted by persons who experience internal HIV stigma. Many of them avoid or make decisions to engage or participate in social activities.
Table 8 illustrates a listing of these reactions.

Table 8: Percentage distribution of respondents' decision not to engage in some activities because of their HIV status in the last 12 months by gender

Response	Male n=79	Female n =133	Total n=212
I have chosen not to attend social gathering(s)	18(22.8)	34(25.6)	52(20.6)
I have isolated myself from my family and/or friends	9(11.4)	26(19.5)	35(13.9)
I took the decision to stop working	9(11.4)	7(5.3)	16(6.3)
I decided not to apply for a job/work or ask for a promotion	8(10)	11(8.3)	19(7.5)
I withdrew from education/training or did not take up an opportunity for education/training	5(6)	14(10.5)	19(7.5)
I decided not to get married	11(13.9)	3(2.3)	14(5.6)
I decided not to have sex	28(35.5)	21(15.8)	49(19.4)
I decided not to have (more) children	11(13.9)	19(14.3)	30(11.9)
I avoided going to a local clinic when I needed to	3(3)	6(4.5)	9(3.6)
I avoided going to a hospital when I needed to	1(1.3)	8(6)	9(3.6)

These responses are multiple response, so they don't add up to 100% considering all the categories

Table 8 indicates that, 18 (22.8%) males and 34 (25.6%) females reported that they have chosen not to attend social gatherings, whereas 28 (35.5%) males and 21 (15.8%) decided not to have sex. A relatively small proportion have refrained from seeking health care; 3 (3%) males and 8 (4.5%) females. These revelations show how self-inflicted human rights violations that ought to be deterred conventionally through a series of interventions.

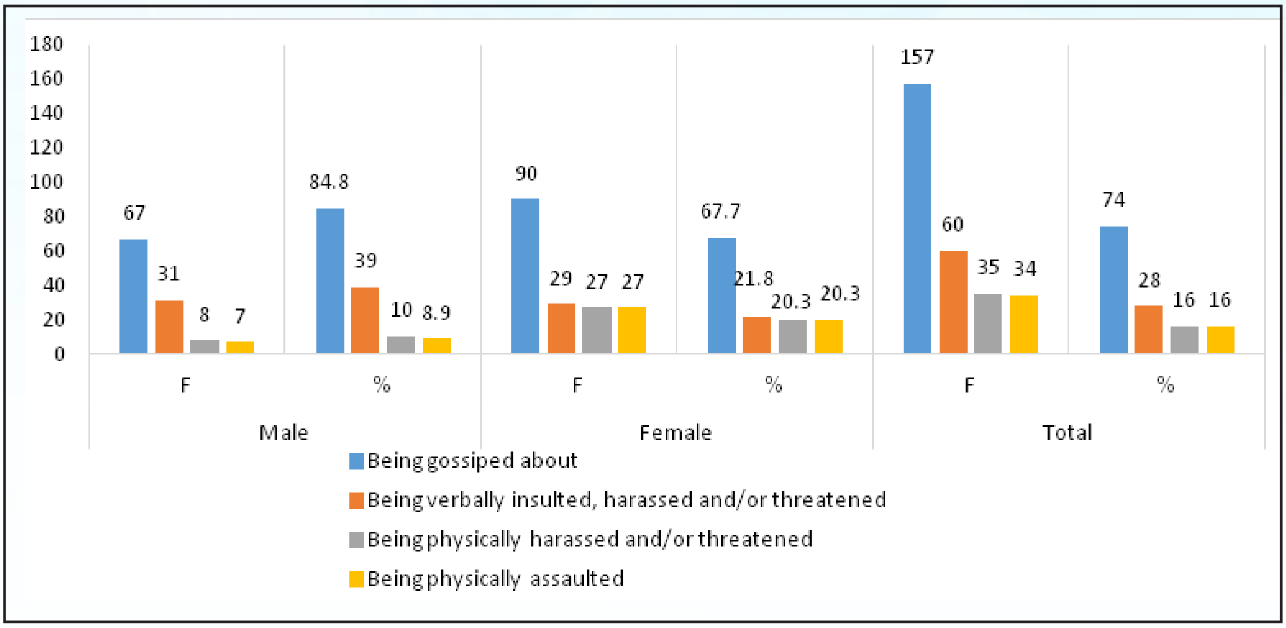
A listing of contextual barriers that interfere with young people's access to SRH services
Through FGD, the PLHIV below 15 years were guided to discuss, the possible factors that prevent young people from seeking SRHR services from a clinic/hospital of their choice: Listing of the reasons is below

- Pill burden "Scared of pills because they are big and many''
- Self-stigma "ashamed of many things"
- Peer pressure "wrong advice from friends about not going to clinics"
- Low self-esteem "general fear to go to clinics"
- False information in society "we shall die quickly because the medicine are very expensive you will not manage"
- Still young (parent consent): "we often need permission from parents"

3.2.3.2 Anticipated HIV stigma

This sub section explores if the respondents have been fearful of some aspects of external stigma/ discrimination happening to them.

Figure 4: Respondents that were fearful that some forms of stigma would happen to them by gender



F= Frequency derived from the count and total sample which responded

About 157 (74%) of respondents were fearful that gossip would happen to them during the last 12 months. Fewer males 67(84.8%) vs. 90(67.7%) females were fearful. Similarly, higher proportions of females, mentioned anticipated fears of insult and physical assault compared to the males. By implication, the YPLHIV held high anxiety issues about HIV related stigma which never happen in practical sense since only 20% experience HIV related stigma. Dealing with such anxiety is key to awareness raising interventions for HIV stigma reduction.

3.2.4 Rights, Laws and Policies

This sub section presents findings related to client's awareness of existing law and policies that protect and promote the rights of PLHIV including the young people. The application of such knowledge to effect and promote positive changes is explored.

3.2.4.1 Existing laws relating to HIV and human rights

Some of the laws and declaration have an international stature but Uganda ratified several of them. Some of these laws include; the Uganda Constitution of 1995, the cardinal law that protects the rights of all persons, without discrimination of any kind.

Some of the laws that manifest commitment of the government to deter discrimination include;
The Employment Act 2006 that strengthens provisions of anti-discrimination of all workers despite Health status; the Domestic Violence Act 2010 that provides for protection to all family members against violence to include assault and psychological torture.
In line with the PLHIV stigma index, similar questions that sought experiences of YPLHIV about laws, rights, and polices were explored.

Table 9: Percentage of respondents who have heard of the UN Declaration of Commitment on HIV/AIDS and National HIV/AIDS Policy by gender

Response	Male n N=79	Female n N=133	Total n N= 223
Heard of the Declaration of Commitment on HIV/AIDS which protects the rights of people living with HIV	36(45.6%)	38(29%)	74(33%)
Ever read or discussed the content of this Declaration	15(19%)	28(21%)	43(19%)
Heard of the national HIV/AIDS policy which protect(s) the rights of PLHIV	27(34.2%)	28(21%)	55(25%)
Ever read or discussed the content of this policy	4(5.1%)	17(13%)	21(9%)

Per table 9, 36(45.6%) males and 38 (29%) females had heard of the Declaration of Commitment on HIV/AIDS which protects the rights of people living with HIV. However, a small proportion 15 (19%) males and 28(21%) females, had ever read or discussed the content of this declaration. Additionally, 27 (34%) males and 28 (21%) females had heard of the National HIV/AIDS Policy which protect(s) the rights of PLHIV, yet only 4 (5.1%) males and 17 (13%) females had ever read or discussed the content of this Policy.

3.2.4.2 Self-reported Experiences of stigma and discrimination in the 12 passed months

Owing to the HIV positive status, the PLHIV stigma index survey explores key negative events that happened to individuals living with HIV in that last 12 months. They are asked whether the events that happened or were experienced were linked with the individual's HIV status (Table 10). The events discussed relate to extreme cases of discrimination in the continuum of HIV related stigma.

Table 10: Percentage of YPLHIV who reported discriminatory experiences linked to their HIV status

Response	Male	Female	Total
I was forced to submit to a medical or health procedure (including HIV testing)	7(3.3)	10(4.7)	17
I was denied health insurance or life insurance because of my HIV status	1(0.5)	1(0.5)	2
I was arrested or taken to court on a charge related to my HIV status	0	2(0.9)	2
I had to disclose my HIV status to enter another country	0	4(1.9)	4
I had to disclose my HIV status to apply for residence or nationality	0	0	0
I was detained, quarantined, isolated or segregated	2(0.9)	0	2
None of these things happened to me	71(90)	117(88)	188 (84)

multiple response options

Table 10 generally shows that majority 71(90%), males vs. 117 (88%) females, respondents had not experienced discriminatory practices linked with HIV status in the past one year preceding the study. That few 7(3.3%) males Vs. 10(4.7%) female's revealed aspects of being forced to submit to medical or health procedure including HIV testing. This finding implies that there are still some forced procedures with the care setting and these procedures affect the females slightly more than the males. Capacity building and positive change interventions for health workers are needed in some instances.

3.2.5. Effecting Change

This sub section presents information about how the YPLHIV manage to support themselves and others in overcoming situations where their rights are violated because of their HIV status. The sub section also explores the client's awareness and close relation with support agencies in the geographical location.

3.2.5.1 Experiences of effecting changes

The concept of effecting change signals a situation where the YPLHIV has managed on his/her behalf or supported another YPLHIV to respond or cope with stigma and discrimination from others. For someone to effect change, a close link with existing support institutions that promote human rights for YPLHIV is also paramount.

The findings indicate that more females, 54 (54%) and fewer 16(20%) males are aware of organizations or groups to go to for support regarding stigma or discrimination. However, more males, 26(33%) vs. 17 (13%) female have confronted, challenged or educated someone who was stigmatizing and/or discriminating against a YPLHIV. The lower proportion of females who have ever confronted or support another YPLHIV could be linked to deep rooted gender variations between females and males that sometime lead to low self-esteem and non-less courageous character.

The respondents who mentioned knowing support organizations listed organizations such as those of: people living with HIV support groups; 9 (11%) male's vs. 30 (23%) females followed by network of people living with HIV 6(8%), vs. 8(6%).

Individually, respondents were asked to mention if they have supported those living with HIV on issues of stigma and discrimination and what kind of issues that were tackled. (Table11)

Table 11: Type of support respondents have provided by gender

What types of support did you provide	Male N=79	Female N=133	Total N= 223
Emotional support (e.g. counseling, sharing personal stories and experiences)	23 (29%)	38(29%)	61(27%)
Physical support (e.g. providing money or food, doing an errand for them)	14(17%)	8(6%)	22(9%)
Referral to other services	11(14%)	15(11%)	26(12%)

Multiple response options, totals may not add up to 100%

Per Table 11, the most mentioned type of support was in the category of emotional support 23(29%) for males vs. 38 (29%) for females. The kind of support has been predominantly promoted over time by several agencies.

3.2.5.2 Individual power to influence decisions

These findings are based on respondents' feelings particularly the power to influence the decisions in spheres that devoid ridicule and promote the wellbeing of YPLHIV in their communities (Table 12).

Table 12: Persons who felt could influence HIV related policy level matters to address stigma by gender

Response	Male n (%) N=79	Female n (%) N=133	Total n (%) N= 223
Legal/rights matters affecting YPLHIV with HIV	43(54)	22(16)	65 (29)
Local government policies affecting YPLHIV	37(46)	5(0.3)	42 (18)
Local projects intended to benefit people living with HIV	23(29)	13(10)	36(16)
Uganda government policies affecting YPLHIV	14(17)	2(1)	16(7)
National programs/projects intended to benefit YPLHIV	7(9)	1(0.7)	8(4)
None of these things	28(35)	92(70)	120 (54)

Multiple response options

The notable issues form Table 12 indicate that generally YPLHIV felt they have the power to influence some decisions on key matters that would promote an enabling environment to address HIV related stigma. Overall, the proportion of males who revealed this was higher than the females.

3.2.5.3 Addressing HIV stigma and discrimination at Organization level

Given the lived experience of PLHIV in general HIV programing and as part of the greater involvement, questions relating to what organizations of people living with HIV specifically those that center their effort on HIV stigma redress are explored. The concern is out of the many actions that the organizations are executing, what should be the most important that they ought to execute to address stigma and discrimination. (Table 13)

Table 13: Respondents suggestions about what organization should be doing to address stigma and discrimination

Response	Male n (%) N=79	Female n (%) N=133	Total n (%) N= 223
Advocating for the rights of YPLHIV	51 (65%)	56(42%).	107(48%)
Providing support to YPLHIV by providing emotional, physical and referral support	44(56%)	44(33%)	88(39%)
Advocating for the rights and/or providing support to particularly marginalized groups (men who have sex with men, injecting drug users, sex workers)	10(13%)	17(12.8%)	27(12%)
Educating people living with HIV about living with HIV (including treatment literacy)	35(44%)	45(34%)	80(36%)
Raising the awareness and knowledge of the public about AIDS	39(49%)	33(25%)	72(32%)

Multiple response options allowed

As per the ranking of the most important issues that organizations should be doing (Table 13), the most important action is advocacy 107(48%), followed by provision of emotional support 88(39%) and subsequently, education and awareness 80 (36%).

The finding shows no consensus between males and females on most of the important actions that organizations should be executing, except for domain of advocacy for the rights and or providing support to particularly marginalized groups, 10 (13%) males vs. 17 (12.8%) females. This means the females and males could be having different priorities that need to be harmonized for subsequent support actions toward HIV stigma reduction.

SECTION: 3 EXPERIENCES OF TESTING, DIAGNOSIS, DISCLOSURE, TREATMENT AND HAVING CHILDREN

The section of testing and diagnosis explores experiences related to HIV testing and diagnosis of HIV results. Unlike other experiences, this section reflects on the time when the individual tested and was diagnosed with HIV the first time. The content involves reasons for undertaking the test, the decision-making process and what happened during the testing/diagnosis process.

3.3.1 HIV testing experiences, decision making and counseling experiences

Almost all HIV treatment procedures recommend HIV counselling and testing before any treatment, care and support services at health facilities. Like adults, the young people could have varying reasons for undertaking the HIV test (table 14). In this survey, its assumed that whoever participated in the study must have taken an HIV test at one time previously.

Table 14: Reasons for testing, decision making

Reasons for undertaking HIV test	Frequency n (%)
Employment	4(.1.89)
Pregnancy	20(9.43)
To prepare for a marriage/sexual relationship	4(1.89)
Referred by a clinic for sexually transmitted infections	5(2.36)
Referred due to suspected HIV-related symptoms (e.g. tuberculosis)	28(13.21)
Husband/wife/partner/family member tested positive	8(3.77)
Illness or the death of husband/wife/partner/family member	36(16.98)
I just wanted to know	95(44.81)
Other	12(5.66)
Total	212(100)
Decision making before undertaking HIV	
Yes, I took the decision myself to be tested (i.e. it was voluntary)	144(67.92)
I took the decision to be tested, but it was under pressure from others	18(8.49)
I was made to take an HIV test (coercion)	8(3.77)
I was tested without my knowledge – I only found out after the test had been done	42(19.81)
Total	212(100)
Counseling services during HIV testing	
I received both pre- and post-HIV test counseling	176(83.02)
I only received pre-test HIV counseling	6(2.83)
I only received post-test HIV counseling	17(8.02)
I did not receive any counseling when I had an HIV test	13(6.13)
Total	212

Reasons for HIV testing

The reasons for taking an HIV test for young people generally contrast with those of the adult population documented in the previous stigma index. The population of young people who undertook an HIV test with a major reason of just wanting to know was 95(45%), vs. 715(35%), similarly the proportion which undertook the test for pregnancy related reasons in this study was slightly higher (9.2%), compared to 7% in the adult study. Though quite small, there are about 8 (3.4%) who test because their husband/wife/partner/family member tested positive.

Decision making before undertaking HIV test and counselling

Whereas many 144(67.92) respondents reported to have taken the decision to be tested by themselves, a big proportion 42(20%) were tested without their knowledge, yet some 18 (9%) who took the decision to test were under the pressure to do so. In the most recent stigma reduction survey, the comparative statistics are quite different, showing that young people were generally under pressure to test, and many were tested without the knowledge. Given the possible age differences, it is quite hard to confirm the deliberate process of HIV which could have been spearheaded by the caregivers at the time to manage care process. The result table 14 further indicate that a large majority 176 (83%) received both pre- and post-test counselling. This service access could be leveraged as an opportunity for promoting SRHS.

3.3.2 Disclosure and Confidentiality

This sub section presents experiences related to disclosure of HIV status. The YPLHIV were asked how other people first learnt of the HIV status of the YPLHIV and the immediate reaction those people exhibited at the YPLHIV status. Additionally, information on the process of disclosure is presented.

Table 15: Percentage distribution of how different groups of people first got to know about respondent's HIV status

Response	I told them n (%)	Someone else told them with my	Someone else told them without my consent n (%)	They don't know my HIV status n (%)	N/A	Total n (%)
Your husband/wife/partner	68(33)	20 (9.4)	7(3.3)	29(13.7)	88(41.5)	212(100)
Other adult family members	102(48.1)	38(17.9)	30(14.2)	26(12.3)	16(7.6)	212(100)
Children in your family	44(20.8)	25(11.8)	20(9.4)	85(40.1)	38(17.9)	212(100)
Your friends/neighbors	46(21.7)	9(4.3)	29(13.7)	100(47.2)	28(13.2)	212(100)
Other people living with HIV	80(37.7)	44(20.8)	22(10.4)	47(22.2)	19(9)	212 (100)
Co-workers)	16(7.6)	2(1)	4(1.9)	58(27.4)	132(62.3)	212(100)
Your employer(s)/boss(es)	9(4.3)	1(0.5)	3(1.4)	50(23.6)	149(70.3)	212(100)
Your clients	9(4.3)		3(1.4)	66(31.1)	134(63.2)	212 (100)
Injecting drug partners			1(0.5)	34(16)	177(83.5)	212(100)
Religious leaders	19(9)	3(1.4)	7(3.3)	96(45.3)	87(41.1)	212(100)
Community leaders	12(5.7)	4(1.9)	8(3.8)	100(47.2)	88(41.5)	212(100)
Health care workers	90(42.6)	26(12.3)	19(9)	36(17)	41(19.3)	212(100)
Social workers/counselors	35(16.5)	21(10)	16(7.6)	64(30.2)	76(35.9)	212(100)
Teachers	28(13.2)	6(2.8)		56(26.4)	122(57.6)	212(100)
Government officials	5(2.4)	3(1.4)	3(1.4)	99(46.7)	102(48.1)	212(100)

According to table 15, specific groups of people first learnt the HIV status of the respondent through self-disclosure by the index client. Among those disclosed to by the index client him/herself included; adult family members, 102(48%), followed by health care workers 90(42%), other people living with HIV 80(37.7%), husband/wife/partner 68 (33%), children in family 44(20.8%) social workers, teachers and others in ascending order. It is also noted that that 44 (20.8%), revealed that other peopled living with HIV revealed the client status without their permission whereas, 29 (13%), and 26 (12%), said their partners, and family respectively said other adult household members are not aware of their HIV status. This data reveals the need for supported disclosure efforts.

3.3.2.2 Non-Voluntary disclosure/ forced disclosure

Whereas disclosure ought to be completely a voluntary activity particularly for adults and grown children, at times there emerges undue pressure both from YPLHIV and those who are not living with HIV. This sub section explores such undue pressure and the frequency of occurrence when it happens.

Table 16: Percentage of respondents that reported pressure to disclose their HIV status

Pressure to disclose	Frequency n (%)				
	Often	A few times	Once	Never	Total
Frequency of pressure from other individuals living with HIV or from groups/networks of people living with HIV to disclose your HIV status?	14(6.6%)	7(3.3%)	9(4.3)	182(85.9%)	212 (100%)
How often did you feel pressure from other individuals not living with HIV (e.g. family members, social workers, on-governmental organization employees) to disclose your HIV status	22(10.4%)	17(8%)	20(9.4)	153(72.2%)	212(100%)

Approximately 14% of the respondents revealed having had pressure from other individuals living with HIV to disclose their HIV status in contrast to 38% individuals not living with HIV. On the whole, about 11 (5%) of the respondents said a health care professional (doctor, nurse counselor laboratory technician) has ever told other people about the clients' results without their consent. Generally, in terms of confidentiality, most 169 (78%) respondents were sure that their medical records would be kept completely confidential whereas 41(19%) were not sure.

3.3.2.3 Description of reactions generated after disclosure

In behavioral psychology, whenever individuals face a new unexpected situation, they respond through a process called "reaction formation". In HIV stigma, those who learn of a client's HIV status for the first time are bound to react differently.

Table 17: Percentage of respondents who reported various reactions of people when they first knew about their HIV status

Response	Very discriminatory	Discriminatory	No different	Supportive	Very supportive	Not applicable	Total
Your husband/wife/partner	11(5.2)	11(5.2)	19(8.9)	39(18.4)	18(8.5)	114(53.8)	212
Other adult family members	3(1.4)	13(6.1)	21(10)	75(35.4)	63(29.7)	37(17.5)	212
Children in your family		5(2.4)	41(19.3)	50(23.6)	9(4.3)	107(50.5)	212
Your friends/neighbors	5(2.4)	15(7.1)	29(13.7)	37(17.5)	6(2.8)	120(56.6)	212
Other people living with HIV		4(1.9)	49(23)	91(42.9)	8(3.8)	60(28)	212
Your co-workers		2(1)	16(7.6)	13(6.1)	2(1)	179(84.4)	212
Your employer(s)/boss(es)	2(1)	3(1.4)	7(3.3)	11(5.2)	1(0.5)	188(88.7)	212
Community leaders	1(0.5)	1(0.5)	21(10)	12(5.7)	2(0.9)	175(82.1)	212
Health workers		1(0.5)	24(11.3)	66(31.1)	53(25)	68(32)	212
Social workers/counselors			23(10.9)	50(23.6)	15(7.1)	124(58.5)	212
Teachers			4(2)	25(11.8)	3(1.4)	180(84.9)	212

Generally, Table 17 indicates that support was given the YPLHIV following disclosure. The health workers and other adult family are reported as having demonstrated a very supportive environment. These findings generally confirm that the disclosure outcome are many times positive than negative. Among the negative outcome as per data from Table 17 11(5%) of the husbands/wife/partner were very discriminatory upon learning of the positive status of the respondent.

3.3.3 TREATMENT AND REPRODUCTIVE HEALTH RIGHTS

The stigma index is an empowering process, but the goal is to enable people living with HIV access care and treatment services. Given the effectiveness of the treatment and most recent development in treatment of HIV, it is critical to understand drug access and the experience faced by those who have children.

3.3.3.1. Description of Respondent's general health and support from health workers

Many of the respondents self -reported their health status to range from excellent to poor.

Table 18: Percent distribution of the respondents by self-perceived status at the time of survey by gender.

Health status	Male n (%)	Female n (%)	Total
Excellent	5(2.4)	26(12.2)	31(14.6)
Very good	19(9)	34(16.)	53 (25)
Good	40 (19)	43(20.3)	83(39.2)
Fair	11 (5.2)	24(11.3)	35(16.5)
Poor	4 (1.9)	6(2.9)	10(4.7)
Total	79(37.3)	133 (62.7)	212(100)

The greatest number 83(39%), mentioned that their health was good, followed by those who said their health was very good 53(25%). Major gender difference is seen in this table 18:

Others indicated that in the last 12 months, 139 (65%) out of 212 held constructive discussions with a health care provider about HIV-related treatment options. Similarly, a slightly lower proportion, 72 (33%) females, vs. 34 (16%) males, reported to have held constructive discussion with a health care professional on other subjects such as reproductive health, sexual relationships, emotional well-being and drugs use.

In terms of program implication, the proportion of YPLHIV whose health ranged from good to excellent is approximately 80%, indicating a good milestone that need to be improved. Interventions that mobilize YPLHIV from to seek services and care and treatment services require regular maintenance to avoid any interruptions in the services.

From the qualitative data, the young ones (12- 15 years) revealed some awareness of why they take medicines every day. The YPLHIV were prompted to discuss the question why do you take medicine every day? Below are the responses- verbatim

- To have life.
- To reduce the intensity of the HIV virus.
- To prevent the virus.
- To prevent the viral load.
- ARVS give you strength.
- It gives one life.

The commonest motivation from the narrative for the YPLHIV to take ART is about life and how ART is associated with giving life. This motivation factor should be used in communicating with YPLHIV about the role of ART.

3.3.3.2 Reproductive health rights and experiences

In this survey, reproductive health rights directly link to the goal of GUSO project, that is, to contribute to creation of an enabling environment for YPLHIV to access youth responsive health services. This increases uptake of services contributing to reduction of new HIV infections amongst adolescents and young people. Table 19 presents core reproductive health related experiences that reflect the status of reproductive health rights experienced by YPLHIV.

Table 19: Percentage of YPLHIV with experiences related to reproductive health / rights by gender

Reproductive health experiences	Gender	Yes	No	N/A	Don't know	Total
Since being diagnosed as HIV-positive, have you ever received counseling about your reproductive options?	Male	34	42	3		79
	Female	77	49	7		133
Has a health care professional ever advised you not to have a child since you were diagnosed as HIV-positive?	Male	7	72	0		79
	Female	17	107	9		133
Has a health care professional ever coerced you into being sterilized since you were diagnosed as HIV-positive?	Male	3	75	1		79
	Female	2	122	9		133
Is your ability to obtain antiretroviral treatment conditional on the use of certain forms of contraception?	Male	19	26	5	29	79
	Female	24	70	1	38	133

From table 19, the proportion of both males and females who have received counselling about reproductive options is quite low 34 (43%) males' vs. 77(58%) females. However, a few cases revealed that their ability to obtain antiretroviral treatment is conditional on the use of certain forms of contraception. Other findings indicate that 79 (37.1%) mention to have received PMTCT while as 29 (13.7%) were not aware of whether such treatment existed, others 22(10.4%) did not have access to such treatment and same proportion reported to have had HIV when they were pregnant.

This data implies a timely need to integrate deliberate SRHS with HIV Testing Services (HTS) for the YPLHIV. The interventions should not only focus on awareness raising but a series of collaborative effort among agencies to provide comprehensive SRHS for the priority population. With this evidence, continued work on advocacy for services should be enhanced in the short run.

4. CONCLUSION

HIV related stigma among the YPLHIV was 19.1% on average for components of internal stigma and 20.8% for components that measure external stigma. Within the internal forms of HIV related stigma, feeling ashamed because of being a PLHIV was the most reported by 133(59.6%) respondents. The high proportion of those who felt ashamed could be associated with the related young age of the respondents. Several gender differences with respect to internal forms (blaming self, feeling suicidal, feeling of being punished, and feelings of guilt) manifested most among the male respondents. Further research is needed to explore the causes or pathways to the gender differences especially those skewed towards the males.

Regarding external HIV related stigma, being gossiped about was the most mentioned by experience by 109(49%), The proportions that revealed exclusion experience were 22 (10.4%) with respect to social gathering,18 (2.7%) family activities 17(8%), religious places or places of worship. Overall, discriminatory practices were high among YPLHIV unlike exclusion from places of worship.
There is therefore evidence that HIV related stigma has a bearing posing critical barriers for the YPLHIV access SRH/HIV services. From the qualitative data, the external forms of HIV related stigma were mentioned more as causing specific barriers to accessing sexual reproductive health services.
In terms of access, most respondents (95%) are getting ART services and majority reported to be in good health. However, access to specific SRH was comparatively lower. The emphasis on integration of SRHS into HIV programing should be emphasized as the two are complementary. In this case the broader benefits of SRH should be the focus, and advocacy on HIV stigma should be at a more strategic level to create this environment.

5. METHODOLOGICAL LIMITATIONS

The study was generally limited in sample size to make inferential and other lower level disaggregation. The study reached out only to 223 respondents in total. But 13 respondents with incomplete data were not considered in analysis. Therefore, most analysis tables are calculated out of 212 respondents who had completed records.

Secondly in all HIV stigma studies in African regions, the sample of females is usually higher than that of males (2:3). This also was experienced in this study where approximately 84 and 139 were male and female respondents respectively. Ordinarily this would imply use of weights but, given the small numbers, the analysts, preferred to determine proportions within categories of males separate from females. On most tabulated tables, the N= has been shown as either 79 individuals for males and 133 for females.

Owing to different experiences, some respondents could not answer some questions or some questions become not applicable given the preceding responses. That meant that any statistical disaggregation would not make meaningful conclusions because of the relatively small number of respondents.

6. STUDY STRENGTHS

The study explored the young people (14 to 24 years) key experiences about HIV stigma. Previously stigma level experiences were only explored among the adult population 18 years and above. This study has provided key issues in the domain of HIV stigma especially among PLHIV and how this HIV related stigma could be a key barrier to access of reproductive health services among the young people living with HIV.

7. RECOMMENDATIONS

Given the integrated nature of the sexual reproductive health services, the transitional nature of young people living with HIV, the number of players in the program and apparent policies these recommendations are specific to each player and sector.

7.1 Network of YPLHIV

- It is highly recommended that the network of YPLHIV continues to lobby and work with CSO to ensure SRHS and HIV integrated services access and uptake. SRHR and HIV services are so critical for YPLHIV.
- Owing to specific life and transition challenges to adulthood which most YPLHIV revealed. Social behavioral change communication interventions (SBCC) like those promoted by the USAID funded communication for health communities and the DREAMS program should be used to reach the YPLHIV with messages that give them knowledge, skills, positive attitudes and resilience to overcome the barriers and challenges to services uptake or adherence to recommendations.
- Advocacy remains key to gaining the required human rights such as the right to health information and care. GUSO project strategies incorporates advocacy as core activity. The most important thing is that advocacy should emphasize timely and routine sensitization on SRHS and HIV by engaging local leaders, parents, cultural and religious leaders to advocate for adequate and quality SRHS.
- The UNYPA should champion the Peer to peer approach. This approach remains a good avenue to reach the YPLHIV and requires strengthening to enhance their potential to seek and demand for SRH and HIV services thereof.
- Adoption of social capital approaches is equally recommended. There is need to strongly and continuously engage social units including families, churches, and clubs, in the Y+Beauty pageant campaign. Solicit support from the Child and Family Protection Units at Police to get actively engaged in the fight against stigma related settings in the community.

7.2 NAFOPHANU

- The National Forum of People Living with HIV/AIDS Networks in Uganda (NAFOPHANU) should play steering role as one of the lead Civil Society Organizations to create an enabling environment for the GUSO project to meet its objectives. The existing community level structures which NAFOPHANU deals with should be leveraged to deal with the apparent HIV care seeking barriers among the YPLHIV country wide. Part of the enabling environment creation should involve: taking an actively be mobilizing of the YPLHIV, resource mobilization, advocacy, capacity building of YPLHIV as well as sharing of lessons learnt during implementation of PLHIV programs.

- NAFOPHANU expertise should be used to play a liaison role in reaching out or creating new alliances with key grass root agencies contribute to overcoming the structural barriers and supporting the operationalization the networks of YPLHIV

- That data has pointed to a general need to empower YPLHIV: NAFOPHANU together with other CSOs need to embark on an empowerment process for YPLHIV. This can be mainly achieved through operationalizing the existing guidelines of SRHR services provision in Uganda. Some of the guidelines that promote empowerment are contained in the MOH consolidated guidelines for prevention and treatment of HIV and nationally approved commitments by Government of Uganda. In this recommendation, empowering the young people is a great tool for mainstreaming access to services as well as plugging the information gaps that young people often have.

- NAFOPHANU and other CSOs should embrace dialogue with YPLHIV sustainably. Continuous dialogue with YPLHIV should be deemed increased guided solidarity YPLHIV, for purposes of taking up SRH and sharing age appropriate information. Through dialogue, the YPLHIV will be equipped with knowledge, skills and solutions to the structural barriers faced in accessing SRHS.

- NAFOPHANU and other COS, should harness community support and participation: Both on going and upcoming interventions require community acceptance and support. It is therefore recommended that CSOs need to undertake strategies and activities that strengthen interventions aimed at generating community support for use of sexual and reproductive health services by young people. Involving the wide community has several benefits instead of only focusing on the target YPLHIV.

- NAFOPHANU should disseminate findings from the stigma study to the government and partners with clear recommendations. Spear head advocacy on the rights of people living with HIV with focus on Positive Health Dignity and Prevention.

- Packaging anti-stigma messages should be considered important in awareness on HIV related stigma in the project area and the country at large. These should be formatted in easy to read languages and in simple formats such as: flip charts, posters, fliers, talking points and simple booklets.

- NAFOPHANU and its partners should ensure availability of health information, well translated and customized for local consumption. This implies that Information, Educational and Communication materials should be made in a simplified way preferably in the local language.

7.3 Services providers / CSOs

- Encourage and build the capacity of YPLHIV to be actively involved either as volunteers or as employees in developing and implementing stigma and discrimination reduction projects in providing support of fellow PLHIV individually and support groups and other organizations.
- There is also need to mentor Young Positive Champions as agents of change to ensure their meaningful involvement in HIV response in their communities.
- Strengthen counseling services by providing in-depth counselling training to the counselors and establishing a system that provides appropriate supervision and quality of counseling services.
- There is need to include HIV related stigma and discrimination indicators as part of the district and national HIV response M&E system to monitor and evaluate progress over time.
- Service providers should ensure availability of adequate and appropriate SRH products and services such as condoms, contraceptives, and counseling for YPLHIV to consume whenever need arises. This should be tailored to the demand of the services to ensure comprehensive coverage of the project area and the country at large.
- Service providers are requested to provide periodic trainings for both peer educators and health workers on HIV and SRH service delivery. Also, paralegal training should be considered to ensure protection and promotion of human rights among YPLHIV.
- Service providers should ensure delivery of youth friendly services to attract attention of the YPLHIV to seek and demand for HIV and SRH services.
- Conducting outreach activities as a way of extending service provision to the communities is vital to reach YPLHIV in their local communities.
- Health workers should ensure provision of intensive adhering counseling to the YPLHIV so as to maintain or increase the current 97% ART.
- Health workers need to consider giving long term appointments to YPLHIV in the school setting (say 3 months) to avoid defaulting the dose. Also, instituting nurses' availability in schools to always attend to the YPLHIV and also remind them to take their drugs in the right quantities and at the right time. This creates a supportive environment for the YPLHIV in the school setting.
- Strengthening the role of expert clients in community, police and health facility staff will create a supportive structure that will also establish and fortify health facility-family linkages to ensure that HIV related stigma cases are dealt with in harmony putting confidentiality into consideration.

7.4 Government of Uganda

In this study, the Government of Uganda, the MOH and development partners are all appreciated for improving the proportion of young people accessing ARVs in the three districts. Going forward, the following Policy level actions are needed as a way of improvement;

- Formulate specific policies targeting this sub-group. Such policies will guide development of programs that will ensure services provision for young people in a youth friendly way. It is critical to enforce Integration of Sexual Reproductive Health (SRH) and HIV services as priority action.
- The Government should work with CSOs and other administrative units to enforce local by-laws that protect rights of young people living with HIV.

- The Government in collaboration with non-governmental organizations should put in place strategies to meet the special needs of adolescents including education, stigma free environment, counseling and services in the areas of gender relations and equality, violence against adolescents, responsible sexual behavior, responsible family planning practice, family life, reproductive health, sexually transmitted diseases, HIV infection and AIDS prevention.

- The local governments should put in place income generation and self-sufficient mechanisms for people living with HIV as well as supporting the ability and capacity of PLHIV networks to better serve and support YPLHIV. Life skills development among YPLHIV such as entrepreneurship and apprenticeship schemes should be created to enhance income earnings among YPLHIV.

- The government and its partners should ensure creation of human rights awareness among YPLHIV especially SRH rights, health rights, access to information and justice.
- There is need to simplify the policies and guidelines that respond to the needs of YPLHIV.

7.5 The donors/ funders

- The donor community is requested to fund interventions designed specifically to increase demand for adolescent sexual and reproductive health (ASRH) services and those intervention that avails the services and SRH supplies in the region. Those living with HIV need specialized attention during adolescent stage.

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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 (PLHIV). To that end, the methodology is designed to capture respondents' 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 respondents' 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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